Transcending boundaries
Transcending boundaries
Interactive Learning and Action at the interface of HIV/AIDS and agriculture

ACADEMISCH PROEFSCHRIFT
ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. L.M. Bouter,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de faculteit der Aard- en Levenswetenschappen
op woensdag 26 november 2008 om 10.45 uur
in de aula van de universiteit,
De Boelelaan 1105

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“Behind the search of causalities there always lies, directly or indirectly, the search for values”

(Meinecke, 1862-1954)

To the members of the support groups for poor and HIV/AIDS-affected households who were willing to engage in a process of change
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Transcending boundaries; the title refers to the boundaries between women and men, between young and old, between ‘hard science’ and ‘soft science’, between action and research, and between HIV/AIDS and agriculture. It is about the members of the support groups on HIV/AIDS and food security in Msinga, a sub-district of the Province of KwaZulu-Natal in South Africa, who were willing to engage in a process of change. When I started this journey in October 2002, I could not have imagined the experiences and adventures it would bring. I would not have liked to miss any moment of it. Even though it brought moments of sorrow and grief, it also brought moments of happiness and joy.

The German historian Meinecke once said: “The search for causalities always leads, directly or indirectly, to a search for values”. This thesis was no exception. The study shows that perceptions and attitudes towards HIV/AIDS and people living which HIV are deeply engrained in people’s culture. To understand HIV/AIDS and be able to address it, we need to understand the underlying values. This is not only true for the members of support groups of poor and HIV/AIDS affected households, but also for researchers and service providers, whose involvement and commitment is required. It also counts for me personally.

Throughout my career I have searched for an occasion to unite my interests in social and biological sciences, to combine action and research, and to work in a development context. The PhD position at the Athena Institute gave me the chance to engage in action and research in the context of HIV/AIDS and agriculture. An agricultural NGO, based at the University of KwaZulu-Natal, enabled me to work in a HIV high-prevalence area in South Africa. It has provided me with an opportunity and a new direction in my life.

When I was about to start with my research, I talked to Gabriel Rugalema, who did his PhD thesis in Tanzania on the impact of HIV/AIDS on rural households. He explained to me that there is only one thing that is important: “to listen to the people”. One of my former supervisors, Lucien Hanssen once said: “we do not need to teach people how to give answers, but how to ask questions”. I cannot agree with them more. This thesis is about listening to people’s concerns, problems, ideas and sug-
gestions. Listening to people seems obvious, but it is not easy. Too often we are concerned with our own ideas and lives. This thesis is also about empowering people to take the future in their own hands, and to raise questions on HIV/AIDS. It is also about raising questions to service providers and researchers, and those who are in power and control. I hope that the people in Minga learned as much from us, as we did from them.

Looking back at this study, I could not have wished for a better preparation than my own childhood. Growing up in big rural farmer family made it easier to understand what I heard and saw in the rural areas of KwaZulu-Natal. Life may be very different in different parts of the world, but often I had the feeling that the lives of the people in Msinga were more similar to that of my own family, than to the urban lives of many people in their own country.

I am proud that the people in Msinga gave me the name Mr. Mkhize, a commonly respected and well known local surname. It gave me the feeling to be one of them. The symbol which is used at the start of each chapter and on the cover of this thesis represents a ‘Zulu love-letter’. According to folklore, this was a message given by a maiden to her lover, not in written form, but made from stringing coloured beads in a set pattern. In the past – i.e. pre-European influence – seeds would have been used and painted with natural colours (clay, ochre, plant extract, etc.). The symbol is a free expression of my love for the people in Msinga.

I hope that this thesis will inspire and motivate others to engage in a process of change in order to prevent and mitigate the impact of HIV/AIDS.

Kees Swaans,
Hanoi, October 2008
1.1 Aim of the Thesis

AIDS is one of the world’s, and particularly sub-Saharan Africa’s, most important social and development concerns. In 2005, an estimated 38.6 million people worldwide were living with HIV, almost 4.1 million became newly infected and an estimated 2.8 million died of AIDS. The majority of all people with HIV live in sub-Saharan Africa. Infection is concentrated in the sexually active and working population, with women infected at earlier ages than men, and rather more women infected than men. Although the prevalence of HIV/AIDS is higher in urban populations, it is increasingly being matched in rural areas (UNAIDS, 2006, 2008). Given the vast number of people being infected and the slow roll-out of antiretroviral medicines, the overall impact of AIDS related morbidity and mortality is expected to rise over many years to come (Gillespie, 2006; UNAIDS, 2006, 2008).

HIV/AIDS is a multi-dimensional, phased phenomenon with several, partly overlapping waves: a wave of HIV infection, followed by an ‘epidemic’ of opportunistic diseases; followed years later by AIDS illness and death. Depending on the prevalence of the disease and availability of treatment, there is an accumulation of economic and social impacts at the household, community and regional level (Gillespie, 2006). Recent figures indicate that the mortality rates in some countries, such as Uganda and Brazil, are decreasing. However, most countries have not yet reached the top of the mortality wave, while the impact wave has only recently started in the majority of affected countries (UNAIDS, 2008). Each wave is shaped by different factors, and with the progression of the HIV/AIDS epidemic in time it will be more difficult to deal with the complexity of several co-existing ‘epidemics’ in the future (Loevinsohn and Gillespie, 2003).
There is a need to respond urgently to the enormous challenges posed by HIV/AIDS. It is argued that development programs should build in interventions that anticipate the likely impact of AIDS, design approaches that minimize HIV transmission, and mitigate the impact on development work (Collins and Rau, 2000; Mullins, 2001). Where initially the health sector was held responsible to take action in response to HIV/AIDS, one has come to realise that HIV/AIDS is shaped by factors that go beyond the responsibility of the health sector alone. A truly multi-sectoral approach to address HIV/AIDS in the context of people’s livelihoods is crucial (FAO, 2003; UNAIDS, 2004).

However, the required focus on the complexity of the HIV/AIDS epidemic – in terms of problems, multi-sectoral nature and number of stakeholders and institutions who are expected to play a role in its prevention and mitigation – is not complemented by a thorough understanding of key issues and strategies on how to intervene effectively in the present situation. In this thesis we attempt to conduct the preparatory groundwork in terms of theoretical and methodological specification which is needed to develop these complex programs in a more effective and sustainable way.

**Food Security and Agriculture**

Food insecurity is one of the main problems in relation to HIV/AIDS in sub-Saharan Africa. HIV/AIDS does not only exacerbate food and nutrition insecurity as people are weakened and unable to engage in production activities, but poverty and food insecurity may lead people to engage in ever more risky strategies to ensure a livelihood (see Loevinsohn and Gillespie, 2003; Weiser et al., 2007). However, the relation between HIV/AIDS and food and nutrition insecurity depends on many factors. Various organisations and institutions in the international community, have urged for a better understanding of the role food and nutrition security can play in the fight against HIV/AIDS (FAO, 2003, 2004; Gillespie, 2006; UNAIDS, 2006).

Meanwhile, the ability of households and communities to ensure their food and nutrition security in the face of AIDS is being severely challenged. Affected households try to adapt, e.g. by changing household composition, intra-household relocation of labour, and diversification of household activities. New forms of households are developing as a response to the impact of HIV/AIDS. However, analysis of ‘coping’ with HIV/AIDS suggests that in the vast majority of cases, affected households do not ‘cope’ in the sense of succeeding to preserve an acceptable livelihood (see Barnett and Whiteside, 2002; Rugalema, 2000). A household affected by HIV has increasing constraints on their time and resources. Once the skills base, financial and physical assets are depleted, it will be very difficult to re-establish these. Households are
struggling for their day-to-day survival, and caring for others, and do not have the ‘luxury’ of engaging with long-term development efforts (Mullins, 2001). However, in all situations, some individuals and groups are better off than others depending on wealth characteristics, gender, generational structure, livelihood structure, and social networks (SADC FANR, 2003).

Most African livelihoods rely (partly) on agriculture. Although the agricultural sector is severely affected by HIV/AIDS, farming itself can also be seen as a potential strategy to reduce the impact of HIV/AIDS on food security (Müller, 2004, 2005). However, it requires an agricultural production system that is better adapted to the specific situation of poor and HIV/AIDS-affected households. Although the first publications of the relation between agriculture, food security, and HIV/AIDS date back to the end 80s, early 90s (Barnett and Blaikie, 1992; Gillespie, 1989), it has taken almost ten years, before international agricultural organisations have called for action.

There is evidence that agricultural organisations working in research, development and extension can contribute to the prevention of HIV’s spread and the mitigation of AIDS’ impacts in rural areas (see Gillespie and Kadiyala, 2005; Loevinsohn and Bigman, 2001; Ngwira et al., 2001), but it is also clear that there is still a rather poor base of evidence to guide action: systematic evaluation of experiences is rare and most studies are scattered and of a small scale (Gillespie and Kadiyala, 2005; HSRC, 2003; Ngwira et al., 2001).

Studies have shown that for the development of sustainable innovations, knowledge on technical, socio-economic and cultural aspects needs to be incorporated in the research process (see Leeuwis, 2004). Still, the knowledge and experiences of the intended beneficiaries themselves have often been neglected. Rural populations already employ various strategies to respond to the negative impact of HIV/AIDS on farming productivity (see Gillespie and Kadiyala, 2005; Loevinsohn and Bigman, 2001). So far, there is no systematic account of (potential) innovations and strategies that prevent and mitigate the impact of HIV/AIDS on food security and rural livelihood, let alone how to promote and stimulate these innovations. One of the main problems is that agricultural research agendas in most African countries do not respond adequately to the social and technical transformations in the agricultural sector as result of HIV and AIDS (Loevinsohn and Bigman, 2001; Loevinsohn and Gillespie, 2003). Another problem is that most studies on HIV/AIDS focus on impact assessments, providing snapshots of a specific moment in time. Longitudinal studies are needed to get a clear sense on how to respond to HIV/AIDS in a specific context (Barnett and Whiteside, 2002).
Interactive Approaches

Development programs and projects have often contributed little to real and lasting change on the prevention and mitigation of HIV/AIDS. This is mainly because of the complexity and dynamics as a result of the interaction between the physical environment (‘hard system’) and human action (‘soft-system’). Scientists and development practitioners have particularly stressed the importance of using integrated and interactive approaches to mitigate the impact of HIV/AIDS on agriculture and rural development (see FAO, 2003, 2004; Gillespie, 2006; Gillespie and Kadiyala, 2005; HSRC, 2003; Loevinsohn and Gillespie, 2003). In contrast to top-down approaches – often based on positivistic thinking – interactive approaches ensure a complete integration of knowledge through participation of a variety of stakeholders and mutual learning. The context is an integrated part of the problem identification and eventual solution. Results are promising so far, but because interactive approaches are rather new various issues regarding theory, general quality standards, and sustainable implementation remain unclear.

Particularly at the interface of HIV/AIDS and agriculture, there is little systematic knowledge to build upon. HIV/AIDS is different from most other diseases and shocks. HIV/AIDS is affecting agricultural production due to the reduction of household labour; the disruption of traditional social security mechanisms and forced disposal of productive assets (e.g. for medical care and funerals); the loss of inter-generational knowledge and skills; and morbidity and mortality among extension staff (FAO, 2004). HIV/AIDS, thus, adds a new dimension to both agricultural innovation and the application of interactive approaches.

Clear guidelines for good practice are scarce, albeit findings from a workshop on HIV/AIDS, agriculture and rural development in South Africa, suggest that interventions should combine prevention, mitigation and care, be sensitive to the variety of needs of households, go beyond labour-saving technologies, and learn from practice (HSRC, 2003). One of the outcomes of this workshop was that good practice should be based upon evidence what works, not merely on seemingly good ideas. We need more experimentation and creative approaches, backed by evidence of successful interventions. These can then influence policy and practice more widely. Action research was mentioned as one way of assessing interventions for understanding what does and does not work in specific situations, for different types of households.
This thesis aims to contribute to the (further) development of a conceptual and methodological framework for interactive approaches to agricultural innovation in the context of HIV/AIDS, in order to realize better informed, more sophisticated and effective development programs for the improvement of food security and well-being among poor and HIV/AIDS-affected households.

1.2 Outline of the Thesis

Chapter 2 and 3 present respectively the theoretical background and the research design. In chapter 2, we first elaborate on a better understanding of the driving factors behind the HIV/AIDS epidemic and its impact. Subsequently, a conceptual and methodological framework for action is presented. Chapter 3 gives an overview of the objectives and relevance of this study, the research questions, the methodology, the validity checks that were build in, and the ethical guidelines that were adopted during the study. Also the case is presented of which many of the findings of this thesis are the outcome; an action research project in Msinga, a HIV high-prevalence area in the Province of KwaZulu-Natal, South Africa.

The chapters 4-8 of this thesis present the findings of the study. These chapters have already been published or submitted for publication. They are slightly adapted to ensure consistency of terminology and reference style. In addition, ‘headings’ of sections may have been altered, while excessive overlap between the research design of this study and the methodology sections of the original articles has been reduced (i.e. related to ‘ethical’ guidelines and the explanation of the overall project). The chapters form a chronological reflection of the various phases of the action research project in Msinga and successively address the different research questions.

At the start of the overall project, a conceptual study was conducted to gain insight into the key issues and challenges with respect to the design and implementation of interactive approaches to innovation development at the interface of HIV/AIDS and agriculture. The findings are presented in Chapter 4.

Chapters 5 and 6 form the descriptive-analytical part of the study and comprise the first few phases of the project. Chapter 5 gives a detailed account of the impact of HIV/AIDS among rural households in Msinga to identify entry points for action. Chapter 6 focuses on HIV/AIDS-related stigma and discrimination, which emerged as one of the main problems to address HIV and AIDS in the study area.
The next two chapters, 7 and 8, form a reflection of the implementation and action part of the project. Chapter 7 elaborates on the Farmer Life School, one of the more promising strategic innovations to HIV education among farmers. It analyses the strengths and weaknesses of this method in a HIV high-prevalence area, and presents some of its implications. In chapter 8, an account is given of the overall action research project. The interactive approach applied in Msinga is evaluated, using both process and outcome indicators. Key issues are identified and discussed.

Finally, in chapter 9, the main research question is revisited. It presents the main conclusions and discusses emergent findings. The chapter closes with some recommendations for further research.
2.1 HIV/AIDS, a Development Concern

As mentioned in the previous chapter, AIDS is one of the world’s, and particularly sub-Saharan Africa’s, most important social and development concerns. AIDS has affected all sectors of economic productivity in sub-Saharan Africa, including agriculture, the main source of livelihood for the majority of the region’s population (see Barnet and Whiteside, 2002, Müller, 2005). The way the HIV/AIDS epidemic is experienced, however, depends on the stage and progress of the HIV/AIDS epidemic, which may be highly dynamic and variable in space and time (UNAIDS, 2006, 2008). Barnett and Topouzis (2003) distinguish three stages communities may go through: AIDS-initiating, i.e. very low HIV prevalence and no AIDS impacts, AIDS-impending, i.e. rising HIV prevalence, with the majority of infected people in the asymptomatic phase, and AIDS-impacted, i.e. when households and communities feel the impact of AIDS as infected people become sick and eventually die. Each stage needs its own specific response. Preventive approaches, aimed at strengthening resistance, have to take precedence in the early stages of the epidemic, whereas impact mitigation and the strengthening of household and community resilience needs to be more prominent in the latter stages (see also Gillespie, 2006).

In order to be able to address the HIV/AIDS epidemic, we first need to have a better understanding of the factors and mechanisms that drive the epidemic and its impact. This chapter starts with a discussion of the main driving factors and presents a conceptual and methodological framework for action. The chapter closes with some concluding remarks.
2.2 Understanding the HIV Epidemic and Its Impact

This section elaborates on the complexity of factors that shape the HIV epidemic and its impact by describing a general framework on HIV/AIDS determinants, impacts and responses. Then we take a closer look at the impact of HIV/AIDS on individuals, households and communities, where the impact is felt first and most. Next, the relation between HIV/AIDS, food security and subsistence farming is explored, using a livelihoods perspective, while the implications for potential strategies to prevent and mitigate the impact of HIV and AIDS are being discussed.

2.2.1 HIV/AIDS, a Complex Phenomenon

The complexity and interrelatedness of factors that shape the HIV/AIDS epidemic and its impact is reflected in a model of Loevinsohn and Gillespie (2003) (Figure 2.1). In their model, they make a distinction between ‘causes’ and ‘consequences’ of HIV infection. ‘Causes’ refer to the determinants and responses that influence the susceptibility to HIV (i.e. the risk of getting infected), while ‘consequences’ refer to impacts and responses that affect the vulnerability to AIDS (i.e. the threat of being negatively affected by HIV/AIDS). The susceptibility and vulnerability context are formed by different levels, whereby the more immediate levels, the micro-biological and micro-environment, are embedded and influenced by the more distant ones, the meso- and macro-environment (Loevinsohn and Gillespie, 2003).

Figure 2.1: HIV/AIDS determinants, impacts and responses (Loevinsohn and Gillespie, 2003)
Several determinants can be distinguished that determine the susceptibility to HIV, such as other diseases, virus load, virus subtypes, malnutrition, knowledge, autonomy, behaviour, movement, but also more distant factors play a role, such as the livelihood system, violence, culture and wealth. The impact after infection depends on the vulnerability context, which may be shaped by other diseases, malnutrition, death, gender, assets, and entitlement structures at the more immediate level, and farming and livelihood systems, community institutions, stigma and laws at the more distant levels. It is also important to realise that HIV/AIDS is not an exogenous force from outside, but endogenous in the sense that it is affected by a range of responses, varying from the provision of ARV medicines, to behaviour change programs, and supportive policies.

There are a few implications that can be derived from the model, and which are relevant for strategies to address HIV/AIDS: (1) the HIV/AIDS epidemic is not only determined by biological, and behavioural factors – the initial focus of HIV/AIDS interventions in the 80s and 90s – but also by social, cultural, economic and political factors; (2) whether it is the individual, household, community, district, country or region, different aspects play a role at each level; (3) the determinants that shape the susceptibility context are not necessarily the same as the factors that determine the vulnerability context; (4) HIV/AIDS is affected by a range of actions and interventions, but there is a risk that actions at different levels – focussing on different aspects – are counterproductive due to their impact on other levels and aspects.

Not all factors will be equally important to explain local epidemics of HIV/AIDS; each situation is context specific. However, what stands out is the complexity of different types of factors that play a role at different levels of social organisation.

2.2.2 The Impact on Individuals, Households and Communities

The impact of AIDS is felt first and worst at the individual, household and community level. But as Barnett and Whiteside (2002) point out, it is also here, beyond clinical and medial consequences, that it is hardest to measure. In the absence of treatment, infected individuals can expect to experience periods of illness that increase in frequency, severity and duration. The impact of individual ill-health and death depends on who the individuals are, their place in society, and the resources, they, their households, communities and societies have available (SADC FANR, 2003). But individuals live in networks of relationships, and it is less clear what the impact will be on the broader society and community in which he or she lives and functions (Barnett and Whiteside, 2002).
Because HIV in Africa is mainly sexually transmitted, it tends to ‘cluster’ in families: when one member falls positive, it becomes more likely that another will be infected as well (Chapoto and Jayne, 2006). The measurement of impact on households during illness is difficult. Illness ranges from not feeling well to complete inability to function. It is difficult to unravel these complexities with survey methods, partly because they will not be able to trace households which have dissolved, they are not able to take into account the complex relations between clusters of households, and the epidemic and its impact are still evolving (Barnett and Whiteside, 2002). In addition, the concept of a household varies between different cultural contexts, while deaths in individual households have implications for other households because of their interdependence (Barnett and Whiteside, 2002; Drinkwater, 2003).

Increasingly agencies and governments see ‘communities’ as having ‘the solution’ to both prevention and impact issues (see Barnet and Whiteside, 2002; Binswanger et al., 2006). They are seen as vital, because it is ever more realized that interventions do not work if the socio-economic and community environment is not supportive. The definition of ‘a community’, however, is not clear. In reality, a range of interrelated factors determine how individuals interact and if they collectively constitute a community. Communities may develop, but also divide around specific issues such as HIV/AIDS. While they may have a role to play, they can not be seen as the only answer. Some ‘communities’ simply do not have the resources. In others women may not have the same role and rights as men, and may even suffer active discrimination (Barnett and Whiteside, 2002).

2.2.3 HIV/AIDS, Food Security and Subsistence Farming

One of the main problems in relation to the impact of HIV/AIDS is access to food. During the 2001-2003 southern African food crisis millions of people were in direct need of food aid (Loevinsohn and Gillespie, 2003). In South Africa alone, fourteen million people (30%) experienced food insecurity in 2001 (Mullins, 2001). Although many factors played a role, a SADC FANR study (2003) showed that HIV/AIDS had a strong and negative impact. It also suggested that these impacts are complex. Especially in rural and semi-urban areas, HIV/AIDS is exacerbating food insecurity as people are weakened and unable to engage in any production activity (Gillespie and Kadiyala, 2005). At the same time, poverty and food insecurity may lead people to search for jobs as migrant labourers and other non-farm activities, making them more susceptible to HIV (Shah et al., 2001, Chapoto and Jayne, 2005). In addition, seasonal migrant workers might put their (rural) wives at a very high risk to HIV-infection upon return (Zuma et al., 2003).
To gain a better understanding of the impact of HIV/AIDS on people’s lives and the role of food security, it is helpful to sharpen our focus on household, community, and institutional interactions. This can be done by integrating the concepts of susceptibility, vulnerability, resistance, and resilience to HIV/AIDS in a livelihoods framework (see Carney et al., 1999; Gillespie, 2006; Gillespie et al., 2001). Figure 2.2 presents such a framework. The livelihoods model is complementary to the more universal figure on the multiplicity of factors that shape the HIV/AIDS epidemic, providing a simple tool and frame of reference for researchers and practitioners to communicate effectively about how HIV and AIDS affect and are affected by people’s livelihoods (see Gillespie, 2006).

**Figure 2.2: Adapting the livelihoods framework to HIV/AIDS (Gillespie, 2006)**

Starting at the top of the figure, the macro-context, shocks and trends, determine – to a certain extent – the susceptibility and vulnerability context. After HIV has entered a household or community, the type and severity of its impact on assets – mediated by various institutional structures, processes and programs – will determine the type of strategies a household adopts. Strategies may differ in terms of resistance to HIV or resilience to the impact of AIDS that they confer upon the household, and lead
to various outcomes, which themselves condition future susceptibility and vulnerability. As with Figure 2.1, the cycle is dynamic and iterative. In the negative, it is a potentially downward spiral, in the positive it is may be a pathway out of poverty.

Households are said to be more food secure when food availability, access to food, stability of food supplies, and quality of food are in balance with each other. For rural households availability of stable quantities of nutritious food depends on food production (using mainly family labour, land, and other resources), food purchase (using household income), assets that can be quickly turned into food or cash when necessary, and social claims on others through custom and societal structures such as family and community networks (De Waal and Tumushabe, 2003; Topouzis and du Guerny, 1999). Livelihood-based analysis of linkages between food security and HIV/AIDS shows that the impact is systemic, affecting all aspects of people’s lives; and that effective analysis of the causes and outcomes of HIV/AIDS requires a contextual understanding of livelihoods unique to certain areas and/or social groups (FEG, 2002; Harvey, 2004).

The HIV epidemic seems to affect agriculture disproportionately relative to other sectors (IFAD, 2001), because the structure of agricultural sector, especially the sub-sector of small-scale farming, is less able to absorb the impacts of human resource losses associated with the pandemic (Topouzis and du Guerny, 1999). In severely affected rural areas, there are indications of declining labour availability as HIV-infected farmers fall ill and eventually die; liquidation of household assets in the pursuit of treatments; erosion of the agricultural knowledge base; and a shift of farming objectives among survivors towards the short term. Impacts in terms of declining yields and areas in production, as well as in the adoption of less labour and capital-intensive crops and livestock have been identified by several studies (Barnett and Halswimmer, 1995; Rugalema, 1999; Fox et al., 2004; Yamano and Jayne, 2004).

The situation may even become worse, realizing that problems with food production may lead to poor nutrition, and consequently compromised immune systems. HIV-infected individuals have higher nutritional requirements than normal, particularly with regard to protein (up to 50% increased), and energy (up to 15%). Such interactions are thrown into stark contrast for the poor, and particularly the rural poor, who are more likely to be malnourished prior to infection (Barnett and Whiteside, 2002). In the extreme, it may even lead to what De Waal (2002) has termed ‘new variant famine’.1

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1 The ‘new variant famine’ is not a short-term episode of acute food insecurity like conventional famines, but a new kind of acute food crises where there is limited recovery.
2.2.4 Strategies to Reduce Susceptibility and Vulnerability

The international community, governmental, and non-governmental organisations, have tried to prevent and mitigate the impact of HIV/AIDS on individuals and households using various strategies, such as food relief programs, social and financial support, food-for-labour programs, and gardening projects (see Barnett and Grellier, 2003; Gillespie, 2006; Gillespie and Kadiyala, 2005; Harvey 2004). Although these programs are required to support the neediest, they are unlikely to be the most appropriate and sustainable solution for the majority of African families (see Müller, 2005). Most programs are not only too expensive to implement on a large scale, but also face the risk of making people more dependent on external aid (Drinkwater, 2003). In addition, these programs may not always be well targeted or effective as result of top-down planning, while ignoring people’s living conditions, as well as their ideas and potential (see Gillespie, 2006). Gardening projects or income generating activities seem to be more successful to improve food security, but they often have a narrow focus on food production without addressing other aspects that drive the HIV/AIDS epidemic (Bishop-Sambrook et al., 2004; Chapoto and Jayne, 2006).

Recently there has been a more concerted effort to stimulate evidence-based interventions at the interface of HIV/AIDS and agriculture. In particular the Regional Network on AIDS, Livelihoods and Food Security (RENEWAL) program of the International Food Policy Research Institute (IFPRI) has enhanced research in sub-Saharan Africa to understand the two-way interactions between HIV/AIDS and food and nutrition security, and to improve the effectiveness of food and nutrition-relevant policy and programming in the context of the epidemic. Although there are studies that have looked at community-driven responses, scaling up, multi-sectoral approaches and mainstreaming (Binswanger et al., 2006; Kadiyala, 2004; Gavian et al., 2006; Drimie and Mullins, 2006), only rarely do these studies monitor and evaluate how (local) innovation and strategies can best be stimulated and supported (but see Djeddah et al., 2006; Loevinsohn, 2006).

Recent studies have highlighted the complexity and context-specificity of the spread of HIV and the impact of AIDS (Gillespie et al., 2007; Gillespie and Kadiyala, 2005). This supports the need for tailor-made responses and more insight in the conditions and procedures that make these responses effective. The importance of healthy and nutritious food has only become more important with the roll-out of ARV medicines. This requires innovative techniques and new ways of sharing knowledge and experiences, while taking into account people’s own wishes and capacities.

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2 see www.ifpri.org/renewal
2.3 An Interactive Approach

An interactive approach is most capable of coming to terms with problems that are embedded in complex causal connections. Interactive approaches emphasize that close interaction with stakeholders is needed (1) to gain access to all sorts of relevant knowledge, insights, experiences, needs and/or creativity; (2) to access relevant networks, resources and people, and (3) to generate the required involvement and (process) ownership (Leeuwis, 2004). An interactive approach represents a realistic response to understanding and then addressing some of the major health problems the world currently faces, such as HIV/AIDS. In this study we would like to focus on three major elements, inherent to interactive approaches (see Zwaan and Mur, 2002): a system perspective, participation and interdisciplinarity.

2.3.1 A System Perspective

In more complex societal problems, components and characteristics of both physical (hard) systems and social (soft) systems are converging and showing interaction. We call these complex systems. For example in the case of HIV/AIDS, biological, economic, social, cultural, and political factors shape the epidemic and its impact (Barnett and Whiteside, 2002; Loevinsohn and Gillespie, 2003) (see figure 1.1). In system approaches the focus is on the interactions and dynamics between various elements of the system and how the system behaves as a whole.

For research and decision making, it is important how one looks at the system. What are the borders, the time scale, and the level we are going to look at? Besides the internal relations, it is important to be aware of the relations of the system with its external environment, so that findings can be placed within the context of a larger system. At the same time, it is possible to differentiate smaller sub-systems. When practical problems are concerned, stakeholders have to come to a common understanding of the problem, and formulate objectives for interventions that concern the system they like to understand and respond to. This requires a joint fact finding process through an interactive process (van Keulen en Walraven, 1996; Zwaan and Mur, 2003).

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3 Leeuwis (2004: 56-57) actually mentions several arguments for organizing change processes in an interactive way, varying from pragmatic reasons (as mentioned in the text), ideological/normative ones (the argument is here that citizens have a wish, a moral right and/or a duty to actively involved), political ones (to emancipate and empower particular groups) and to increase accountability. However, he acknowledges that one could argue that at a higher level the use of interactive approaches always has pragmatic connotations; after all the wish to empower people is a goal usually set by some in order to affect the position of others. Therefore, I have focused here on the pragmatic reasons.

4 see also IDRC Ecohealth: www.idrc.ca
The communicative process of consensus building between various stakeholders based on joint fact finding can be seen as social learning. This process can lead to a common agreement and action, leading to a change, innovation or transformation of the problem situation. This process concerns all actors who are involved (Woo-dhill and Röling, 1998). It can be a facilitated process, but also autonomous based on gained insights and interaction, and can go along with conflicts and negotiations due to the different stakes at play.

The essence of a system is that the interaction and dynamics between the various elements lead to properties, which are different than the sum of the various parts. Some have argued that systems involving dynamic interaction between physical and human elements are too complex to predict. For example Hagmann et al. (2002) argue that the analysis is always based on moving reference points and targets, and that we should give up the notion that we can ever analyse, understand and control all the factors in complex, non-linear systems like livelihoods and ecosystems from outside. Instead, reaction to changes, e.g. through intervention, is most revealing; action research induces changes in certain components in the system; the reactions will reveal insight in the interactions between the parts and which other parts of the system must be understood and dealt with (Hagmann et al., 2002; Lewin, 1946).

In practice, this implies a focus on parts of the system and their interaction in order to study the dynamics of the whole system (Bawden, 1995; Hagmann et al., 2002). It requires the ability to understand and facilitate that there are many other problems and issues that one does not know, but play an important role. System approaches do not exclude reductionism (Zwaan and Mur, 2002). Fundamental and applied research can be applied within the context of interactive approaches to gain more insight in different parts of the systems. However, this approach requires considerable flexibility in planning; activities have to be adapted after each cycle of learning and exploration when new, higher priority problems reveal themselves (Hagmann et al., 2002).

2.3.2 Participation

Interactive approaches involve the participation of stakeholders at various levels of the system. However, the degree of participation may differ between stakeholders and may change over time. Several typologies have been developed to be able to distinguish between various levels of participation (Arnstein, 1969; Biggs, 1989; Pretty, 1994). Most of these typologies evolve around ‘information input’ and ‘decision making authority’. In this section we will present ‘Arnstein’s Ladder of Citizen
Chapter 2

Participation. Arnstein (1969) developed a typology of eight levels of participation. The eight types are arranged in a ladder pattern with each rung corresponding to the extent of citizens’ power in determining the end product (see Figure 2.3).

![Arnstein's ladder of citizen participation](image)

**Figure 2.3: Arnstein’s ladder of citizen participation**

The bottom rungs of the ladder are manipulation and therapy. These two levels have been contrived by some to substitute genuine participation, although they are actually non-participative. The aim is to cure or educate the participants. The proposed plan is best and the job of participation is to achieve public support by public relations.

Informing and consultation progress to levels of ‘tokenism’ that allow the have-nots to hear and to have a voice. Still, they lack the power to ensure that their views are followed up; there is no assurance of changing the status quo. Placation is a higher form of ‘tokenism’. It allows citizens to advice, but retains for power holders the right to judge the legitimacy or feasibility of the advice.

Further up the ladder are levels of citizen power with increasing degrees of influence on decision making. In a partnership, power is in fact redistributed through nego-
tiation between citizens and power holders. Planning and decision making responsibilities are shared, e.g. through joint committees. In the case of delegated power, citizens hold a clear majority of seats on committees with delegated powers to make decisions. The public now has the power to assure accountability of the program to them. Citizen control means that have-nots handle the entire job of planning, policy making and managing a program.

The typology of Arnstein helps us to define ‘participation’ in the context of development programs and projects. However, the ‘ladder’ of Arnstein also suggests that there is a highest level of participation. Many other authors have also emphasized that only higher levels of participation can lead to sustainable results (Chambers, 1994a,b, 1997; Pretty, 1994, 1995). Some, however, have indicated that there is no ‘best’ level of participation (Okali, 1994). Leeuwis (2004: 251-259), even questions whether descriptions of levels of participation are useful and whether it makes sense to strive to maximize participation. He raises various concerns, including amongst others:

- **The limited conceptual relevance of the notion of ‘decision making’.** ‘Eventual decisions’ usually do not result from a rational decision making process, but are influenced by various social processes, including learning and negotiation. One could argue that participation should not only be measured in terms of ‘decision making’, but also in terms of involvement in learning and negotiation.
- **Conflict management may require ‘top-down’ intervention and stakeholder exclusion.** Changes hardly ever occur without social tensions and conflicts. This may require process interventions, which are hard to imagine that they take place in a ‘fully participatory’ way and in agreement with all stakeholders.
- **The significance of agreed upon rules.** It is too simplistic to equal all forms of leadership and authority as ‘non-participatory’. Participants may agree to certain rules and hand over – temporarily – part of their own ‘power’ to others when they think that this may lead to better results (e.g. in case of a sports-team or an orchestra).
- **Innovation may require strong leadership within communities.** Meaningful change often does not occur without leadership. There may be a tension between fostering leadership and striving to full and equal participation.
- **The need to alternate between instrumental and participatory intervention.** Instrumental and interactive forms of communication can alternate successfully (e.g. instrumental forms may create appropriate conditions for interactive approaches, while interactive approaches may increase legitimacy of instrumental ones). Also in terms of cost-effectiveness, it may not be feasible to repeat the whole interactive process with every group of potential beneficiaries.
Participation is a scarce resource. Participation takes time, energy and resources. This means that participatory approaches need to be well prepared so that optimal use can be made of available time.

Boundaries posed by the politics of intervention and development. Participatory projects usually take place in a complex institutional setting. Various parties may have a different perception what it should be about. The ‘frames’ that become dominant are bound to constrain local participants.

In case of interactive approaches at the interface of HIV/AIDS and agriculture we need to be aware of the intervention and political dimensions of participation. We should not only ask ourselves who should participate, but also to what extent, when and how, participation is most effective.

2.3.3 Interdisciplinarity

Since the 1960s there is an increasing recognition that knowledge on technical, socio-economic and cultural aspects needs to be incorporated in the research process for developing sustainable (science-based) innovations (Cernea, 1991; Dusseldorp and Box, 1990). Since then, various multi- and interdisciplinary approaches have been developed and applied. What these approaches have in common is that information is collected in the following knowledge domains: the physical/ecological domain, the institutional domain, cultural/shared values domain, and the personal/intentional domain (see e.g. Bunders et al., 2000; Wilber, 1998). Various scientific disciplines are involved in knowledge generation within the different knowledge domains. The multi- and interdisciplinary approaches are, however, different in the way data collected within the different domains is integrated, as well as in the type of data collected. In multidisciplinary approaches, researchers from a variety of disciplines collaborate in one research program, but without integration of concepts, epistemologies or methodologies. More profound knowledge integration is achieved through interdisciplinary research. In this case, researchers from various disciplines work on the same topic with common objectives and research questions.

A fundamental criticism of the interdisciplinary approach is that, like in multidisciplinary approaches, ‘end-users’ are not necessarily and systematically included in the decision making process (see Jasanoff, 1990; Irwin, 1997; Wynne, 1992). It is still largely insensitive to the knowledge and interests of various stakeholders. With culturally distant and diverse end-users this may lead to misinterpretation and, consequently, inappropriate innovations (Scoones and Thompson, 1993). It was realised that local knowledge and different societal perspectives and interests needed to be included in the innovation process through the active participation of potential end-
users and other stakeholders (Cornwall et al., 1993; Scoones and Thompson, 1993). This gave rise to so-called transdisciplinary approaches (see Klein et al., 2001).

Transdisciplinarity is a recent trend within interdisciplinarity, and originated from the increasing demand for relevance and applicability of academic research and for new holistic views of knowledge; boundaries between and beyond disciplines are transcended, and knowledge and perspectives from different non-academic sources are integrated (see also Gibbons et al., 1994; Gibbons and Novotny, 2001; Klein et al., 2001). In contrast to multi- and interdisciplinary research, transdisciplinary research ensures a complete integration of knowledge through participation of a variety of stakeholders with conflicting interests (including end-users) and mutual learning between the different stakeholders. The context is an integrated part of the problem identification and eventual solution. Transdisciplinary research is characterised by its stronger orientation towards public perspectives and its practical, problem-solving efforts, comprising both empirical and theoretical components. Transdisciplinary problem solving has various strengths. It promises to identify problems earlier, to democratise science, to produce socially-robust knowledge, to allow contextualisation, to speed up implementation, and to integrate different kinds of knowledge and produce new insights and knowledge. Table 2.1 illuminates the character of inter- and transdisciplinary research in contrast to the single and multiple approaches.

The integration of knowledge is, however, far from easy and straightforward. It may be least complicated in those situations where the scientific knowledge is more compatible with the local knowledge system (e.g. participatory plant variety testing). Scientific knowledge is not per definition the exclusive domain for academic scientists. Local people experiment as well and develop people’s science, e.g. in farming practices (Richards, 1985). Also in situations where the physical environment has been transformed into a ‘natural’ laboratory, the integration of knowledge will become less complicated, since scientist and client perspectives converge. Methods for knowledge exchange and integration have been relatively successfully used in Participatory Rural Appraisal (PRA) (for problem identification, prioritisation and selection of options) and joint (both farmer and scientist) experimentation (see Chambers, 1994a,b; Reijntjes et al., 1992).

The integration of local and scientific knowledge becomes more complicated in situations which need the concerted action of a group of people (e.g. prevention of dengue fever or malaria). The various stakeholders involved need to develop a greater understanding of the multiple perspectives on complex problem situations, and arrive at least partially, at ‘a shared reality’ or ‘collective or distributed cognition’ as a
basis for ‘collective action’ (see e.g. Röling, 2000, 2002). Under these conditions, social influences will have an important effect in shaping the local knowledge system. Although scientific knowledge may still play a role, it is less dominant. In addition to the four basic areas of learning (i.e. perceptions, theory, values, action), cognitive change may (be facilitated to) take place with regard to perceptions of (various forms of) risk, self-efficacy, trust and social influence (Leeuwis, 2002).

There might even be a further complication for the integration of local and scientific knowledge for those problem situations which are ‘messy’, such as trypanosomiasis or HIV/AIDS. Ford’s (1971) description of the disease trypanosomiasis might be a good example. Trypanosomiasis was a disease that involved human worlds intersecting with animal host - insect vector relations, leading to complex modifications of epidemic patterns. In some cases populations learnt to live with their diseases, by developing an (often largely intuitive or behavioural) understanding of the way disease network connections were changing in response to human environmental impact. Ford saw this type of bio-social management as a kind of co-evolution. Dynamic ‘distributed’ (i.e. network wide) responses as a result of changing local notions may prove to be important in the eventual adaptation of populations to particular problem situations (Ford, 1971; Richards, pers. comm.). Where in case of trypanosomiasis a kind of ‘collective’ or ‘distributive’ cognition might have evolved over time, this is not yet the case for relatively new diseases, such as HIV/AIDS. Especially in the case of HIV/AIDS, local notions are often related to taboos, moral issues, and stigmatisation. This often leads to a revival of esoteric knowledge (such as witchcraft), often reflecting social tensions and conflicts between different social actors (Vangroenweghe, 1997). Transdisciplinary research might help to re-construct local notions (i.e. discourse) of social actors in a positive way to arrive at a network wide response to HIV/AIDS. It is questioned however whether approaches and methods applied in problem situations of relatively ‘low’ complexity, also work in these more complex problem situations.

5 Leeuwis (2002: 392) states: “In the case of ‘collective cognition’, coherence is forged primarily through shared perceptions, theories, values, and aspirations resulting in truly ‘collective action’. The idea of ‘distributed cognition’ recognises that stakeholders may well work together and engage in complementary (e.g. coherent) practices while significant cognitive differences remain. Here ideas, values and aspirations may be overlapping or mutually supportive, but are not necessarily ‘shared’.”

6 This does not mean that relatively ‘old’ diseases, which have been present for a long time, are not a problem. Because of rapid changes over space and time, a ‘collective’ or ‘distributed’ cognition may break down, or not be able to adapt to new challenges.

7 Also people-wildlife conflicts often reflect tensions between different social groups, sometimes expressed in notions related to witchcraft (Knight, 2000).
### Table 2.1: The character of single-, multiple-, inter- and trans-disciplinary research (after Allbrecht et al., 1998)

<table>
<thead>
<tr>
<th></th>
<th>Problem/ problem boundary</th>
<th>Teamwork/collaboration</th>
<th>Role of conceptual framework</th>
<th>How knowledge is applied</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Single-disciplinary</strong></td>
<td>The problem is what a single discipline thinks it to be.</td>
<td>None.</td>
<td>Arises from a single discipline.</td>
<td>Production of ‘specialized’ knowledge and reductionistic accounts of problem or intervention.</td>
</tr>
<tr>
<td><strong>Multi-disciplinary</strong></td>
<td>The problem is what several disciplines working independently think it to be; hard disciplinary boundaries are placed around the problem facets.</td>
<td>None or limited; disciplines work independently on distinct facets of a broadly conceptualized problem.</td>
<td>Mutually exclusive conceptualizations juxtaposed and broadly cumulative.</td>
<td>Interventions suggested by isolated, discipline-specific problem explanations.</td>
</tr>
<tr>
<td><strong>Inter-disciplinary</strong></td>
<td>The problem is what several disciplines working together agree it may be. Aspects of the problem from disciplines not included may be ignored. The health problem is defined by the totality of ‘soft’ boundaries between the various disciplines working together.</td>
<td>Collaboration using limited knowledge-bases. Different disciplines address inter-connected aspects of a specifically defined problem, mainly bringing to bear their own theories and conceptual frameworks.</td>
<td>Isolated explanations of a problem from a limited number of disciplines are assembled and connections among them are sought.</td>
<td>Interventions sensitive to an explanation of the problem informed by understanding the connections among participating disciplines.</td>
</tr>
<tr>
<td><strong>Trans-disciplinary</strong></td>
<td>The problem is defined as part of an open, dynamic system operating at multiple levels. The problem broadly expands to include all relevant disciplinary and local insights.</td>
<td>Open-ended collaboration. All disciplinary and local insights required to define the problem are assembled.</td>
<td>Common conceptual framework is sought which will be usable by any discipline (or non-discipline), achieving a new insight about the problem.</td>
<td>Interventions with the greatest possibility of success follow from a synthesis of knowledge from disciplinary collaboration and local perspectives.</td>
</tr>
</tbody>
</table>
To make approaches effective and partnerships sustainable, we need to explore the ‘nature’ of the problem and build on local knowledge and dynamics (see Honkon- nou, 2001). It is clear that in complex problem situations, the integration of both scientific and local knowledge systems may have an important positive impact on the problem situation. Still there is a need to gain better insight into how we can enhance knowledge integration consistently over longer periods of time.

2.4 Concluding Remarks

Interactive approaches have been applied rather successfully to address various agricultural and health problems (although many constraints and difficulties have also been described). Often, however, it concerns problems of relatively low complexity. For example in agriculture, local ‘farmer’s science’ is not that very different from the ‘nature’ of academic science. Interactive approaches seem, however, even more relevant for more complex problem situations, such as HIV/AIDS – i.e. when a wider variety of societal actors is (needs to be) involved and non-scientific knowledge becomes more influential.

It is questioned, however, whether the methods, which are used for knowledge integration in the field of less complex problem situations, also work for these more complex problem situations. It is anticipated that the process of integration and its validation become more complicated as the local and scientific knowledge systems become increasingly more varied and different in ‘nature’. It is expected that a better insight in the impact of HIV/AIDS on rural livelihoods and the process of ‘innovation’ will contribute to a further specification of the use of interactive approaches in the context of HIV/AIDS.
Chapter 3

Research Design

“There is no single objective reality and one way of knowing, but only ‘multiple realities’ constructed by human beings.”
(Guba and Lincoln, 1989)

3.1 Objectives and Relevance of the Study

The overall objective of the present study is:

\[
\text{To contribute to the (further) development of a conceptual and methodological framework for interactive approaches to agricultural innovation in the context of HIV/AIDS; this in order to realize better informed, more sophisticated and effective development programs for the improvement of food security and well-being among poor and HIV/AIDS-affected households.}
\]

Specific objectives are:

a) to gain a better understanding of the process of agricultural innovation within interactive practices in the context of HIV/AIDS;
b) to develop a (general) methodological framework for the facilitation and realization of agricultural innovation in the context of HIV/AIDS;
c) to contribute to a better informed, more sophisticated and effective interactive practice to agricultural innovation in the context of HIV/AIDS for sustainable rural development.

It is anticipated that participation of various stakeholders and integration of different perspectives becomes more complicated as the variety of relevant societal actors increases and the local and scientific knowledge systems become increasingly different in ‘nature’. It is expected that a better insight in the relation between HIV/AIDS and people’s lives and the process of developing ‘appropriate’ agricultural innovation(s)
through joint collaboration, contributes to a further specification of interactive approaches at the interface of HIV/AIDS and agriculture. This is not only scientifically relevant, but also socially. Interactive approaches to the development of ‘appropriate’ agricultural innovations may be a sustainable alternative to the improvement of food security and well-being among many rural families in Africa that (partly) depend on agriculture as a source for food and income. Moreover, without more effective strategies to address the HIV/AIDS epidemic, it may be impossible to reach the Millennium Development Goals, agreed on at the United Nations Millennium summit in 2000, with the overall objective to cut world poverty by half by the year 2015 (UN General Assembly, 2000; UN, 2004).

Based on the objectives, this chapter gives an overview of the research questions, the methodology (including the case description), validity checks, and the ethical guidelines that were adopted during the study.

### 3.2 Research Questions

As mentioned in the previous chapter, interactive approaches are most relevant for complex problems, such as HIV/AIDS, but it is questioned whether the methods, which are used in less complex problem situations, also work for these more complex problem situations. Interactive approaches are a relatively new phenomenon; especially at the interface of HIV/AIDS and agriculture there is not that much experience. Interactive approaches are rarely systematically analysed. Successful experiences, where they exist, are limited to the localities where they are implemented, and proven mechanisms for replicating or up-scaling are still lacking.

Therefore, the main research question is:

> Which key issues and strategies can be identified to realize effective interactive approaches to agricultural innovation in the context of HIV/AIDS?

The main research question falls apart into the following sub-questions:

I. **What are the key issues in the design and implementation of interactive approaches to agricultural innovation in the context of HIV/AIDS?**
   - What lessons can we draw from practice?
   - What challenges can be identified in the context of HIV/AIDS?
   - What are the methodological implications of these challenges?
II. How can the identified methodological elements as a tentative framework for interactive approaches to agricultural innovation be applied in the practical context of HIV/AIDS?

a) How can the selected problem situation be characterized?
   - What is the impact of HIV/AIDS on poor and HIV/AIDS-affected rural households and individuals?
   - What are the underlying factors and mechanisms that drive the HIV epidemic and its impact?
   - What innovations and strategies can be identified and devised to prevent and mitigate the impact of HIV/AIDS on rural livelihoods of households?

b) How can interactive approaches to agricultural innovation in the context of HIV/AIDS be made more effective?
   - How effective is the tentative methodological framework to stimulate and sustain innovation development to prevent and mitigate the impact of HIV/AIDS on rural livelihood of households?
   - How can the methodological framework be further specified based on practical experiences?

3.3 Methodology

In this section, a description is given of the general approach, as well as a detailed case-description, the research methods and techniques that were used during the study and the research team.

3.3.1 Approach

The study starts from the viewpoint that social actors can have different perceptions on the same matter. Guba and Lincoln (1989) say that there is no single objective reality and one way of knowing, but only ‘multiple realities’ constructed by human beings. These multiple ‘realities’ are not governed by a limited set of causal relationships, but actively given shape and meaning by ‘social actors’, in other words they are socially constructed. Therefore the research is an explorative study. This means that the purpose of the research is to understand and interpret the reasons for people’s social actions, the meaningful relationships which different groups of people conceive and engage in, and the practices and interactions which emerge from that. In explorative research ‘statistical significance’ of relations between the empirical phenomena which are described is not important. Its validity is based on what is called the ‘sociological
significance. This implies that the researcher’s interest is to assess whether the descriptions of these conceived relationships, are meaningful, understandable, and convincing for the people involved and for the outside world (Guba and Lincoln, 1989).

Action-research is used to increase resistance and resilience of affected households to HIV/AIDS, and to improve the understanding of the constraints and opportunities among stakeholders to accomplish this. Action and research guide each other in an iterative way, increasing both action and research outcomes. Social events are studied within their social and natural context, focusing on ‘local relevance’, instead of ‘global relevance’. Extrapolation is based on the validity of the analysis rather than the representativeness of the studied events. The aim is to understand and develop strategies that households can employ to reduce susceptibility and vulnerability to HIV/AIDS in a specific context; results can then be compared to other initiatives and inform new ones. Rigor of the research process is retrieved by following an iterative, ‘spiral-like’ procedure whereby information and interpretations from earlier phases in the project are challenged in later phases. Both data collected as literature read are part of this. Questions and methods are gradually refined along the way, leading to a better understanding of the situation being studied.

In answering the main research question, both theoretical and empirical research is needed. The research design consists of two elements: 1) case study analysis, comprising literature review and interviews in relation to interactive practice and HIV/AIDS; 2) practical testing of identified methodological elements in the context of HIV/AIDS. The overall process is not a linear succession of both phases but a dynamic and cyclic process in which tentative results of the case study analysis are tested and refined in the practice of the interactive research approach in an iterative way. This does not mean, however, that there is not a logical order of research questions. The research process will start with addressing research question 1, followed by question 2a and question 2b. Throughout the research process, a flexible approach was adopted. The collection of data was not tightly organised in advance. Depending on what was heard and seen, and practical limitations, the planning of the research process was adapted when necessary. In time, the research questions are addressed in a parallel and iterative way throughout the research process.

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8 According to some academics action research or interactive approaches is not ‘scientific’, as the role of the scientist changes from ‘developing knowledge’ to facilitating interactive processes with various social actors. However, others have responded to this criticism by emphasising that it may contribute to reflection and theory on interactive processes, which does not mean that other actors cannot be involved. The research may also contribute to the development of new methodologies and methods as result of reflection on processes. There is, however, a lot of discussion whether science should restrict itself to reflection, instead of taking part in the process itself. However, taking part in the process may lead to ‘tacit’ knowledge which is difficult to understand or derive as an ‘outsider’. Therefore, it was decided to take an active role in the project.
The main research method which is used is the case study. The selection of the case is guided by the possible contribution to certain conceptual problems, and to an improved understanding of the research problem that it promises to deliver. For this thesis, the study area of Msinga in the Province of KwaZulu-Natal in South Africa was selected. The case study is ideal for the purpose of this research in the sense that it is a HIV high-prevalence area and a rather typical rural traditional area in sub-Saharan Africa in terms of farming-livelihoods. It is a-typical, however, in the sense that South Africa has a relatively good health and social support system, while it recently started with the roll-out of ARVs. Experiences in a setting like this may provide interesting insights for other countries in sub-Saharan Africa as well.

3.3.2 Case Description

To test the outcome of the case study analysis – in terms of methodological elements – it is needed to start from a broad practical framework for interactive research and apply this in an a specific development context – in this case the Msinga sub-district in KwaZulu-Natal, South Africa. Msinga is one of the four Local Councils in Umzinyathi District, an area of 1762 km2, and an estimated population of 160,000 people. Msinga is a traditional rural area, with an estimated HIV prevalence over 20%. In the last few years, a network of HIV/AIDS services has been developed in this area, varying from Voluntary Counselling and Testing, Mother to Child Transmission Program, treatment of opportunistic infections, TB DOT program, home-based care (HBC), a hospital, ARV treatment (still in development), a hospice, support groups, place of safety, and social welfare grants (see Box 3.1 for more background information on the HIV/AIDS epidemic in South Africa and its response).

One of the main organisations to support HIV/AIDS infected and affected people and responsible for the HBC-system in the Msinga is a community managed health centre. In 2003, the health centre started to establish support groups around HIV/AIDS and food security. With the help of HBC workers, people from affected families were identified who were willing to participate. Three groups were initiated. These groups were distributed over several Traditional Authority areas. The sizes of these groups varied from 35 to 64 members and consisted predominantly of female farmers, varying in age. The groups were represented by elected committees. Although irrigation farming is present in Msinga sub-district, most of the support groups were farming in rain-fed areas, where the impact of HIV/AIDS is likely to be worse.
Chapter 3

Box 3.1: The HIV/AIDS Epidemic in South Africa and its response

The first case of AIDS in South Africa was reported in 1982. Home to more than 5.7 million people living with HIV, South Africa is one of the countries hardest hit by the HIV/AIDS epidemic. HIV prevalence in South Africa is 18.1%. Women account for over half (59%) of adults aged 15 and over estimated to be living with HIV in South Africa. In 2007, an estimated 350,000 South Africans died of HIV/AIDS-related diseases. HIV/AIDS-related diseases have been cited as the major cause of premature deaths in the country – AIDS-related deaths are estimated to have accounted for nearly half of all deaths in 2006. Overall death rates, from all causes, have increased by about 80% largely due to HIV/AIDS. HIV is spread primarily through heterosexual sex in South Africa.

The epidemic has already had a profound impact on many aspects of South African society and is projected to affect the country’s demographic structure and its economic, education, and health sectors if not more is done. There is significant variation in the epidemic’s impact by region, with the highest rates occurring in KwaZulu-Natal and Mpumalanga, and the lowest in the Western Cape and Northern Cape. Recently the Government of South Africa started with the roll-out of antiretroviral medicines (ARVs) for free; it is planning to scale-up access to ARVs over the next few years.

The mission statement of the National HIV and AIDS and TB Program is to: (a) prevent the spread of HIV, STI and TB infections, and (b) to mitigate the impact of the dual HIV and AIDS and TB epidemics on society. The country, and the Department of Health, is guided by the HIV and AIDS/STI Strategic Plan for South Africa, 2000-2005, and the TB Medium Term Development Plan. These plans aim to improve multi-sectoral participation, and to ensure that all spheres of society play an active role in the achievement of the goals of these strategic plans.

Since several years, local health centres have been set up to support HIV/AIDS infected and affected people. These often community managed health centres in which several governmental departments (i.e. Department of Health, Department of Social Development, Department of Agriculture, and Department of Education) have combined efforts. In South Africa they often work closely together with lay workers (home-based carers, lay counsellors, DOT supporters etc.) principally in response to an expansion in budgets and programs for HIV, most recently the roll-out of antiretroviral therapy (ART). In 2004, the term community health worker was introduced as the umbrella concept for all the community/lay workers in the health sector.

Source: HIV/AIDS Policy Fact Sheet, July 2008
In 2003, the community-managed health centre in Msinga initiated an action research project in collaboration with an agricultural NGO from the University of KwaZulu-Natal and the Athena Institute from the VU University Amsterdam. Role players in agriculture and health were brought together to mitigate the impact of HIV/AIDS among rural households. The aim was to stimulate discussion among support groups of HIV/AIDS-affected people, mostly women, on how HIV/AIDS impacts on their lives, to discuss and negotiate ways of protecting themselves against HIV and the impact of AIDS, and to achieve food security and well-being at the household level through agricultural innovations in the context of HIV and AIDS.

A specific participatory methodology selected for this study, which is appropriate for the purpose of agricultural innovation based on mutual learning between different stakeholders, is the Interactive Learning and Action (ILA) approach developed by the Athena Institute of the VU University Amsterdam (VUA) in the Netherlands (Broerse, 1998; Bunders and Broerse, 1991) (see Box 3.2). The approach falls within the family of Participatory Action Research. The approach can be applied for different kind of problem situations, and has been applied successfully in several countries, including countries in Asia and Africa.

**Box 3.2: The Interactive Learning and Action approach (ILA)**

The Interactive Learning and Action (ILA) approach was originally been developed by members of the Athena Institute for gearing agricultural innovations towards the needs and interests of small-scale farmers in developing countries (Broerse 1998; Broerse and Bunders 1999; Broerse and Bunders 2000). However, the approach has also been applied to patient participation in health care in the Netherlands (Caron-Flinterman et al., 2005).

The ILA approach should not be regarded as a blueprint; it provides principles and guidelines. Within these boundaries, it has to be adapted and specified to the specific context of application. The seven principles of the ILA approach are:

a) Small scale farmers and/or other beneficiary groups play a prominent role in decision making;
b) The innovation process is based on a shared vision;
c) The development of trust relationships is facilitated. Trust is recognized as crucial if team members are to obtain sensitive information and tacit knowledge. It also encourages mutual learning and risk-taking behaviour;
d) Mutual learning between participants is facilitated; reflexivity is a key element, as well as feedback and feed-forward mechanisms;
Box 3.2: (continued)

e) Coalition building is enhanced to ensure the availability of sufficient and appropriate support (i.e. endorsement, backing, approval, and legitimacy) and resources (i.e. knowledge, funds, materials, and time) to maintain momentum;
f) Different types of knowledge are integrated, particularly formal and informal knowledge and knowledge from different stakeholder groups;
g) An interdisciplinary team facilitates the process.

The activities can be roughly divided into the following phases:

1) *Initiation and preparation* In this phase, the interdisciplinary team is established and gathers preliminary, contextual information. Project objectives, tasks and roles, cost norms and other guidelines for management and implementation are further specified.

2) *Collection, exchange, and integration of information* In this phase, perspectives, needs and interests of the different actors are identified and analysed and an inventory is made of past and current research related to the topic of interest. Meetings and workshops are organised for exchange and integration of identified knowledge, perspectives, and needs of the actors.

3) *(Public) priority setting and planning (agenda setting)* This phase allows all actors involved to review and reflect upon preliminary results from the previous phase, to set priorities, and to establish a detailed plan of action.

4) *(Program) implementation* The plan of action produced in the previous phase forms the input to the fourth phase, in which specific programs or projects are formulated and implemented.

The phases can be broadly distinguished on the basis of their chronology; the outcome of the previous phase being the input for the next. However, the phases overlap, as each consists of activities which may be undertaken several times in a different order throughout the process. In this way, an interactive and iterative, instead of linear process, evolves.

Besides these general guidelines on how to structure activities, the ILA approach includes a rich tool kit of methods and techniques for knowledge integration and interaction from which the research team can draw as required. These method and techniques range from literature study, various types of interviews and questionnaires, to a wide variety of group-based methods such as focus groups and workshops, designed for different purposes including brainstorming, dialogue, integration, and consensus. Also various visualisation, diagramming and prioritisation techniques are included.
Within the boundaries of its key characteristics, the ILA approach had to be adapted to the context of HIV/AIDS. A few decisions were made. Since the marginalized position of women and the silence surrounding HIV/AIDS were seen as a major concern, the project emphasized capacity building and organisational development among women through a process of group-based learning, while the concern for safety and confidentiality was taken seriously.

The project took place from November 2003 to June 2006 with financial support from the RENEWAL program of IFPRI and the VU University (see Figure 3.1. for an overview of activities). The first three phases of the ILA approach took place from November 2003 to September 2004. During the initiation and preparation phase a project team was established, a first assessment was made of the local setting, contact was made with the local community, and agreement was reached between stakeholders on general issues and procedures for collaboration. Basic data was collected through reports and interviews with key informants and different social groups to obtain general information about the project area, health, agricultural and social conditions, informal and formal networks, and perceptions, attitudes, and practices in relation to HIV/AIDS. In addition a literature review was conducted on innovation development in relation to HIV/AIDS and agriculture; relevance was analysed in the context of this case study, leading to a ‘tentative methodological design’. Finally a meeting with key stakeholders was held to come to a shared agreement and commitment on a collaboration to prevent and mitigate the impact of HIV/AIDS on people’s livelihoods. A joint proposal was submitted and granted by the RENEWAL program of IFPRI, and ethical approval was obtained.

During the second phase, information was collected in relation to the constraints, needs, and interests of different stakeholders involved. The team organised dialogues with key stakeholders, and analysed and integrated information and knowledge. In this phase promising innovations and strategies to prevent or mitigate the impact of HIV/AIDS among affected families were identified. It started with an appraisal of the situation in relation to rural livelihood, farming and HIV/AIDS from each of the actors involved. This was also the stage in which more information was retrieved on constraints and opportunities to change the situation. In undertaking this activity, the team generated awareness of the process on the part of relevant individuals and institutions, enlisting their support for later activities. This phase allowed all involved

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9 Women are not only more susceptible than men and boys to contract HIV, but they are also more vulnerable to the impact of AIDS, e.g. as care taker or as result of property grabbing when they become widow.(see Barnett & Whiteside, 2002; Swaans et al., 2008b).
to obtain a basic understanding of the relevant issues and points of view of the various participants. In addition, it was the objective to come to a shared understanding among the different social groups and stakeholders of the problem situation, and constraints and opportunities of identified innovations and strategies to change this situation. Furthermore, in this phase a basic training on sustainable farming, committee skills, and business administration was given among representatives of the support groups.

During the third phase stakeholders sought consensus on priority issues, common goals and plan of action. Therefore, a workshop/meeting was organised with relevant stakeholders. Although farmers or others may decide they wish to test relevant options at any stage of the process, it is advisable at some time to organise and hold a priority setting and planning workshop that brings together all actors involved. The objectives of such a workshop/meeting are: (1) to allow review and criticism of the team’s findings by a wider audience, (2) to legitimise the findings, (3) to allow room for new contributions, (4) to enhance the visibility of the needs of the farmers, and (5) to establish a plan of action. Discussions at the workshop should lead to consensus on the most important topics to be tried out. The plan of action that resulted from this phase formed the input to the fourth phase, in which specific projects were formulated and implemented.

The fourth phase of the ILA process covers the implementation, i.e. the phase in which participants determine and take action, monitor progress and evaluate results. A first learning cycle bridged the period October 2004 to September 2005. A second learning cycle was conducted from October 2005 to June 2006. Sessions were organised with each support group to develop a training curriculum based on the action plan. A variant from the Farmer Field School, i.e. the Farmer Life School (FLS), was used for group-based learning and joint experimentation in order to stimulate farmers to monitor and analyse their own situation and activities. In regular meetings results of the projects were evaluated and adapted. Evaluation through interviews, focus groups, and feedback-workshops took place in relation to process and outcome, after each learning cycle; former phases were revisited for the further adaptation and refinement of the framework. In this way farmers and stakeholders learn respectively through FLS sessions and partner meetings (1st order learning); farmers and stakeholders learn how to learn through reflection (2nd order learning).\(^{10}\)

\(^{10}\) There might even be learning about learning how to learn through this thesis (3rd order learning).
Figure 3.1: Flow diagram of the various phases and activities conducted in the action-research project in Msinga from November 2004 to June 2006.
3.3.3 Research Methods and Techniques

As the study aims to design, analyse and further develop an interactive methodology based on theory and practical experiences, a variety of research methods were included. The research procedure took place in a phased fashion based on the research questions.

The first sub-question, focusing on the key issues for design and implementation of interactive approaches at the interface of HIV/AIDS and agriculture, comprised a more conceptual study. Its results served as input for a ‘tentative’ conceptual and methodological framework. The second sub-question concerned the practical application of the ‘tentative’ design in the context of a HIV high-prevalence area. The first part of the second question, focusing on constraints, opportunities, and potential innovations and strategies for the implementation of interactive approaches, mainly involved descriptive-analytical research related to the case study. Findings were used to adapt and further specify the design of the interactive approach. The second part, whereby identified innovations/strategies were implemented and tested in practice, was more action-oriented. It involved the monitoring and evaluation of a specific method (the FLS), as well as the monitoring and evaluation of the overall approach (the ILA).

The different units of observation and analysis that can be distinguished in the study were:

- Individual members from poor and HIV/AIDS-affected families;
- The lives of poor and HIV/AIDS-affected households (and their social networks);
- The support groups for members of poor and HIV/AIDS-affected households;
- The actor network within this project;
- The larger ‘community’ (local and institutional context) of each support group.

Qualitative methods, such as interviews, focus groups, discussions, often using visualisation techniques, were used to allow individuals or groups to express themselves from their own perspective; quantitative elements, for instance in the form of a questionnaire, were used when appropriate to get a better understanding of the diversity and representativeness of basic characteristics.

Below, the different parts of the study and methods used, including the ways of sampling, data collection and analysis, are shortly described. Further details can be found within the different chapters.
**Part I: Key Issues for Design and Implementation**

The first part of the study aimed to gain insight into the main lessons and challenges with respect to the design and implementation of interactive approaches to agricultural innovation in the context of HIV/AIDS. It was mainly based on literature review and interviews/discussions with researchers, development practitioners, and extension workers in the field of agriculture, rural development and HIV/AIDS in South Africa:

- A *literature review* was carried out to derive key issues and strategies with regard to the design and implementation of interactive approaches. Because experience with interactive approaches at the interface of agriculture and HIV/AIDS was limited, the review mainly focused on case study analysis in the field of agriculture and natural resource management. Literature was also used to support findings related to specific challenges in the context of HIV/AIDS.
- In addition to the literature review, various *interviews and informal dialogues* were held between April 2003 and June 2004 with researchers, practitioners, and extension workers related to the published case studies or to the topic of HIV/AIDS. This contributed to a better understanding of interactive approaches and the complexity of the problem situation. Moreover, it revealed information which had not been published.
- Furthermore, a *group discussion* was organised in November 2004 in KwaZulu-Natal with representatives of (research) institutes, governmental and non-governmental organisations from the provincial and national level in realm of the above mentioned collaboration to develop strategic recommendations for interventions on HIV/AIDS and food security.

Literature and reports from interviews, informal dialogues and the group discussion were analysed with regard to key issues, themes and challenges, for interactive approaches at the interface of HIV/AIDS and agriculture.

**Part II: The Practical Application of the ‘Tentative Design’**

The analysis of the first part of the study resulted in a ‘tentative’ conceptual and methodological framework for the facilitation and realization of agricultural innovation in the context of HIV/AIDS. The second part of the study concerned the application of the ‘tentative’ design in the HIV high-prevalence area of Msinga (South Africa). Role players in agriculture and health were brought together to improve food security and well-being among poor and HIV/AIDS-affected households. Members of three support
groups, representing 146 households, participated in the study. Mainly women were selected as they are generally responsible for food production in the households, and they also face the burden of the HIV/AIDS impact as caregivers and childminders.

*a) The Characterization of the Problem Context*
First, an assessment was made of the current situation. It involved an in-depth study of the factors and mechanisms that contribute to the impact of HIV/AIDS, as well as the identification of ‘innovations’ and strategies to prevent and mitigate the impact. The study focused in particular on the role of HIV/AIDS-related stigma and discrimination, which emerged as one of key issues in the context of Msinga.

From April to July 2004, the members of the three support groups were consulted about the impact of HIV/AIDS on their lives. As the study aimed to explore how people cope with the impact of HIV or AIDS, ethnography was found most appropriate for collecting and connecting results gathered through fieldwork. The study was carried out in three steps: focus groups, a questionnaire, and in-depth interviews:

- To explore people’s perceptions of livelihood and farming two *focus groups* were organised with each support group. Participation in each focus group varied from 7 to 11 people. Visualisation techniques served as a basis to discuss household structure and daily life; the roles of women, men and children; socio-economic profiles; and the relation between farming and rural livelihood.

- Based on the focus groups and the livelihoods framework, a *questionnaire* was designed to explore the diversity among households and their relation with HIV/AIDS. In total 129 Zulu-speaking individuals responded to the questionnaire, almost all women, between 21 and 80 years old. The questionnaire was divided into five sets of open and closed questions related to household structure, rural livelihood, farming, health and HIV/AIDS.

- *In-depth interviews* were conducted with HIV-infected or -affected support group members to get better insight into the impact of HIV or AIDS on people’s lives and how they respond to it. In total 10 participants were selected. They differed in several aspects, such as young/old, male/female, HIV-infected and using/not using ARV medicines, or affected by illness/death/taking care of orphans. The in-depth interviews were guided by a list of topics related to the way a participant might cope cognitively, emotionally and practically with HIV or AIDS in their household.

The data on the impact of HIV/AIDS on people’s lives were analysed with support of an adapted livelihoods framework. The qualitative data were categorised in topics and clustered according to larger themes. Where appropriate, the findings were
quantified with data from the questionnaire. The data from in-depth interviews were analysed for similarities and differences in impact and response.

In addition to the impact of HIV/AIDS, a study was conducted on stigma and discrimination from April to June 2005. Perceptions and experiences of stigma were explored from various perspectives (support groups, men and women, young and old, the health care system). The research procedure took place in a phased fashion using a range of participatory methods and techniques with different target groups:

- HIV/AIDS-related stigma and discrimination was first explored among members of support groups for women living with HIV/AIDS. Two focus groups, one with 7 and one with 5 participants, were held to gain insight into their experiences of stigma and discrimination and the strategies they employed to cope with it.
- Stigma as expressed in the communities was further explored with women of one of the support groups for poor and HIV/AIDS-affected households. Four focus groups, with respectively 5, 5, 4 and 12 participants, were held to get a better understanding of various manifestations of stigma amongst this group. In addition, in-depth interviews were held with 3 members of one of the support groups.
- To examine the diversity of stigma, the information retrieved during the former steps was verified and discussed during a focus group with 6 HIV-infected men and a focus group among youth – 10 boys and 10 girls – of a local high school.
- To gain more insight in the (personal) experiences of health care providers with stigma and discrimination and consequences for health interventions, in-depth interviews and informal conversations were held with 3 HBC workers, the head of the HBC-program, a social worker, VCT- staff, and the head of the antiretroviral (ARV) program of the local hospital.

The data on stigma and discrimination was subjected to thematic analysis based on a conceptual framework to analyse manifestations and consequences of stigma and discrimination in relation to their social context.

*b) Testing and Evaluation of the ‘Tentative’ Framework*

Innovations and strategies identified to address the impact of HIV/AIDS in general, and HIV/AIDS-related stigma and discrimination in particular, were implemented within the context of the overall project. The FLS was identified as a specific method suitable for group- and discovery-based learning among support group members as part of the overall approach (ILA). Both the FLS and the overall ILA were monitored and evaluated for their effectiveness and to identify lessons for further specification of interactive approaches to agricultural innovation in the context of HIV/AIDS.
As the FLS is a relatively new method, a pilot study was conducted among the three support groups in Msinga. Although the pilot in South Africa was designed according to the main principles and guidelines of the FLS (Chhaya et al., 2004; du Guerny et al., 2002), it was adapted to the local context for practical implementation. A relatively 'short' curriculum was developed, inspired by the main concepts of the FLS, but with an emphasis on group building through participation and (discovery-based) learning. It was based on a livelihoods perspective, gradually shifting the focus from agriculture to health and HIV/AIDS, while emphasising linkages between them. From October to December 2004, a 6-week trial was conducted with each group. The FLS, including sessions and follow-up visits, was organised for one growing season. As this was an exploratory study on the strengths and weaknesses of the FLS method in a HIV high-prevalence area, qualitative methods were found to be most appropriate for monitoring and evaluation:

- **Extensive reports** were drawn up of the FLS sessions for post-hoc analysis. These contained detailed descriptions of the methodology, setting, conditions, attendance, presentations, discussions, group dynamics, experiments, and progress. In addition, field reports were maintained for the remainder of the season.
- In January 2005, experiences from participants were captured by **semi-structured interviews**, to obtain more insight into the influence of HIV/AIDS on participants and the garden groups. In total, 14 people (13 women and 1 man, between 26 and 67 years of age) were selected. Participants varied in their degree of participation during the FLS sessions, personal situation and HIV/AIDS impact. Questions were related to the effectiveness of the sessions and influencing factors.
- In May 2005 the overall design, content, expectations, and outcomes of the project in general, and the FLS sessions in particular, were evaluated. Discussions were held with each group and interviews were conducted with key persons. In addition, a discussion was held with the facilitation team and the overall project coordinator.

Qualitative data were subjected to thematic content analysis (Flick, 1992), using the key elements of the FFS/FLS, i.e. participation, learning, and empowerment (Braun et al., 2006; du Guerny et al., 2002; Pontius, Dilts and Bartlett, 2000), and respective subdivisions as the core categories of the coding frame.

The overall methodology was evaluated from March to May 2006. The method of ‘responsive evaluation’ was applied to evaluate the ILA approach on the extent it realized effective participation and interaction (Greene and Abma, 2001). It is not only qualitative but also participatory, including views from all relevant stakeholders. A stepwise process of data collection, analysis and validation was initiated:
The first step concerned data collection from project documents to reconstruct important activities and events.

To gain information on perspectives and experiences, semi-structured interviews were held with 3 members of the project team, 4 representatives of project partners, 6 members of each support group (representatives, active and non-active members), and 2 other relevant stakeholders. Questions addressed the evaluation criteria as well as the interviewees' experiences and feelings.

The photo-voice method was used to add and validate the information gained from support group members. Photo-voice is a participatory action strategy to enable people to identify, record, and represent their own perspectives on important issues in their life, and is an innovative way to access information about the impact of development interventions; 12 support group members (4 from each group) were selected and interviewed about the stories behind the pictures.

Based on the analysis of the interviews, separate validation sessions were held with the project team and each support group. To stimulate reflection and discussion in the support groups, the members that participated in the photo-voice method were asked to present a selection of their pictures.

Interviews were recorded and interview reports were analysed by coding (Flick, 1992) based on an evaluative framework that was developed for this study. Detailed notes were made during the sessions and newly derived insights and information was integrated in the overall analysis.

In Figure 3.2, an overview is presented of the relation between the different types of research, the research questions, and the chapters in which the questions are addressed in this thesis. The conceptual part of the study addresses question 1. It aims to identify the key issues – based on lessons and challenges – for design and implementation of interactive approaches to agricultural innovation in the context of HIV/AIDS. This is addressed in chapter 4. Outcomes of the conceptual study inform the design of the ‘tentative’ conceptual and methodological framework that is applied in the practical context of Msinga. The descriptive-analytical part of the study addresses question 2a. It characterizes the problem situation in Msinga in terms of impact of HIV/AIDS, the underlying factors and mechanisms, and potential innovations and strategies that can prevent or mitigate the impact of HIV/AIDS; outcomes further shape the design of the framework. Findings are discussed in chapter 5 and 6. The action-oriented part of the study addresses question 2b. The effectiveness of the applied methodology and suggestions for improvement are discussed chapter 7 and 8. Finally, the main research question is addressed in chapter 9, by relating the findings and conclusions of the various chapters with each other.
Chapter 3

3.3.4 Research Team

The descriptive-analytical study, which was conducted within the overall framework of the ILA approach, was a team effort. For the study on the impact of HIV/AIDS on people’s livelihoods, the research team consisted of six persons: the PhD-fellow and a Master-student from the Athena institute, the coordinator of the overall project and a community facilitator from the agricultural NGO, and two translators/collaborators. The team discussed the reports of the focus groups with respect to clarity and differences between the groups. To complete the questionnaire, support group members were interviewed at home by one or two people; the data were integrated in a spreadsheet to obtain an overview and more insight. In-depth interviews were conducted by two females, i.e. the Master-student of the Athena Institute and one translator; interviews were recorded and transcribed into English. The interviews and focus groups

Figure 3.2: Visual presentation of the relation between various types of research, the research questions and the chapters in which the questions are addressed.

3.3.4 Research Team

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on stigma and discrimination were conducted by a female Master-student from the Athena Institute in collaboration with a female and/or male translator. Information of the focus groups was noted down and worked out directly afterwards. In-depth interviews were recorded on tape and transcribed into English. The transcripts were reviewed by the collaborators/translator.

The action-oriented part of the study was also a joint collaboration. The team that conducted the pilot with the FLS consisted of two community facilitators from the agricultural NGO and two researchers (the PhD-fellow from the Athena Institute, and a Master-student from Wageningen University in the Netherlands). All had extensive training in participatory approaches. For the facilitation of specific topics, (local) professionals were invited. The researchers of the facilitation team produced detailed reports of each FLS session, which were validated by the other team members. Field reports were maintained by the community facilitators and discussed with the overall coordinator of the project. Follow-up interviews were conducted by the Master-student with the help of a translator (both female). Interviews were recorded and subsequently transcribed into English. A freelance South African researcher conducted the reflection process with the support groups and the project team. The evaluation process of the ILA approach was facilitated by a Dutch Master-student of the Athena Institute in collaboration with two community facilitators from the agricultural NGO.

During this period, the author alternated between the VU university Amsterdam (the Netherlands) and the agricultural NGO in Pietermaritzburg (South Africa). In total he spent six periods (varying from 2-4 months) in South Africa for data collection and preliminary analysis. In addition, he was involved in the overall monitoring and evaluation of the project from November 2003 till June 2006.

3.4 Validity

Various strategies have been used in order to enhance the validity of results and conclusions and to minimize effects of researcher bias and influence. The following strategies are shortly described: triangulation; observation, informal talks and meetings; staying in the research area for longer periods; checks of preliminary findings among the research population; discussion with research-peers; and the involvement of independent researchers.

The main strategy to enhance validity was triangulation, i.e. the exploration of various data sources with various methods, whereby similarities and differences are used.
to increase the accuracy of information. It reduces the risk of systematic biases or limitations of a specific method (Maxwell, 1996). In the conceptual study, triangulation was achieved by comparing findings from published case studies with data from interviews and a group discussion with a variety of key persons representing different fields of expertise within the field of agriculture, HIV/AIDS and innovation development, including both practical and theoretical perspectives. During the descriptive-analytical part of the study, triangulation was achieved by combining both quantitative and qualitative methods. In this way not only a better insight in the diversity of impact among poor and HIV/AIDS-affected households was realised, but also how they made sense of it. To explore stigma and discrimination, a combination of participatory methods was applied, while exploring perspectives from various social groups in the community and health care providers. Finally, in the action-oriented part of the study, detailed reports and field data were combined with follow-up interviews and discussions with participants. To gain a better insight in the effectiveness of the FLS method and the ILA approach, not only support group members were involved, but also the facilitators and the various stakeholders in the project.

In addition, ethnographic research methods were employed. This involved exploring the respondents’ perceptions, actions and motivations, in-depth, and employing methods such as participatory and direct observation, and informal talks and meetings. As mentioned before, the researcher’s interest is to assess whether the descriptions of conceived relationships are meaningful, understandable and convincing for the people involved and for the outside world (Guba & Lincoln, 1989). The researchers resided in the research area during the data collection and preliminary analysis, so that what took place was encountered first-hand and could be well understood in relation to the context. In addition, the presence of project staff and researchers in the study area since the end of 2003 stimulated an atmosphere of trust and respect in interaction with participants.

To enhance validity further, preliminary findings were regularly presented for feedback to project partners and (representatives of) support groups involved in the process. This reduced the risk of misinterpretations, while it gave participants the opportunity to further clarify and explain emergent findings. To avoid subjective conclusions, research-peers were asked to react to emerging findings. By theorising, challenging, and making sense of the data and of what was observed, experienced and ‘felt’, the study made an attempt to understand the underlying mechanisms.
Finally, in all data collection methods, researchers were involved who were independent from the overall action research project. This further minimized effects of personal researcher’s bias or influence. This was especially important in the evaluation of the FLS method and the ILA approach.

3.5 Ethical Guidelines

An important aspect of working on HIV/AIDS is the concern for safety and confidentiality between project members and infected and affected people and families. Working in other areas, such as agriculture, where information given by respondents seems less sensitive, the ethical aspects of research have often been taken less seriously in practice. As this study took place at the interface of HIV/AIDS and agriculture, ethical approval was obtained from the Ethics Committee for Social Research of the University of KwaZulu-Natal. The following guidelines were used throughout the study:

a) Information obtained is codified for reasons of confidentiality. Collaborators in the project agree on a code of conduct on how to deal with sensitive information in the research area.

b) Research findings are fed back to participants for comments and corrections. Throughout the action research, transparency of information and outcomes is guaranteed, so that participants are able to benefit immediately from insights or innovations that could prevent or mitigate the impact of HIV/AIDS.

c) The research is designed in such a way that potential negative side effects on the participants are minimized.

d) Participation is on a voluntary basis. Participants and support groups can decide at any moment to withdraw from the project.

e) To avoid stigmatization of the support groups, linkages are established with the wider community when appropriate.

f) In case the phase of data collection leads to other spin-off activities in the community they will be open for those who are not part of the support groups.

g) Key intellectual contributions to the proposal and the project are recognized and respected, as they are in any resulting publication.

Research took place in agreement with project partners and support groups. Participants were fully informed about the nature and implications of the research, and voluntarily consented to participate and disclose information.
HIV/AIDS and Agriculture: A Challenge for an Interactive and Integrated Approach

“It is not only about technologies, but also about different ways of organisation and new groups of stakeholders to work with.”

4.1 Introduction

In Southern Africa, where HIV prevalence has increased above levels previously thought possible, food insecurity is considered one of the main problems in relation to HIV/AIDS (see FAO, 2004; UNAIDS, 2004). Various studies have shown the vicious relation that exists between malnutrition, HIV infection and AIDS impact, driving individuals, households and communities in a downwards spiral of impoverishment (De Waal and Tumushabe, 2003; Gillespie et al., 2001). Especially in rural and semi-urban areas, HIV/AIDS is exacerbating food insecurity as people are weakened and unable to engage in production activity. At the same time poverty and food insecurity may fuel the HIV/AIDS epidemic when people adopt risky strategies to survive (see Loevinsohn and Gillespie, 2003).

Many people in rural and semi-urban areas are largely dependent on small-scale agriculture for their livelihood (Topouzis and du Guerny, 1999). Although agriculture may be severely affected by HIV/AIDS, there is also scope for agriculture to mitigate its impact. In recent years, agricultural organisations – active in research, development and extension – have started to develop alternatives for farmers affected by HIV/AIDS (see Gillespie and Kadiyala, 2005). The need for ‘innovations’ in farming in response to HIV/AIDS is increasingly acknowledged, but the question how the innovation processes can be stimulated and sustained has received less attention.

To deal with the complexity of factors that determines the susceptibility and vulnerability of small-scale farmers to HIV/AIDS, scientists and development practitioners have stressed the importance of interactive approaches integrating agriculture and HIV/AIDS (Barnett and Whiteside, 2002; FAO, 2003, 2004; Gillespie and Kadiyala,
Interactive approaches are participatory in nature and emphasize close collaboration between relevant stakeholders to gain access to all sorts of relevant knowledge, insights, experiences, needs and/or creativity, to access relevant networks, resources and people, and to generate the required involvement and (process) ‘ownership’ (Leeuwis, 2004).

In 2003, the Athena Institute of the VU University Amsterdam joined hands with an agricultural NGO from the University of KwaZulu-Natal and a local community-managed health centre for people infected and affected by HIV/AIDS in South Africa. The aim of this collaboration is to strengthen agricultural capacity as a strategy to mitigate the impact of AIDS in the HIV high-prevalence area of Msinga in the Province of KwaZulu-Natal. One of the first issues that needed attention was the selection of a suitable approach. Based on the suggestions in literature an interactive approach was the obvious choice. But sustainable implementation of interactive approaches is far from easy and straightforward (Bainbridge et al., 2000; Broerse and Bunders, 2000; Chambers, 1997), and particularly at the interface of agriculture and HIV/AIDS there is little systematic knowledge to build upon.

4.2 Objective and Set-up of the Study

This chapter reports on the results of a study to gain insight into the main lessons and challenges with respect to the design and implementation of interactive approaches for innovation development in agriculture in the context of HIV/AIDS. The study was conducted by the Athena Institute within the framework of the abovementioned collaboration. It is mainly based on literature review and interviews with researchers, development practitioners and extension workers in the field of agriculture, rural development and HIV/AIDS in South Africa.

A literature review was carried out to derive key issues with regard to the design and implementation of interactive approaches. Because experience with interactive approaches at the interface of agriculture and HIV/AIDS is limited, the review mainly focused on case study analysis in the field of agriculture and natural resource management. Literature was also used to support findings related to specific challenges in the context of HIV/AIDS.

In addition, 24 interviews (fifteen men and nine women) and various informal dialogues (which took place during three field visits in KwaZulu-Natal) were held between April 2003 and June 2004. The aim was to explore experiences and views of in-
Interviewees regarding the influence of HIV/AIDS on agriculture and people’s lives, the problems they faced in their work related to HIV/AIDS, and how they dealt with it in practice. Not all topics were necessarily addressed in each interview or dialogue.

In addition, a group discussion was organised with eight representatives (six women and two men) from provincial and national level in KwaZulu-Natal in November 2004. The meeting took place in the realm of the abovementioned collaboration to develop strategic recommendations for interventions on HIV/AIDS and food security. Instead of discussing specific questions, each participant was asked to reflect on the planned intervention in Msinga, KwaZulu-Natal, from their own perspective and expertise. Interviewees and participants were senior researchers, directors, managers and project coordinators representing university departments, research institutes, Non-Governmental Organisations (NGOs), Community Based Organisations (CBOs), governmental departments, and regional networks related to HIV/AIDS (see Table 4.1).

Table 4.1: Interviewees and participants according to type of organisation and expertise

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Expertise</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews</td>
<td>University Indigenous knowledge, anthropology, psychology, HIV/AIDS</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Institute/centre Medical, social &amp; economic, gender, psychology, HIV/AIDS</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>NGOs Rural development, agriculture</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>CBOs Health and HIV/AIDS</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Government Health, Agriculture and Social Welfare</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Else Regional network on HIV/AIDS and livelihood</td>
<td>1</td>
</tr>
<tr>
<td>Group</td>
<td>University Head department of consumer sciences</td>
<td>1</td>
</tr>
<tr>
<td>Discussion</td>
<td>Institute/centre Senior researcher integrated &amp; rural development</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Senior researcher psychology &amp; HIV/AIDS</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>NGOs Director of a NGO on rural development &amp; agriculture</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Project coordinator of a NGO on rural development &amp; agriculture</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Government Director Food Security at the National Dept of Social</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Development Manager poverty alleviation &amp; AIDS, Provincial Dept of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Agriculture</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Else Consultant linked to a centre for HIV/AIDS networking</td>
<td>1</td>
</tr>
</tbody>
</table>
Chapter 4

Literature was analysed with regard to key issues in interactive approaches. Reports of interviews, informal dialogues, and the group discussion were sent to interviewees and participants for feedback, and subsequently analysed in relation to main themes and challenges for interactive approaches at the interface of HIV/AIDS and agriculture. The main aim was not to compare various perspectives, but to come to an overall synthesis by integrating findings from literature with experiences in the field. Although findings are mainly related to the South African context, we expect them to have a more general scope and validity.

4.3 Key Issues in Interactive Approaches

Given the great diversity in socio-technical problem contexts and social interaction, it is neither possible nor desirable to develop a generic detailed procedure for interactive approaches. Nevertheless, many scientists and practitioners suggest that being aware of certain principles and guidelines at the process level could considerably increase its quality (Guijt et al., 2000; Klein et al., 2001; Leeuwis, 1999, 2004; Rifkin et al., 2000). Here we would like to mention some of the main lessons derived from interactive approaches in the field of agriculture and natural resource management.

4.3.1 Key Principles

Small-scale farmers need to have a prominent role in decision making throughout the process. It is not sufficient to ‘consult’ them. Active participation of farmers is probably one of the best guarantees for the actual generation of appropriate innovations (see Broerse and Bunders, 2000; Chambers, 1997; Reijntjes et al., 1992). A shared vision is central to building ownership and a focused approach. Commitment to a vision provides participants a sense of direction and willingness to collaborate, overcome difficulties and uncertainties, and take risks (Broerse and Bunders, 2000; Hagmann et al., 2002).

A certain level of trust is crucial for obtaining insight into sensitive information and tacit knowledge, which is necessary for identifying and using the room for manoeuvring, as well as enhancing mutual learning between, and risk-taking behaviour by, different actors involved in the process. Mechanisms need to be created that are conducive to the development of trust relationships (Broerse and Bunders, 2000).

Social learning needs to be facilitated for effective communication and interaction. It is important that each person involved in the process recognizes the others’ expertise and potential contribution to the concerted effort and behaves accordingly. Reflexiv-
Interactive approaches are further characterized by a high degree of knowledge integration. Knowledge regarding more objective phenomena needs to be integrated with knowledge regarding more subjective notions. Part of this is so-called tacit knowledge, which is highly personal and hard to formalize, making it difficult to communicate or to share with others (Broerse and Bunders, 2000; Hagmann et al., 2002; Leeuwis, 2004; Zweekhorst, 2003).

Also crucial for the success of the innovation process is coalition building. A coalition of people from different areas serves as a check-and-balance. Coalition building ensures that sufficient and appropriate support and resources are available to maintain the momentum of a project and guarantee its implementation (Broerse and Bunders, 2000; Hagmann et al., 2002; Leeuwis, 2004; Zweekhorst, 2003).

Capacity building plays an important role to sustain the innovation process. Interactive approaches need to build upon local knowledge, processes and structures and strengthen collective capacity of local groups, institutions, and organisations (Hagmann et al., 2002; Hounkonnou, 2001). The need for capacity building is not limited to farmers, but applies equally to facilitators and other relevant actors (Zweekhorst, 2003).

Eventually, scaling out and up are essential to reach more people more quickly, either through widening the geographic area in which the approach is applied or through moving upwards to involve various levels in an organisation. This may lead to institutionalization when interactive approaches become integrated in the regular programs and activities of an organisation or network (Bainbridge et al., 2000; Hagmann et al., 2002; Lizares-Bodegon et al., 2002; Zweekhorst, 2003).

### 4.3.2 Guidelines for Process Design

The overall process is a dynamic and cyclic process of activities, in which tentative results are tested and refined in practice in an iterative way. In many of these approaches, the following, partly overlapping phases, can be distinguished: 1) initiation and preparation, in which the project team is established, a first assessment is made of the local setting, and contact is made with the local community; 2) problem
setting, in which various stakeholders participate, obtain commitment, and agree on general issues and procedures for collaboration; 3) direction setting, in which participants exchange information, address conflicts and seek consensus on priority issues, common goals and plan of action; and 4) implementation, in which participants determine and take action, monitor progress and evaluate results (Broerse and Bunders, 2000).

Essential elements for interactive approaches are a well-filled tool box of methods and tools for different functions, which can be adapted to the local context and dynamics (Broerse and Bunders, 2000; Leeuwis, 1999, 2004; Loevinsohn et al., 2002). In relation to farmer experimentation, tools can be used to learn about visions and values, understand key natural and social processes, and enhance the experimentation process through exposure to options (Hamilton, 1995; Loevinsohn et al., 2002).

Monitoring and self-evaluation are integral parts of the action learning cycle. It is important to distinguish learning at different levels. Farmers may want to monitor and evaluate their plans, activities and experiments, stakeholders may be interested in more effective collaboration and communication, while researchers and facilitators may be more interested in the effectiveness in enhancing these processes. To stimulate learning and ownership among participants, it is important that assessment takes place by participants themselves, based on quality criteria and standards for process implementation (Hagmann et al., 2002).

A key determinant for success in interactive approaches is process facilitation. Facilitators lead the process but not the outcome and direction (Groot and Maarleveld, 2000). Supportive elements are: clear orientation, vision and values, empathy and the ‘culture of inquiry’, and a clear understanding of the process design and steps (Hagmann and Chuma, 2002). Facilitating learning in agriculture and natural resource management also requires knowledge about ecological principles and practices (Hagmann and Chuma, 2002; Hamilton, 1995; Loevinsohn et al., 2002). A team approach, consisting of persons with different disciplinary background may be preferred (Broerse and Bunders, 2000).

For an overview of key principles and guidelines for process design see Table 4.2. Although not all principles and guidelines will be as relevant in each situation, they can be seen as building blocks for a more enriched approach in the context of HIV/AIDS on which we will elaborate in the next section.
Table 4.2: Key principles and guidelines for process design for interactive approaches derived from experiences in agriculture and natural resource management

<table>
<thead>
<tr>
<th>Key principles</th>
<th>Process Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>– Farmer central</td>
<td>– Action learning cycle</td>
</tr>
<tr>
<td>– Shared vision</td>
<td>– Large variety of tools and methods</td>
</tr>
<tr>
<td>– Level of trust</td>
<td>– Participatory Monitoring and Evaluation</td>
</tr>
<tr>
<td>– Social and experiential learning</td>
<td>– Process facilitation</td>
</tr>
<tr>
<td>– Integration of knowledge</td>
<td></td>
</tr>
<tr>
<td>– Coalition building</td>
<td></td>
</tr>
<tr>
<td>– Capacity building</td>
<td></td>
</tr>
<tr>
<td>– Scaling out, up and institutionalization</td>
<td></td>
</tr>
</tbody>
</table>

4.4 Voices from the Field: The Challenges Faced

HIV/AIDS adds a new dimension to agricultural innovation and the application of interactive approaches. When development practitioners and extension workers want innovation(s) in farming to be effective in the long term, they cannot close their eyes for the impact of HIV/AIDS on farming itself, but also not for the social mechanisms and aspects that play a role in the susceptibility and the vulnerability to HIV/AIDS. Various specific challenges induced by HIV/AIDS have been identified and are discussed below.

HIV/AIDS and Poverty

Changing our approach from working with community groups to working with individual homesteads confronted us with a face of poverty we had not seen before. A father spending the little money he had on medicines, doctor’s visits, traditional healers, and still seeing his child die. Young adolescents physically and mentally affected by the loss of their parents. A grandmother left with her grandchildren and no income to speak of.

This quote from a representative of a NGO working with small-scale farmers, clearly illustrates the intimate relation between HIV/AIDS and poverty. A household affected by AIDS has increasing constraints on their time and resources. Once the skills base, financial and physical assets are depleted, it will be difficult to re-establish these. Members are struggling for their day-to-day survival, and caring for others, and may not have
the ‘luxury’ of engaging themselves in long-term development efforts. This leads to a widely shared feeling of frustration among development practitioners and extension workers. It does not only imply that many affected households are invisible to service providers, but also that they become more vulnerable to other shocks and stresses.

Participation in the context of poverty is a scarce resource. Interactive approaches will have to be flexible enough to allow people to become involved. At the same time, interactive approaches focusing on HIV and AIDS need to take a broader rural livelihood perspective to be effective (see also Gillespie et al., 2001; Harvey, 2004). Realizing that progress will be hard to achieve under these circumstances, several interviewees stressed that a long-term commitment and a concerted and collective effort by service providers is necessary.

**Diversity**

Although HIV/AIDS and poverty are often interlinked, not all poor people are equally at risk for HIV infection or vulnerable to AIDS. The combination of factors that make them at risk may be unique to a particular context, group, or individual, while people’s lives and situations change over time (see also Barnett and Whiteside, 2002; Loevinsohn and Gillespie, 2003). As HIV/AIDS often clusters in households due to sexual transmission, it may also increase differences between households in the community. The issue of diversity was not only brought forward in interviews, but also became apparent in field visits. In addition, a senior researcher of a national research institute reminded that we have to be aware that people move in time from one situation to the other. A diversity of services is needed to support people in various stages of the disease trajectory and with respect to their personal situation. However, it also requires a better understanding of the factors that determine people’s situation. Current approaches are not always well adapted for this, as illustrated by a representative of a university department working with people living with HIV:

*Much attention has been paid to collective processes, but not on how individuals can develop themselves within these. We need to have a better understanding of people’s individual situation, how individuals deal with it, and how it affects them.*

A careful exploration of people’s specific situation may help facilitators to get a more in-depth understanding of the relation between HIV/AIDS and food security and the relevant factors that play a role in order to develop flexible, but tailor-made programs. Qualitative and ethnographic research methods over longer time frames are
necessary to unravel the complexity and dynamics of the impact of HIV/AIDS on food security (see also Barnett and Whiteside, 2002). A practical tool is the HIV/AIDS susceptibility and vulnerability pathway. It can be used in group discussions to help people understand the factors that drive their susceptibility and vulnerability, and identify opportunities that may increase their resistance and resilience (Bishop-Sambrook, 2003a). Opportunities can also be provided by looking for synergy between constraints and opportunities of different groups, for example, when old people without the energy to do hard work, rent out land to youngsters who do not have access to land (Loevinsohn and Gillespie, 2003).

**Stigma and Gender**

Interviewees and participants agreed that the main challenge for interactive approaches in the context of HIV/AIDS is related to stigma and gender inequality. Although the HIV/AIDS epidemic is shaped by many factors, it is profoundly a social epidemic; it is a taboo in many cultures and deeply ingrained in social norms and values (see also Cornwall and Welbourn, 2002; Walker *et al.*, 2004). HIV/AIDS triggers stigma and discrimination. The widely held notions about HIV/AIDS do not come out of the blue, but build upon pre-existing fears and prejudices about poverty, gender, sex and sexuality, and race. They reinforce existing social stereotypes and inequalities (Deacon *et al.*, 2005; Parker and Aggleton, 2003; UNAIDS/WHO, 2003).

One of the respondents, a project coordinator of a CBO, said:

*People are aware that HIV/AIDS is there, but they do not accept it. HIV/AIDS is for people who are immoral. That is why there is stigmatization. When they would admit that HIV/AIDS can occur in their family, it takes away their dignity. Some say it is the disease of the poor, so they cannot have it. (...) Sometimes people are just locked up, because families do not want that others find out, or they are afraid that they get HIV/AIDS as well.*

HIV/AIDS-related stigma and discrimination may in particular affect women and girls, as they are more susceptible to HIV infection than men or boys, due to their physiology, social and cultural imbalances and economic dependence. They are also more vulnerable to the impact of AIDS. They tend to bear the extra burden of caring for others, households maintenance and food production. This burden also shifts from people in their productive age to children and grannies, with the number of child-headed households and orphans increasing. HIV/AIDS stigmatization aggravates their situation, as assistance from the extended family and the community, their main safety net, is severed.
It seems obvious that issues of stigma and social inequalities eventually need to be addressed at community level and beyond. Creating a safe environment in which people feel free to talk will be critical. One may want to start with more individual and personal based methods, to build a sense of trust and relationship with participants. However, group and community based approaches are necessary to change group values and commitments, and to address other issues of social inequality.

In relation to gender, peer education has been promoted in conjunction with sexuality education to create safe spaces for girls and women to work on gender identity and social issues, and gain skills to act assertively in situations in which they are vulnerable (see also Adams and Marshall, 1998; Tallis, 1998). Some of our interviewees argued that gender inequality can only be addressed when also men are involved in development programs. A methodology that focuses both on women and men is Stepping Stones, a training package in gender, HIV/AIDS, communication and relationship skills (Welbourn, 1995).

One of the main problems remains, however, the economic dependency of many women on their husbands, making it difficult for them to have control over their decisions. Recently there has been more attention for improving this via credit and enterprise development programs for disadvantaged women (see also Kim et al., 2002; UNAIDS, 2004).

**Mobilization of Stakeholders**

Since HIV/AIDS, more than most other issues, is considered a taboo, the initiative for HIV/AIDS-related development programs often relies with outsiders. Although contextual circumstances may justify outside intervention, there needs to be a deliberate effort from the start to include the main stakeholder, the HIV/AIDS-affected households, in the design and content of the project and to take people’s needs and priorities into account. Building trust relations is crucial, as expressed by a head of home-based care workers in one of the districts in KwaZulu-Natal:

> Zulu people are loving people, but they do not trust. If you come today, they will ask: ‘who is this’, ‘what does he come to do’. They will not tell anything. You have to visit them over and over again. You need to build a relationship with them, and then you can ask more.

Building trust takes time and is often built on listening to people, taking them seriously and addressing their day-to-day problems; especially when working on sensitive issues as HIV/AIDS, trust will partly be determined by honest and clear commu-
nunication and follow-up on ethical guidelines. However, if trust remains at this level, it is not likely that the process will lead to concrete follow-up after the development of action plans. Stakeholders may not be automatically motivated to become involved in the field of HIV/AIDS and agriculture, for example, they may not see what their contribution can be, they have other obligations, or their organisations may not allow them. Some interviewees mentioned that it is especially difficult to involve researchers and scientists. However, their participation is felt necessary to develop effective innovations and strategies.

A concept which may be helpful to involve stakeholders in an interactive process is the ‘HIV/AIDS lens’ (Gillespie and Kadiyala, 2005; Loevinsohn and Gillespie, 2003). The lens provides a way of looking at programs and policies from an HIV/AIDS perspective. It is designed to support reflection among stakeholders of how a particular situation or particular policy may be increasing or reducing the risks people face either of contracting HIV or of suffering severe consequences from AIDS-linked illness and death. More specifically, in an interactive process of action, monitoring and evaluation, the lens can be used as a tool for reflexive learning among stakeholders and clarify options for response.

Integrating Different Perspectives

While collaboration between various stakeholders is widely encouraged by most of the interviewees, some researchers stressed that effective collaboration between stakeholders is complicated. Different actors and organisations can be seen as having their own culture. According to Jasanoff and Wynne (1998: 16): ‘They can be regarded as different forms of life that engage in the production of their own knowledge, ideas, beliefs and meanings, and sustain these activities in turn through characteristic practices and discourses’. In integrated and interactive approaches, it is important to be aware of these differences, as they may frustrate social learning and cooperation as illustrated by a Medical Doctor from a Christian hospital:

*I have given workshops for traditional healers, but I do not work together with them. I think they do more harm than good, and I do not believe in ancestral spirits.*

Integration of different perspectives poses an additional challenge for approaches at the interface of health and agriculture. Not only do professionals in health and agriculture belong to different types of organisations with their own culture, practices, knowledge and discourses, the way knowledge is produced at the local level around health and agriculture is also quite different. While most people in rural areas grow up with farming and develop knowledge and skills on the basis of indigenous knowl-
edge, observation, and trying out, health and diseases are often the domain of a few specialized people in the community. In combination with the fact that causes of diseases are often invisible to the naked eye, it may lead to different ways of explanation and give rise to esoteric knowledge. A respondent who had worked in a Zulu community gave an example of his friend who died of AIDS:

One day, he told me that he was bewitched. Several signs [in Zulu-culture] pointed in this direction. (…) His house was struck by lightning, one day there was a snake in his house. Another time, there was chaos at his school, because children had seen the Tokoloshe [dwarf-like (evil) supernatural beings invisible to adults]. This is what he would tell to people and his family. His family spent a lot of money to help him, but he was diagnosed as being bewitched.

An important phenomenon in the case of HIV/AIDS is the emergence of myths which can lead people to engage in behaviours that place them or other people in dangerous, risky or difficult situations, for example, the myth that having sex with a virgin can cure HIV/AIDS. This is a disturbing belief when realizing that South Africa has one of the highest rape rates worldwide.

Although it widely recognized among interviewees that the combination of local and scientific knowledge may help to overcome some of the problems related to HIV/AIDS, it is questionable whether approaches and methods applied in problem situations of relatively ‘low’ complexity, also work in these more complex problem situations. Some of the organisations that were visited actively experimented with methods such as discovery-based learning, drama education, sports as metaphor, and/or story telling to bridge different perspectives. At the moment, however, there do not seem to be any clear cut ‘strategies’ to face this challenge.

**Innovation(s) in Response to HIV/AIDS**

From the interviews, it becomes apparent that the majority of AIDS survivors in rural areas are orphans, middle-aged widows, and elderly. They need risk-free survival strategies, assuring household food security as well as cash income to pay for other basic necessities. The development of appropriate survival strategies for small-scale farmers requires a substantial paradigm shift on the part of research and extension. A respondent of an international NGO in South Africa indicated:

*There is need for a system that supports ‘the poor’. (…) Still the problem is that the agricultural department and the researchers involved in the agricultural system are very much focused on commercial farming.*
The lack of support for small-scale farmers was not only mentioned by many respondents, but also became obvious in discussions with agricultural extension workers. In addition, agricultural research organisations do not seem to respond adequately to technological needs of affected households and communities, although several research opportunities have been identified, such as lighter agricultural implements that can be handled by women and children, reduced tillage options, and support for expanded post-harvest processing (Bishop-Sambrook, 2003b; SAfAIDS, 1998). So far, most direct technical support in response to AIDS appears to have come from NGOs in the form of micro-credits and incentives for improving diets (such as keeping home gardens, and raising poultry and small livestock) and ensuring diversity and nutritional quality of food crops (see also Gillespie and Kadiyala, 2005). A potential source of information, which has been largely ignored so far, are farmers themselves, as acknowledged by a project leader of an international network on HIV/AIDS and rural livelihood:

_It is a good bet that people have altered the use they make of land-based resources in response to HIV/AIDS. (...) We know very little about such innovations, but we can’t assume there isn’t any._

A stronger focus on identification of initiatives, including aspirations and constraints, may provide a rich source of information for further development and dissemination. And, as expressed by a director of an agricultural NGO:

_It is not only about technologies, but also about different ways of organisation and new groups of stakeholders to work with._

Because the majority of farmers affected by HIV/AIDS are subsistence farmers, most interviewees and participants argue that agricultural innovation should be seen in a broader livelihoods perspective. A methodology that may be suitable to integrate agricultural innovation, rural livelihood and HIV/AIDS is the Farmer Life School, a discovery-based learning approach to help (groups of) farmers to achieve a more holistic understanding of the way they live and the factors that contribute to or detract from a healthy life (du Guerny _et al._, 2002).

**Hope, Optimism and Self-initiative**

_A difficulty with the communities is that people are very passive. When you ask them what they can, they say that they can’t do anything. We have to make them aware that they can do much more themselves than they think._
With this quote of a development practitioner working in the field of agriculture the general perception of respondents regarding the attitude of many rural poor in South Africa is characterized well. Some argued that this is indirectly supported by development programs, which provide people with free resources without capacity building. HIV/AIDS only tends to deepen these feelings of helplessness and despair. The uncertainty and fear of illness and death, and the impoverishment of individuals, households, and communities affected by HIV and AIDS may eventually lead to depression (De Waal and Tumushabe, 2003).

This implies that interventions need to create ‘emotionally safe spaces’, whereby people are valued, supported and affirmed, and in which a process is offered to give feedback and receive feedback empathically and without judgement. This may not only have a positive impact on the individual, but may create a supportive environment for others as well (see also Salomon, 2004). Current programs are, however, generally considered inadequate to address the complexity of HIV/AIDS, as brought forward by a representative of the National Department of Social Development in South Africa:

*Counselling is a key issue. We need to heal the soul before dealing with the external. (...) One of the problems is that counselling services and competencies were not meant to facilitate development; their program does not fit into the strategy.*

Interventions should ‘tap into the potential of an individual, discover what makes a person tick, and aim to match an individual’s aspirations with broader development goals’ (Salomon, 2004: 1). A methodology that is developed around this notion is Transformational Leadership. It is designed to fundamentally transform the context by giving individuals and groups of people at all levels the technical, cognitive, and conceptual competencies to do so, and to take control of their own future (Salomon, 2004). This is important as the HIV/AIDS impact is increasingly felt among staff and management of service providers, undermining their capacity to support.

Another development which may have a big impact on the mental well-being of people infected with HIV is the roll-out of affordable antiretroviral (ARV) medicines. This may not only change the disease from being fatal to chronic, but may also stimulate people to go for blood testing and disclose themselves to others. A Medical Doctor indicated in one the interviews that this may also contribute to a reduced stigmatization of people with HIV/AIDS.
**Additional Competencies of Facilitators**

Adequately addressing the above-mentioned challenges ultimately puts a high demand on the knowledge and skills of the facilitators of interactive processes in relation to HIV/AIDS. Facilitators have to be trained in both health and agriculture as well as other related topics, in order to operate in new partnerships. They need to be able to motivate a wide variety of stakeholders to work in ways they have not worked before in areas they have not gone before. According to several interviewees, this may in particular be a challenge for extension services. They are not always familiar with participatory approaches and extension workers often lack the necessary skills. However, not all skills have to (or can) be embodied in one person. A team of facilitators with various backgrounds is likely to be necessary.

An additional point of attention that emerged as highly relevant in the interviews is the importance of ethics. Facilitators have to take into account the extra concern for safety and confidentiality when working on HIV/AIDS. How to focus efforts on affected families without the risk of stigmatizing them? Sometimes projects focus on poverty to prevent this dilemma, and integrate HIV/AIDS in their approach. Depending on the situation, either option may be appropriate; however, an open and honest communication is considered essential. Although it is up to the participants themselves to decide individually whether they want to participate on the basis of informed consent, it was stressed by interviewees and participants that programs and policies have to provide a supportive environment and flexible approaches to overcome secrecy and stigmatization and/or sickness and time constraints. The HIV/AIDS lens may be useful in this respect by creating awareness among relevant stakeholders about the complexity of factors that determine the susceptibility and vulnerability to HIV/AIDS and the implications of programs and policies. Ethical guidelines need to be developed and discussed with participants. In case of research, ethical approval needs to be obtained from the respective ethical committee.

The challenges, key issues, and methodological consequences as discussed are summarized in Table 4.3.

**4.5 Conclusion and Implications**

Agricultural innovation in the context of HIV/AIDS is a highly complex process. For interactive approaches to be effective, we need to understand the relations between agriculture, rural livelihood, and HIV/AIDS. Although key principles and guidelines
for process design derived from agriculture and natural resource management remain unconditionally valid, target group specific circumstances, the sensitivity of HIV/AIDS, and the variety of relevant stakeholders pose extra challenges. Secrecy and stigmatization in relation to HIV/AIDS raise serious concerns about the feasibility of interactive and integrated approaches in a situation of high HIV/AIDS prevalence. How to involve all stakeholders when some of them are being marginalized and do not want or are not able to participate? The key issue in interactive approaches revolves around the question who actually participates and how to involve people who most need it, but for whom it is most difficult to do so? Although a process oriented approach based on trust and learning has high potential to explore the livelihood system and develop appropriate solutions together with farmers vulnerable to the impact of HIV/AIDS, it can only do so in a supportive environment.

The HIV/AIDS epidemic is a unique disease, which requires a new and innovative response. The impact of HIV and AIDS on small-scale farmers and their households asks for a radical shift from conventional approaches in agricultural extension and education. It requires a more holistic or integrated perspective and a stronger emphasis on interactive approaches and competency development. At the same time, it is important to implement and test interactive approaches in practice based on the lessons of this study. Together with similar experiences, this will contribute to a better understanding of what works and does not work, which may lead in the longer term to a mature practice of interactive approaches at the interface of HIV/AIDS and agriculture.
Table 4.3: Challenges, key issues, and methodological consequences related to innovation development in agriculture in response to HIV/AIDS

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Key issue</th>
<th>Methodological consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poverty</td>
<td>Increasing constraints on time and resources</td>
<td>Flexible approach</td>
</tr>
<tr>
<td></td>
<td>Increased vulnerability to other shocks and stresses</td>
<td>Livelihood perspective</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Long-term commitment and assistance from other service providers</td>
</tr>
<tr>
<td>Diversity</td>
<td>Not all people equally at risk for HIV infection or AIDS impact</td>
<td>Diversity of services to support people in various stages in the disease trajectory and/or personal situation</td>
</tr>
<tr>
<td></td>
<td>May lead to increased diversity among households</td>
<td>Qualitative and ethnographic research methods over longer time frames</td>
</tr>
<tr>
<td></td>
<td>Dynamics in time</td>
<td>Use of methods to explore factors that drive the epidemic and its impact (e.g. via Susceptibility and Vulnerability pathway)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Synergy between constraints and opportunities of different groups</td>
</tr>
<tr>
<td>Stigma and gender</td>
<td>Taboo and deeply ingrained in norms and values</td>
<td>Creating safe environment</td>
</tr>
<tr>
<td></td>
<td>Triggers stigma and discrimination</td>
<td>Peer education in conjunction with sexuality education; involving women and men (e.g. via Stepping Stones)</td>
</tr>
<tr>
<td></td>
<td>Women more vulnerable than men</td>
<td>Specific credit and enterprise development programs for women</td>
</tr>
<tr>
<td>Mobilization of stakeholders</td>
<td>HIV/AIDS is sensitive issue and taboo; initiative often relies with outsiders</td>
<td>Build trust relations; honest and clear communication and follow-up on ethical guidelines</td>
</tr>
<tr>
<td></td>
<td>Stakeholders do not see contribution, have other obligations, or are not allowed to become involved</td>
<td>Emphasis on social organisation of user group to create ownership and action</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Creating new partnerships around HIV/AIDS and food security (e.g. by making use of the HIV/AIDS lens)</td>
</tr>
<tr>
<td>Integrating different perspectives</td>
<td>Wide variety of stakeholders with increased differences between actors in knowledge, ideas, beliefs, meanings, discourses and practices</td>
<td>Social learning and joint problem solving; clear-cut strategies do not seem to exist at the moment</td>
</tr>
</tbody>
</table>
Table 4.3: (continued)

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Key issue</th>
<th>Methodological consequence</th>
</tr>
</thead>
</table>
| **Innovation(s) in response to HIV/AIDS** | - Increased number of orphans, middle-aged widows and elderly due to HIV/AIDS changes user group for agricultural innovations  
- Especially small scale farmers hard hit | - Low risk strategies; focus on food security  
- Respond to technological needs and new ways of (social) organisation by creating new partnerships around local innovation in response to HIV/AIDS with involvement of extension agents and researchers/scientists  
- Identification of initiatives, aspirations and constraints of people who are infected/affected  
- Livelihood focus (e.g. via Farmer Life School) |
| **Hope, optimism and self-initiative** | - Despair, helplessness, and depression  
- Increased passiveness | - Emotionally safe spaces; counselling  
- Tap into the potential of an individual and match with broader development goals (e.g. via Transformational Leadership)  
- ARV treatment |
| **Additional competencies of facilitators** | - Variety of topics, new partnerships  
- Supportive environment required for people who do not want (due to secrecy/stigma) or are not able (due to time constraints/sickness) to participate | - Training in variety of topics  
- Create awareness among stakeholders about the complexity of factors that determine the susceptibility and vulnerability to HIV/AIDS and the implications of programs and policies (e.g. by making use of the HIV/AIDS lens)  
- Work according to ethical guidelines  
- Not all skills need to be embodied in one person; team approach |
Diversity in Impact and Responses among Poor and HIV/AIDS-affected Households

“If I only had power to build a house made of blocks and cement, so that when I die my children have a house that will not fall apart.”

5.1 Introduction

Livelihood analysis is a commonly used tool to analyse the impact of shocks and stresses on people's lives. A number of studies that have systematically looked at the impact of HIV/AIDS in sub-Saharan Africa (e.g. CHGA, 2004; Haddad and Gillespie, 2001; Stokes, 2003) have demonstrated that the impact may strip individuals, households, and communities of all their assets. Households may hardly cope or may not cope at all (Rugalema, 2000). The fierce succession of HIV infection and AIDS-related illnesses and death can drive individuals and their households to impoverishment (Barnett and Whiteside, 2002). Different households, however, are not affected in a uniform way (SADC FANR, 2003). Understanding the differences in impact and responses can play an important role in designing targeted support for HIV/AIDS-affected households (Barnett and Grellier, 2003; White and Morton, 2005; Wiegars et al., 2006).

A thorough understanding must be sought in order to arrive at interventions that challenge the determinants on which the HIV epidemic seems to thrive. Therefore, this study does not merely intend to set out the socio-economic consequences of HIV and AIDS (as does most literature on livelihoods), but tries to gain a more comprehensive understanding of the impact of HIV and AIDS by emphasising the human perspective concerning people's lives. The study was conducted among vulnerable households in Msinga, a sub-district of KwaZulu-Natal Province, South Africa.
5.2 A Livelihoods Framework

Looking at people’s lives from a livelihoods perspective provides us with a way to capture its complexity. A livelihood comprises the capabilities, assets and activities required for a means of living (Chambers and Conway, 1992). A livelihood is sustainable if it can cope with and recover from shocks and stresses. One of the most commonly used models for development understanding and action is the sustainable livelihoods framework developed by the UK Department for International Development (DFID) (1999).

The sustainable livelihoods framework can be described as follows. Situated in a particular environment (historic, political, social, economic), assets in the form of various capital (human, financial, social, natural, and physical) are accessed by households and individuals within households in order to construct livelihood strategies, which in turn result in positive or negative outcomes. In doing so, the role of institutions and organisations has to be taken into account, as they determine to varying degrees the individuals’ and households’ access to resources and ultimately determine the possible livelihood strategies (Müller, 2003).

The livelihoods approach allows for a contextual understanding of people’s lives and considers them as active participants in the construction of their own well-being. However, the approach has been criticised for its socio-economic bias. While it considers people as rational beings, making well-balanced decisions and choices (De Haan and Zoomers, 2005; Müller, 2003), in reality, however, access to diverse capital and the choices people make are socialised into the individual. Individuals have a particular outlook and orientation, developed primarily during childhood and youth, and strongly influenced by class and socio-economic background. This affects one’s interpretations and the sets of actions that seem possible (Bourdieu, 1986). Particularly in the context of HIV/AIDS, where people try to survive day-by-day and face numerous short-term decisions, there is less emphasis on economic aspects and more emphasis on how people think and feel.

To understand the underlying factors and mechanisms that contribute to or mitigate the impact of HIV and AIDS, and what this implies for interventions, we need to look beneath the surface of the sustainable livelihoods framework. We have to understand people’s actions – from how they make sense of the world around them and how they deal with it emotionally, to what extent they are enabled or kept away from using...
resources. This may not only help to better understand people’s behaviour, but also the diversity of their responses. This idea is reflected in various ecological models of human health that have described individual health as an interconnected experience of the body, mind and spirit, nested in a hierarchy of ecosystem levels (Van Leeuwen et al., 1999). To incorporate these notions, the sustainable livelihoods framework has been modified (see Figure 5.1). In the adapted version, people’s agency (the ability to act) depends on the relation between physical properties (the body), perceptions/beliefs (the mind), and emotions/aspirations (the spirit); similar connections can be defined among physical, intellectual and spiritual health at the household and community level (Van Leeuwen et al., 1999). In coping with HIV or AIDS, an individual or a household can draw upon its own resources, but also on various resources in its immediate surroundings. Access to and control over these resources is influenced by institutional structures and processes. Outcomes as a result of responses may in turn lead to changes in people’s immediate and wider environment. Essential to the framework is the intention to understand people’s actions from the emic or insider’s perspective.

**Figure 5.1:** A model of human action in response to HIV and AIDS
5.3 Methods

Msinga is a poor, rural, traditionally Zulu area in the Province of KwaZulu-Natal, South Africa. Estimated HIV prevalence in the area at the time of study was over 20%. From April to July 2004, the members of three support groups of a local community-managed health centre were consulted about the impacts of HIV or AIDS on their lives. The support groups had been created to improve food security for the households involved and they were geographically spread across the Msinga sub-district. Their members were almost all women from HIV/AIDS-affected and poverty-stricken households. As the study aimed to explore how people cope with the impact of HIV or AIDS, ethnography was found most appropriate for collecting and connecting results gathered through fieldwork. This involved exploring the respondents' perceptions, actions and motivations, in-depth, and employing methods such as participatory observation, and informal talks and meetings.

The study was carried out in three steps: 1) focus groups were organised to explore people’s perceptions of livelihood and farming; 2) a questionnaire was used to explore the diversity among households and their relation with HIV or AIDS; and 3) in-depth interviews were held with people infected or affected by HIV, to understand how they cope with the impacts. The research took place in agreement with the support groups. The respondents were fully informed about the nature and implications of the research and they voluntarily consented to participate and disclose information.

To explore how household members perceive livelihood and farming, two focus group discussions were conducted with each support group. Participation in each focus group varied from 7 to 11 people, most between 30 and 60 years old. Apart from one support group in which a man was present, all the focus group participants were women. Visualisation techniques served as a basis to discuss household structure and daily life; the roles of women, men and children; socio-economic profiles; and the relation between farming and rural livelihood.

Based on the focus groups and the livelihoods framework, a questionnaire was designed to explore the diversity among the households. Table 5.1 gives an overview of the participants’ characteristics. In total, 129 Zulu-speaking individuals responded to the questionnaire, almost all women, between 21 and 80 years old. The majority

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11 Data provided by the medical doctor in charge of the ARV program at the hospital in Msinga.
12 In our experience, people in Msinga refer to orphans when both parents have died or when the mother has died, not when the father alone has died (emphasising the role of the mother as caretaker). It is this meaning that is used here.
Diversity in Impact and Responses among Poor and HIV/AIDS-affected Households

(74%) were aged 30–59. Information on the personal situation of the households was provided by home-based care workers and the chairperson of one of the support groups and does not necessarily reflect individuals’ own responses. The questionnaire was divided into five sets of open and closed questions related to household structure, rural livelihood, farming, health and HIV/AIDS.

Table 5.1: Distribution of the questionnaire respondents in each support group in terms of gender, age, and personal situation of the household

<table>
<thead>
<tr>
<th>Number of participants</th>
<th>Sex</th>
<th>Age (years)</th>
<th>Personal situation of the household*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support group</td>
<td>M</td>
<td>F</td>
<td>15-29</td>
</tr>
<tr>
<td>A</td>
<td>64</td>
<td>60</td>
<td>1</td>
</tr>
<tr>
<td>B</td>
<td>35</td>
<td>28</td>
<td>1</td>
</tr>
<tr>
<td>C</td>
<td>47</td>
<td>41</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>146</td>
<td>129</td>
<td>2</td>
</tr>
</tbody>
</table>

* Information was provided by home-based care workers and the chairperson of one of the support groups

In-depth interviews were conducted with HIV-infected or -affected support group members to get better insight into the impact of HIV or AIDS on people’s lives and how they respond to it. In the questionnaire, 17 participants had explicitly mentioned AIDS as the cause for chronic illness or recent death and/or the reason for the presence of orphans in the household, and they were willing to share their experiences. From them, 10 participants were selected for interviews; they differed in several aspects, such as young/old, male/female, HIV-infected and using/not using antiretroviral (ARV) medicines, or affected by illness/death/taking care of orphans. The participants were selected from two areas since in one of the three support groups no one had explicitly indicated AIDS as a cause of illness or death in their household (see Table 5.2). The in-depth interviews were guided by a list of topics related to the way a participant might cope cognitively, emotionally and practically with HIV or AIDS in their household.
Table 5.2: Characteristics of the persons participating in the in-depth interviews

<table>
<thead>
<tr>
<th>Person</th>
<th>Sex</th>
<th>Age (years)</th>
<th>HIV-infected or - affected</th>
<th>Personal situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>26</td>
<td>HIV-positive</td>
<td>Married; 2 children; husband left home temporarily; household size: 4.</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>42</td>
<td>HIV-positive</td>
<td>Married; 3 children; husband has three wives, one deceased; household size: 11.</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>33</td>
<td>HIV-positive, receiving ARVs</td>
<td>Husband absent; 2 children; household size: 10.</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>36</td>
<td>HIV-positive, receiving ARVs</td>
<td>Husband died; 3 children; household size: 6.</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>30</td>
<td>Affected</td>
<td>Married; 3 children; 2 sister-in-laws died of AIDS; 1 sister-in-law was sick; household size: 10.</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>47</td>
<td>Affected</td>
<td>Married; 4 children and 1 grandchild; 4 orphans due to AIDS; household size: 12.</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>56</td>
<td>Affected</td>
<td>Married; daughter died of AIDS; 4 orphans; household size: 11.</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>56</td>
<td>Affected</td>
<td>Husband absent; 8 children; daughter died of AIDS; 3 orphans; household size: 15.</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>&gt;60</td>
<td>Affected</td>
<td>Husband died; daughter died of AIDS; 3 orphans; household size: 5.</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>26</td>
<td>Affected</td>
<td>Not married; parents died of AIDS; cares for brothers and sisters; household size: 7</td>
</tr>
</tbody>
</table>

The research team consisted of six persons. The team discussed the reports of the focus group discussions in regard to clarity and differences between the groups. To complete the questionnaire, support group members were interviewed at home by one or two people; the data were integrated in a spreadsheet to obtain an overview and more insight. In-depth interviews were conducted by two females; these were recorded and transcribed into English. Information obtained was codified for reasons of confidentiality.

Data were analysed using the adapted livelihoods framework, described above. The qualitative data were categorised in topics and clustered according to larger themes. Where appropriate, the findings were quantified with data from the questionnaires. The data from in-depth interviews were analysed for similarities and differences in impact and response. The individual and the household were taken as the units for analysis, while linkages between individual–household and household–community were taken into account. In this paper a household is considered a co-residential unit, including migrant workers, sharing food and/or income.
The researchers resided in the research area during the study, so that what took place was encountered first-hand and could be well understood in relation to the context. Direct observation and informal talks and meetings were used to verify the findings. To further enhance validity, triangulation of the various methods was used. Preliminary findings were presented to representatives of the support groups for feedback, and research peers were asked for their reaction to the emerging findings. In the course of theorising, challenging, and making sense of the data and what was observed, experienced and ‘felt,’ we have endeavoured to reveal the mechanisms that underlie the impact of HIV and AIDS on people’s livelihoods in this setting.

5.4 Results

Taking the adapted livelihoods framework as a starting point, the study examined: 1) the impact of HIV/AIDS-related illnesses (body) on people’s perceptions/beliefs (mind) and emotions/aspirations (spirit) (i.e. the internal environment), and 2) the influence of institutional structures and processes (i.e. the external environment), to better understand 3) people’s actions in response to HIV and AIDS. However, first we describe participants’ livelihoods in Msinga. It gives us the background against which to explore the impact of and responses to HIV/AIDS.

5.4.1 Livelihoods among Vulnerable Households in Msinga

Households in the research area are complex and dynamic, with continuously changing boundaries. The common form of domestic organisation is the patrilineal homestead, which usually consists of several household units. Household composition (i.e. size, age structure and gender division) directly affects the labour force of a household. Responses to the questionnaire indicated that the average number of people sharing food and income was 8 to 9, but it varied from 2 to 22. Most adults at home were women; men had often left the home in search of jobs in towns or cities, while women were expected to take care of the children and domestic activities. There were nevertheless considerable differences among the participants.

Out of 129 households, 81 (63%) had no male household-head anymore; in 18 (14%) the male head of the household was working somewhere else; and in 30 (23%) there was a male household-head at home. This difference may have important consequences. Men are the main role players in reinforcing culturally informed notions and practices related to gender relations, the distribution of household work, and reproduction and sexual relations. Men generally decide on the traditional ceremonies practiced and the use of traditional healers, and they have more control over
financial and natural resources. If *lobola* (bride wealth) has been paid, a woman is under the control of her husband. However, when the husband works elsewhere, his wife usually makes the daily decisions. When a woman does not have a husband anymore, she makes all decisions — even though male relatives can still exert influence. This indicates that in the majority of the participating households, the women were relatively independent in managing their resources, but at the same time it implies that the women were less likely to have access to resources (e.g., land is allocated by traditional leaders to men; the right to use it is usually transferred from father to son through a form of informal inheritance).

Almost all the participants considered themselves poor to very poor. Most households in the study depended on R300–1200 per month. Data from the questionnaire indicated that in a third (33%) of the households, one or more persons worked as a migrant labourer (contribution R300–1000). Many households partly relied on pensions (41%) or child support grants (67%). Foster child grants or disability grants were not common. Although households may gain some money for domestic work, such as gardening, selling wood, roof thatching or selling craft work, its contribution was typically marginal. The participating households had few livestock, and other assets were limited.

While livestock is seen as an indication of wealth and status and plays an important role in ceremonial activities, gardening seems to become more important when alternatives are lacking. Especially among poor families, gardening — which is seen as a responsibility of women — is crucial to overcome periods of food shortage. Crops are mainly grown for food production; the excess is sold or exchanged within the community. Access to water is a significant problem as most poor households depend on rain-fed farming, and this is especially problematic in winter (June to September).

In the focus groups, people mentioned shelter, children’s education, food security, and health as essential livelihood outcomes. In a cultural context where people cannot own land individually, housing provides physical security and a sense of home and belonging; it is also the place where ancestors are buried. Education for children is considered important, but, due to lack of money for school fees, not all children finish secondary school. It is food security, though, that featured in the questionnaire

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13 For comparison, in the year 2000, 40% of South African households earned less than R1104 per month, while 20% earned less than R666 (Statistics South Africa, 2002).

14 At the time of the study, the social welfare grants provided were: disability grant (R740/month), pension (R680/month), foster child grant (R530/month), and child support grant (R120/month).
as a main concern among the households (87%); the majority of households (55%) suffered from hunger during winter (the dry season), while a minority (13%) faced food insecurity after Christmas (i.e. when money has been spent on presents and school fees). In addition, 20% of the households mentioned food shortage as a problem throughout the year (mainly at month’s end). In many cases, the degree of food insecurity experienced was directly related to people’s health situation.

The questionnaire responses indicated that the impact of diseases and death was high. In almost a third of the households (29%) someone was chronically ill, while in almost half (48%) someone had died in the last five years. Even though other diseases and violence are common, AIDS illness seems to have a profound impact. Of the 129 households, 17 (13%) explicitly mentioned AIDS as the cause of a chronic illness or recent death, although the actual number may be higher as AIDS-related symptoms were mentioned in many other cases. Also, the high number of households taking care of orphans (43%) seems related to AIDS illnesses or deaths. Although people make use of both traditional and medical healthcare, most of the women participants said they preferred to go to clinics and hospitals because they considered traditional healers too expensive.

5.4.2 The Internal Environment: Body, Mind and Spirit

To understand how people cope with the impact of HIV/AIDS-related illnesses, it is important to look at how people make sense of HIV infection and deal with it emotionally. This can take many forms: if people believe that they have been bewitched, they know what kind of traditional treatment to seek; if they think an illness is the will of God, they beg for forgiveness and support or else they accept it; and biomedical information can also affect the way people deal with it.

Perceptions of HIV and AIDS refer to the recognition of it as a problem, its cause and symptoms, how it spreads, and how it can be prevented. As HIV and AIDS is still a sensitive subject to discuss, it was often easier for people to talk about others than about themselves. For instance, the answer to the question: ‘Do you know families in this area who are affected by HIV/AIDS?’ was often affirmative. The question: ‘Do you think HIV/AIDS is a big problem in this area?’ was answered with ‘yes’ by the majority of participants (57%). The reason it is a big problem was mostly given

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15 The data on the household’s personal situation regarding HIV-infected members, chronic illness, recent death, and the presence of orphans provided by the home-based care workers and the chairperson of one of the support groups (see Table 5.1) are in general higher than the data revealed by the questionnaire. This may indicate an underreporting of the actual impact of HIV and AIDS by the respondents.
as: ‘because people are dying’; other reasons given were: ‘it is not curable,’ ‘it is a new illness,’ ‘people do not want to talk about it’ and ‘people hide it.’ This indicates that people in the community do not necessarily deny HIV and AIDS, but will commonly deny its presence in their own home.

Most participants were unaware of the precise cause of the disease. Those who received ARV medicines knew that a virus had infected them. This came closest to a medical explanation. Others, especially among the older generation, linked AIDS to the supernatural or to witchcraft. Referring to HIV and AIDS, one grandmother said:

_Boys drink everywhere. They can be bewitched through beer. It is an old thing. People use muti [traditional medicine]. (...) [A person] pours this in your drink, and you will have pains inside._

In the questionnaire and in-depth interviews we also asked people about their knowledge of symptoms of HIV or AIDS. Most respondents knew that ‘people become thin.’ Other answers included: ‘running stomach,’ ‘chest pain’ and ‘vomiting.’ Some answers were: ‘can become mentally disturbed in the latest stage’ and ‘lose hair.’ HIV-infected or -affected persons gave more accurate descriptions, probably because of their own experience and observation. Although people do not always reveal their HIV status, symptoms cannot always be hidden. One woman who took care of her daughter who was ill said:

_First she lost weight. Then she had a big black spot from her ear towards her nose. She had sores in her mouth and tongue and could not eat. Her throat became swollen and she could not speak. After that she could not go to the toilet and she could not pee._

The question ‘How is HIV/AIDS transmitted?’ was very sensitive. Many respondents knew that HIV is primarily transmitted sexually and feel ashamed to talk about it. Besides the answer ‘I do not know,’ the following answers were given: ‘sexual intercourse,’ ‘used razors,’ ‘blood mixes,’ ‘open sores,’ ‘injection’ and ‘sharp objects.’ Other answers were: ‘by touching someone,’ ‘if you use the same pot,’ ‘if you take care of someone’ and ‘you just find it in the house.’ This indicated that people had some general knowledge, but there were many misconceptions about HIV transmission.

Persons who were aware that they are infected with HIV were more knowledgeable about its transmission, most likely because they talked about their condition with caregivers, such as nurses, doctors and home-based care workers. However, it is not
clear whether this understanding necessarily extended to relatives. One grandmother, whose daughter had died of AIDS, said:

_I do not even know how a person gets it. Others say it is a sex disease. A male passes it to a female sexually. And if you eat together with an infected person, even by sitting next to a person who has it, you get it._

Knowledge of transmission does not necessarily lead to prevention of infection. Most adult women in the interviews felt powerless to negotiate safer sex in a context in which fertility and women’s subservience to men are valued. It is also culturally inappropriate for parents to discuss sex with children. Admonitions to children that ‘you have to have good behaviour’ are vague, but some respondents indicated that parents do use the possibilities they have, for example encouraging their children to listen to radio broadcasts about HIV/AIDS.

Like talking about sex, talking about condoms is culturally sensitive. Most respondents indicated that people do not want to use condoms, as it is in conflict with cultural and Christian moral values. Their reluctance to use condoms can be further supported by rumours; according to various participants: ‘they say they cause some illness’; ‘people say condoms have worms, which can be seen when you put water in them’; and ‘people say condoms have holes.’ We observed that children often showed a more accurate knowledge about HIV/AIDS and prevention, probably because they are getting a school education, while many of their parents were uneducated.

Dealing with the ‘message’ of HIV infection usually has a severe impact on the emotional well-being of the individual and the family. Emotions such as denial, fear and hope converge with this disease. When people first hear they are infected, they are often shocked and in many cases will simply deny it. One woman said:

_I did not believe it that time [1996]. I never believed what the nurse told me. I thought she was just joking (…). I did not believe. That is why I went back for another blood test in 2003, to see if they were telling the truth._

The fear of stigmatisation, illness and death, and the prospect of not being able to take care of yourself or your family, can be overwhelming, particularly since HIV and AIDS is a taboo topic. Most participants who were infected could not discuss their fears or talk about it with others. They often coped with their fear by avoiding sexual relations and sharing their ‘secret’ only with someone trusted.
Although people may become physically and emotionally weak because of illness, they do not easily give up. Most interviewed people who were ill tried to take responsibility for some activities in the household. Reasons given for having hope included having a job, getting treatment, being religious, and having children.

Some people mentioned that they are strengthened and comforted by their religion and faith in God. First, faith in God helped them to accept their situation. One woman said:

_This load [the care of three orphans] is given to me by God. I cannot throw it away. Now if God gives you another family you cannot do anything but accept, and you have to accept it with whole your heart._

Second, they may believe that God makes decisions about their lives. One woman said:

_I trust in God. I put everything in His hands. I can tell myself that I am going to die soon, but He knows exactly the day He will call me. I can never lose hope on earth because I am ill. Maybe God keeps me. I ask Him to help, so that I get medicines._

People infected or affected by HIV said they did not only struggle for themselves, but also for their family. One HIV-positive woman said:

_Even now I still want to do something for my children. If I only had power to build a house made of blocks and cement, so that when I die my children have a house that will not fall apart._

Thus, the concern for their children gave individuals the motivation to continue with their life and even to try and set new things in place.

The local hospital had recently initiated support groups for people who are infected with HIV to help them to cope with their condition. One woman who joined was very optimistic:

_There are many of us. We meet once a month. We talk mostly about our health. I ask others how they feel. They also ask me. We laugh and talk about ARVs, that it is better now that we have them._

Via such groups, individuals could get in touch with other HIV-positive people in their area. Some provided each other support and company when they went to the hospital.
5.4.3 The External Environment: Structures and Processes

People’s lives are not isolated, but take shape in a social, cultural, economic and political context. However, institutional structures and processes do not only shape livelihood outcomes, but also have a tendency to create and reproduce systemic inequality. Gender, ARVs, social grants, and distance to public services and markets emerged as key issues in relation to an individual’s or a household’s response to HIV and AIDS.

**Gender**

Women from male-headed households felt particularly constrained by gender relations in this cultural setting. As one said: ‘You can never tell a man what to do.’ Men made the decisions about sex and contraception, and they could practice polygamy. Double standards about sexual freedom put women at risk of contracting HIV from unfaithful partners.

Norms and values are further influenced by religious affiliations. In the context of HIV and AIDS, religion may give people the strength and motivation to fight for their lives, but some churches may forbid contraceptive and condom use. One woman said:

*My husband will say – ‘I am a Christian, I do not use condoms.’ But being a Christian does not mean he does not have sex.*

Gender roles also impinge on women who are infected or affected by HIV. It is men who decide on the use of traditional healers and ceremonies. Although traditional healthcare is closely related to people’s cultural value system, it can create false hopes and strip individuals of their financial resources. Moreover, when a family member is very ill or someone has died, livestock may be slaughtered to maintain good relations with the ancestors, and this also impoverishes a household’s natural resources. In addition, widows and/or their children are susceptible to losing their access to land. Although widows may gain the right of use through their deceased husbands, often they remain dependent on male relatives. Besides, widows’ low social status increases their risk of losing property.

**ARVs**

The local hospital in Msinga started providing free ARV medicines in January 2004. To be HIV-infected is no longer synonymous with a fatal outcome. Those who applied for ARVs were usually in close contact with a home-based care worker who could inform them about the program. However, access to ARVs may be limited for
several reasons. Of the four women interviewed who had applied for ARVs, only two were receiving treatment. One said:

> When I checked, my soldiers were still over 250 [CD4 count] (...). They told me to come back this month; that’s when they will see if the blood soldiers are below 200. Then I will get the pills. When it does not get below, they will not give me, even though I feel weak.

It is not only the CD4 cell count that restricts people's access to treatment, but also the cost of transport to the hospital. Another woman interviewed mentioned:

> I took the test to check if I qualify [for ARVs]. But I did not go for the test results, because I don’t have money to travel.

More than a year later, she still had not gone back to check for the results.

Some women who qualified for ARVs were initially scared to use them. They had heard rumours that if you use them, you will die. But after other people told them they had been taking the medication for some time, they felt assured.

Even when people have access to medicines, the treatment may be compromised by poor nutrition. ARVs need to be taken at regular intervals and on a full stomach. In a follow-up interview, one woman said:

> Some may vomit when taking food before or after medicines. So the doctor advises to find out for yourself what works best. The hospital used to give beans, milk, and porridge, but they don’t do that anymore. But my husband is not working, I am not working, we have to pay school fees and uniforms, so it is difficult to get enough food.

Since food insecurity was a main concern among the households, treatment efficacy may be a serious problem.

Efficacy may be further comprised when people do not comply with the strict treatment regime:

> Three tablets, two times a day, seven days a week (...). I ask my son to give me the medicines. When I go on a long trip, I take a container with me for the medicines for the following day (...). When there is one sachet of medicines left, I will go the hospital to get new ones.
**Social Welfare Grants**

The Department of Social Development provides financial support and assistance. However, with the exception of pensions, it is not always easy to get access to grants. Disability grants are for people who are sick and no longer able to work; they need a letter from a doctor to certify their HIV status. However, those respondents who were HIV-positive complained that since the arrival of ARVs, it has become more difficult to get this grant. One said:

*They [nurses and doctor] treat us very well. It is only the disability grant that he [the doctor] refuses to give us, even if we tell him we have no money to come to the hospital. He says we should try and find it.*

People taking care of orphans can apply for a foster child grant. Both parents’ death certificates are required, as well as the child’s birth certificate. However, this can be problematic. In many households, the father may have left; and should the mother die, no one may know where the father is or what happened to him. Sometimes, the dead are buried without sending them to the mortuary to certify their death. In some cases people may consider certificates and identity papers as part of one’s personal belongings and bury these with the deceased. When people do not have death certificates, a long and tiring process awaits them to get the necessary papers.

The application for a child support grant is easier. Only a child’s birth certificate is strictly required. Although most households with children we visited received child support grants, not everyone seemed aware that the age limit in recent years had increased. Moreover, for many poor households the bureaucratic procedures seem complicated; many people do not know the requirements for applying for a social welfare grant, or where to go or who to contact.

Even when people have the required documentation, they may be constrained by the limited capacity of the Department of Social Development. One woman recalled:

*In January, I went with the home-based care worker to town to apply for foster grants. Someone from social welfare said that she would come to check out the information. She never came (...). Once when I was in town, I asked them about it. They said the social worker has a long list to attend. She is the only one who does the foster grants.*

This case was not exceptional. We encountered one grandmother taking care of the child of her diseased daughter who had been waiting for a grant since 2002.
Distance to Public Services and Markets

Msinga has a relatively good infrastructure of services for people who are infected or affected by HIV. However, most services are concentrated in the main town. Community campaigns and outreach services are either absent or very limited. Although the hospital has a mobile clinic and has started to set up a home-based care system in the rural areas, there are still many areas in the sub-district without good healthcare facilities and up-to-date information. The remote location of many households does not only affect people’s access to public services, but also limits their ability to make a living. Especially among women who are infected or affected, it is difficult to leave their home. Transportation costs, time, lack of information and illiteracy are important barriers.

5.4.4 Human Action in Response to HIV and AIDS

Knowing the psychosocial impact of HIV and AIDS and the influence of institutional structures and processes helps to better understand people’s responses. The impact of HIV and AIDS may be very different when someone is sick, has died, or when orphans are left behind, and thus it relates to the specific situation of an individual or household (SADC FANR, 2003). To demonstrate some of the similarities or differences between households, we present some typical cases in the next sections.

Coping with (chronic) Illness

When, after a period of several years, people infected with HIV become sick and physically constrained, this may have a big impact on a household. They are no longer able to work, for instance as a migrant labourer, and will likely have difficulties carrying out domestic activities.

Box 5.1 presents the story of one woman, Bongokuhle, which is illustrative of many women in Msinga who are HIV-infected. Women typically find out their HIV status during pregnancy when they have their blood checked at the antenatal clinic. Their households mainly survive on child support grants, but they suffer food shortages and have problems paying for school, clothes and transportation. They buy staple food in smaller quantities than before their illness, while their children help in the household by collecting wood, washing, and gardening.

The HIV-infected women who were interviewed in-depth relied firstly on their immediate environment for social support (i.e. kinship ties and social networks). Although they all seemed to accept their HIV status, they kept it a secret or had only told someone they could trust, like a household member, child or mother. Often,
Box 5.1: Experience of a women infected with HIV

Bongokuhle is 26 years old and infected with HIV. She is married and has three young children. Her husband is also sick and has temporarily gone to his parents. She applied for ARV treatment, but does not have money to get the results of her CD4 cell count.

She cannot work. She relies on two child support grants, which she uses to go to the hospital. Her son helps her at home with cooking and fetching water. Sometimes he borrows R20 from his grandmother to buy sweets and sells them. With the profit he buys something extra to eat with maize meal. Last year she planted a garden near a stream. She joins her son and shows him what to do. When she is very sick, her mother comes to stay with them. She only told the home-based care (HBC) worker and one other (HIV-infected) woman about her HIV status. The HBC worker helps her when she is sick. Sometimes she gets a food parcel and news updates on what is going on in town. Sometimes, the HBC worker gives her bus fare if she does not have money to go to the hospital.

Her children regularly leave for school without food. Before, they would buy big bags of flour, sugar, and 80 kg of maize meal. Sometimes it would last until the following month. Now she buys a big tin of maize meal and a small packet of sugar, so that they can have *mcuku* (maize meal mixed with water). Only when there is something ready from the garden do they have something else to eat. She is scared to ask her neighbours for food. At the beginning of the school year she has to ask the teachers to excuse her because she has to pay late. Her children do not have uniforms, and so other children laugh at them.

There are not many employment opportunities. Someone has to take care of her children. Farming can help, but the problems are lack of water and who to sell to. She would like to do chicken farming because no one else is doing that.

However, they had told a home-based care worker, who provided them with emotional and physical support, and sometimes financial support for food or transport. In addition, the home-based care worker acted as an important link to other resources, such as food parcels, medical services, or support groups for people living with HIV. Children played an important role in their motivation to cope with the disease, and most believed that with ARVs they could have a future.

However, not all individuals can count on the same amount of social support. For example, Bongokuhle got help from her mother, while her husband was being treated at his parents’ home; another woman was financially supported by her father-in-law; but one woman, whose boyfriend had left her, depended on her stepmother. She was afraid she would be rejected if her family found out her HIV status. Moreover, an old-
er woman, living in a polygamous household, took care of the orphaned children of the first wife who had died of AIDS illness; meanwhile, she was afraid of re-infection with HIV, yet she relied on her husband for financial support. All the women in the study continuously seem to balance their actions in order to protect themselves and their children against the risk of losing the social and economic protection derived from their husband or other family.

Under these circumstances, financial support through disability grants can make a large difference. However, to the despair of some who have depended on these grants, the government does not want to provide them any longer since ARV medicines are now available. Although early experiences have shown that ARV treatment can mitigate the impact of HIV and AIDS, it is not yet clear to what extent ARVs can enable people to continue to make a living. Two women who had entered the hospital’s ARV treatment program one or two months ago still experienced problems with heavy physical work. Still, they also mentioned positive changes: ‘the pains are not as before’ and ‘my body is feeling better now.’ After receiving treatment for almost a year, one woman said in a follow-up interview, ‘I am still sick, but not as before. I used to lie down, but now I can work with it.’

The Impact of Illness and Recent Death

When HIV illness in a household gets worse, it affects not only the one who is infected but also puts a heavy burden on the caregiver and the rest of the household. In almost all the participating households that had coped with illness in the family, it was the wife, mother, or a female relative who took care of the ailing person.

Box 5.2 presents the story of a woman whose daughter had died of an AIDS illness. The experience of Jabulile shows that households may strive to do anything to prevent their loved ones from dying. Households that take care of someone who is (terminally) ill often consult private doctors and traditional healers even if treatment is expensive. Even though medicines and treatment from clinics and hospitals may be free, transportation and food for patients in the hospital are not. More money may be spent on traditional herbal medicine and special food for HIV-infected people, and less spent on basic food, clothing, and school fees and uniforms.

When someone is terminally ill or dies, a bigger claim is made on social relations. The respondents often mentioned that taking care of ill relatives was not only emotionally difficult, but also withdrew them from other domestic and productive activities. Sometimes, however, they got help from neighbours, for example with planting. Also, when someone dies people rely on each other. Cultural expectations are that relatives
Diversity in Impact and Responses among Poor and HIV/AIDS-affected Households

Box 5.2: Experience of a mother whose daughter died of AIDS

Jabulile is 56 years old. She lives with her seven children and four grandchildren. She also takes care of three children of her diseased brother. Recently, one of her daughters died of AIDS illness after being sick for more than three years.

When Jabulile and her husband first heard about their daughter’s illness, they took her to Johannesburg. First, they went to a private doctor; then to an inyanga (traditional healer), where she got some muti (traditional medicine). Finally, they visited a clinic where they told her she had TB. After treatment, she became sick again. Her daughter stayed for a year in Johannesburg before she died. Throughout this period, she and her husband, who worked in Johannesburg, took care of her.

While she was in Johannesburg some of the children stayed at home. The situation was difficult. Chickens, goats, and the gas-cylinder were stolen, and crops were destroyed. When the children came home from school there was often no food. There has been a big change since her daughter died. Her daughter used to buy dishware and warm clothes for them in winter, and she generally helped to raise the children. Jabulile is scared to tell others that her daughter died of AIDS. When she died, the neighbours did not keep the wake at the household, as is the custom. Even the children say that they never, ever sleep at their neighbours’ homestead when there is a situation like this.

The situation remains bad. She spent all her money when she was in Johannesburg. Her husband used to give them money, but the funeral finished it. Now they eat porridge only. There were pumpkins, but they are finished. Since that, she does not know what to do. They may try mfino (spinach), although it has not grown to the eating stage yet.

and neighbours will attend a wake at the house of the deceased until the day of the funeral. However, on several occasions it was mentioned that neighbours had not come when someone had died of an AIDS illness, which was a painful experience for the deceased’s relatives.

There can be a striking, destructive impact on a household’s natural and physical resources. Some referred to a lack of energy and time to work in the fields; children got hungry, houses were collapsing, and security became compromised. Livestock was often slaughtered in cultural ceremonies related to illness and death, or was sold for meat. Some tried to save money for a coming funeral, consequently putting other things on hold, such as building houses or buying cattle and furniture.

Households with male relatives and migrant labourers seemed to cope better than others. They often had more financial reserves and livestock. However, such households also tended to make more use of traditional healers and private doctors and
could easily slide into poverty. Some respondents from poor families also feared to become dependent on loan sharks, who charge very high interest rates.

**Taking Care of Orphans**

The extra burden of care may shift from taking care of a sick person to taking care of orphans after the person died. Box 5.3 presents the story of a woman who was taking care of her own children and also of those of her sister-in-law who had died of AIDS. Many of the women interviewed said that the death of a person in the household could lead to a more stable situation. Caregivers are often able to go back to their normal routines, although taking on the care of orphans. However, as in Dolo’s case (Box 5.3), many struggled to feed extra children in their household; some households could no longer pay for school fees and uniforms and had to withdraw some children from school.

**Box 5.3: Experience of a woman taking care of orphans**

Dolo is a 47-year-old woman. She is married, has four children and one grandchild. For several years now, she has also taken care of the children of her sister-in-law who died of AIDS in 2003 (the children’s father had died in 2000).

She told the orphans, all girls, that they can always come to her when they need something. She told her children that these orphans are their sisters. Especially at Christmas time, she does not want them to have a problem. She tells them to share their clothes, so that they all look better and people will not notice that they are poor. Her sister-in-law had told her not to tell others that she was HIV-infected — not even the children. She finds it difficult to live with such a big secret. She says she has high blood pressure because of thinking about it. She has considered telling her husband, but she is afraid that he will get angry. There is no one to talk to and no one who can give her advice.

Caring for the orphans has changed their situation. Before, she would buy things that made her children happy, but now she only buys a lot of maize meal, and a pocket of potatoes and beans to eat with the maize meal. During the day, the girls stay together at their own homestead, but at night they stay with her. She is afraid that they might get raped. She decided to take care of them as they were living alone. She never heard of children living alone. She does not want this household to fall apart. She even built a small house to show them that she wants this household to be like their parents wanted it to be.

They are struggling at the moment. They do not have enough money. She went with the home-based care worker to town to apply for foster child grants, where they promised to come and check their situation, but no one did. Farming may help, so even in hard times they may have something to eat with maize meal.
Usually it is the family that provides a safety net for orphans. However, the respondents mentioned that siblings were sometimes separated into different households. Occasionally the orphans had to take care of themselves, which made them prone to theft and violence and left them vulnerable to loss of property to male relatives. As mentioned in Dolo’s story, the emergence of child-headed households in the area is a new phenomenon and it indicates that the social support system is becoming stretched beyond its limits.

Still, even among the households interviewed the diversity of responses to the impact of HIV and AIDS was great: a woman taking care of the children of her sister-in-law, a very old grandmother left with the young children of her diseased daughter, a young man supporting his younger brothers and sisters. Not all the households were able to survive without extra support. Besides the emotional burden, the death of a breadwinner – often a migrant worker – creates an economic gap.

People who take care of orphans can apply for foster child grants, while elderly people can apply for a pension. Those who received social grants were often better off than others. Some, who had been struggling before, were able to buy more adequate amounts of food and send the children to school again. However, some people may be simply too old to take good care of orphans. In one case, a young child was taken away by the in-laws when the child was accidentally burned due to the grandmother’s neglect.

The experiences of the persons presented in Boxes 5.1–3 give an impression of the differences between the responses of households in Msinga. However, the individual’s and household’s situation is often fluid and dynamic in time; financial resources and kinship relations can never be disentangled. Importantly, the impact of HIV or AIDS does not restrict itself to the one infected, but may extend to the household and family, and eventually the larger community.

5.5 Discussion

Although it is difficult to differentiate the impact of HIV/AIDS from other shocks and stresses, the study reveals various factors and mechanisms that contribute to or mitigate the impact of HIV and AIDS. The findings are consistent with the results of other livelihood studies (e.g. CHGA, 2004; Haddad and Gillespie, 2001; Stokes, 2003). The HIV epidemic does not only touch upon human capital (health), but also on financial, social, natural and physical capital. Food insecurity featured as a main
problem among the HIV/AIDS-affected households in this study, as similarly reported in other studies (e.g. Gillespie and Kadiyala, 2005; Loevinsohn and Gillespie, 2003; Steinberg et al., 2002). Many households make decisions on an ad-hoc basis. Although this study shows that money and time allocation, and altered gender and age roles, are important for households to cope, most responses have negative consequences in the long term. However, the livelihood options of poor households are restricted due to limited resources.

While the impact on people’s resource base is widely acknowledged in the literature on livelihoods analysis, the psychosocial impact is hardly mentioned (with the exception of Seeley, 2002). Many of the households in this study seem to live in fear, denial, and hopelessness, while misconceptions and myths around HIV and AIDS are rife. Lack of knowledge and fear culminate in stigma and discrimination, leading to social isolation of those infected or associated with HIV or AIDS. The consequences are widespread and vary from people infected with HIV themselves, their households and families, to those who are afraid to be or become infected. This does not affect only their psychosocial well-being, but also their health- and support-seeking behaviour, and it influences the set of options that seem possible for building and sustaining a living.

Social support mechanisms, in combination with expenditure on traditional ceremonies related to illness and death, have exacerbated the households’ poverty. However, not all households were affected to the same extent. Not only are there large differences between households in terms of orphaned children, chronically ill members, or recent experience of an adult death (see also White and Morton, 2005; Wiegers et al., 2006), but also within these categories. The study shows that in coping with HIV or AIDS, it is the role of social capital that stands out. More than a resource in itself, social capital is the ‘glue’ in society that links people to other resources, and this seems particularly relevant when people are poor (Müller, 2003).

A problem with social capital in livelihood studies is that it has often been seen from a positive perspective. It seems difficult to speak of negative capital or lack of assets in a framework based on strengths. However, social solidarity may not only have its limits – social networks may also reflect power relations, thus benefiting some at the expense of others (Bourdieu, 1986). The findings especially indicate that gender-based inequalities, in terms of access to resources and control over sexual behaviour, are critical areas of concern (with implications for government, community leaders and the population as a whole). Although this has been reported in other documents and literature since the outset of the HIV epidemic, very little seems to have changed.
In addition, the findings suggest that social grants are a vital source of income and food security for households affected by HIV or AIDS. However, many entitled to such support do not receive grants due to bureaucratic rules and legislation. This is especially a concern in relation to access to foster child grants and disability grants; rather than those who need one most, but those with education, money, and the right social networks seem to be in the better position to get these grants.

The provision of ARVs in resource-poor settings is relatively new. Barnett and Grellier (2003) mention it as the only intervention that can recover individual capacity and have an immediate and long-term effect on food security. Indeed, the findings indicate that ARVs can make a crucial difference in the lives of people who are infected with HIV. However, the findings also reveal that people's health may be compromised due to poor nutrition. Moreover, other studies have reported serious concerns about treatment adherence as result of the complicated regime, inadequate patient knowledge, medication side effects, and stigma (e.g. Roberts, 2000; Ware et al., 2006). This may lead not only to reduced effectiveness, but also to increased risk of viral resistance.

The variation in impact and responses demands diversified and holistic programs of development interventions, adapted to the specific needs of households. Households coping with chronic illness at an early stage have to be linked up with medical and social services. Households taking care of orphans often require financial support, while elderly people may need additional assistance. The most problematic situation is households with a terminally ill member, often exacerbated through traditional customs and practices. Although social inequalities related to cultural notions of gender and sexuality are deeply engrained in social norms and values, moderation of customary expenditure on funerals and the reform of customs relating to death and mourning have been reported in other areas of Africa, and could potentially be replicated (HSRC, 2003).

Development efforts need to restore a household’s resource base while addressing psychosocial issues. However, rather than ascribing a lack of resources as the sole cause of vulnerability, being excluded from exchanges others are involved in must be included. Supporting structures and processes that can cope with and support the diverse lives that people live need to be rebuilt (Seeley, 2002). Shifts within social capital will have to take place, and roles and power relations have to be renegotiated. These kinds of shifts are hardly measurable with the use of the sustainable livelihoods framework, yet are essential in understanding how the HIV epidemic has developed until now and will develop in the future.
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The adapted livelihoods framework makes it possible to see what strengths can be built upon. Where existing social networks seem to fail in the context of HIV, home-based care workers and support groups provide people infected with HIV with new networks for emotional support and sharing of experiences (see Van Woudenberg, 1998). However, psychosocial problems and misconceptions about HIV and AIDS are not restricted to people who are infected. Creating safe spaces (for example, through workshops) to transcend existing social networks, exchange perceptions on HIV/AIDS-related issues, and share daily experiences may help break the silence around HIV and AIDS. The same networks may not only provide psychosocial support, but also provide individuals with the required linkages to rebuild and access other resources. Moreover, it may amount to a first step toward addressing and changing existing power relations and networks.

For a highly contextualised issue, such as HIV/AIDS, overall community programs, supported by traditional leaders and local authorities, seem inevitable. Within this framework, farming can play a crucial role, not only to improve food security among vulnerable households, but also as entry point to talk about HIV and AIDS, share experiences, and challenge the underlying mechanisms that drive the HIV epidemic and its impact. Although the study presents data related to South Africa, similar psychosocial impacts of HIV and AIDS on poor rural households have been reported for other countries in sub-Saharan Africa where there is significant misinformation about HIV and AIDS, and stigmatisation and discrimination of people living with HIV (see Nyblade et al., 2003). Therefore, we expect the findings to have a more general scope and validity.
6.1 Introduction

HIV/AIDS-related stigma has the power to undermine the ability of individuals, families and societies to act for their own protection and to provide support and reassurance to those affected (Ogden and Nyblade, 2005). It is generally accepted that efforts to reduce stigma should be an integral part of HIV/AIDS interventions (UNAIDS, 2004), but there is far less agreement on what this should entail (Campbell and Deacon, 2006; Castro and Farmer, 2005; Deacon et al., 2005; Parker and Aggleton, 2003).

Initial strategies to address HIV/AIDS-related stigma were often focused on the individual (Herek et al., 2002) – they attempted to reduce ‘ignorance’ among those who stigmatize by providing them with the ‘facts’ of the illness or about the stigmatized groups and they tried to help those who are being stigmatized to cope by adjusting to stress. Many argue that these individual level health communication approaches have largely failed to address stigma and discrimination (Hayes et al., 2002; Walker et al., 2004). More recently, HIV/AIDS-related stigma has been described as a complex social process, which is embedded in unequal relations of power (Link and Phelan, 2001; Parker and Aggleton, 2003). This has led to a stronger focus on structural interventions to address social inequalities, such as the development of anti-discrimination legislation and poverty reduction. Without denying their importance, it does not seem to be sufficient to address stigma and discrimination within the private (relational) spheres of people’s lives (see Deacon et al., 2005).

This study responds to a recent call in community psychology to bridge the gap between individual and structural approaches (see Campbell and Deacon, 2006). It
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aims to better understand HIV/AIDS-related stigma as a psychosocial phenomenon in order to develop an integrated framework for action. To capture the complexity of stigma and discrimination, the study was conducted in one specific area in KwaZulu-Natal (South Africa) as part of an action research project to prevent and mitigate the impact of HIV/AIDS on vulnerable households.

6.2 HIV/AIDS, a Psychosocial Phenomenon

Goffman (1963) characterises stigma as a ‘mark’ of social disgrace, arising within social relations and disqualifying those who bear it from full social acceptance. People who possess such characteristics acquire a ‘spoiled identity’ associated with various forms of social devaluation. Link and Phelan (2001) define stigma as the co-occurrence of labelling, stereotyping, separation, status loss and discrimination, emphasizing the exercise of power as an essential element. Other writers underline that stigma is linked to power and domination in the community as a whole, playing a key role in the production and reproduction of relations of power and control (Parker and Aggleton; 2003). According to Deacon et al. (2005), however, not all forms of stigma automatically result in overt discriminatory behaviours, while ‘power and domination’ do not always explain stigma within social groups or against dominant groups. Deacon et al. (2005) support a process model by Joffe (1999), based on projecting risk and deviance on ‘outsider’ groups (or groups considered ‘outsiders’ because they deviate from the norm). Whilst such ‘othering’ is common across societies, the targets of stigma often vary, reflecting wider power differentials in particular settings.

To unravel the complexity of stigma and discrimination, Campbell and Deacon (2006) differentiate between the ‘symbolic’, the ‘political’, the ‘material’ and the ‘institutional’ context. The ‘symbolic’ refers to the frameworks of understanding within which people make sense of their life experiences and within which stigma is located. With respect to stigma it often relates to value-based ideology that imposes moral judgments on others (Deacon et al., 2005). The ‘political’ refers to the operation of power in social relations, e.g. between men and women, young and old, rich and poor. It helps to understand expressions of stigma between individuals and social groups, as well as the lack of resistance among many who are stigmatized (Ogden and Nyblade, 2005). The term double stigma or layered stigma is often used, when stigma strikes already marginalized groups, deepening existing social inequalities. The ‘material’ specifically focuses on poverty and deprivation. Several studies have shown that poverty and deprivation are important drivers behind stigma and discrimina-
tion, e.g. of diabetics in Ghana (de-Graft Aikins, 2006), of people with TB in Zambia (Bond and Nyblade, 2006), and of African migrants with AIDS in England (Dodds, 2006). The ‘institutional’ context refers to how institutions may facilitate or mitigate stigmatizing representations and practices.

For the purpose of this paper we will add the ‘biomedical’ context. It refers to negative attitudes and stigmatizing beliefs which are not justified by the medical implications of the disease. These attitudes and beliefs are often based on fear, risk or a threat to a disease that is incurable and can be deadly (Gilmore and Somerville, 1994). Some prefer only to refer to it as stigma when it is part of a wider pattern of stigmatizing beliefs (Deacon et al., 2005). We have decided to include it, because in a HIV high-prevalence area most people who are stigmatized based on their physical appearance or illness are devalued due to the negative associations with HIV and AIDS (see Campbell et al., 2007).

Stigmatizing beliefs and attitudes and discriminating practices are perpetuated and sustained in complex social relations, and internalized in the individual psyche (Deacon et al., 2005). This does not only explain the politics of stigma, but also facilitates a better understanding of people’s behaviour as result of stigma. Even when not enacted through discrimination, the experience of stigma may be internalized and lead to loss of self-esteem and self-devaluation (Carr and Gramling, 2004; Joseph and Bhatti, 2004; Kang et al., 2005). This may result in psychosocial problems and negatively affect health seeking behaviour.

Figure 6.1 presents a visual representation of the relations and linkages between manifestations and consequences of stigma and discrimination and the various contexts in which they are produced and reproduced. Besides biological, social, cultural, economic, and political factors that perpetuate stigma and discrimination, these factors also overlap and interact.

It is becoming increasingly clear that to mitigate the impact of stigma we need to move beyond the individual and concentrate on the broader structural or institutional factors that shape the individual. However, it is not exactly clear how the actions and behaviours of an individual are shaped by the social context (Campbell and Deacon, 2006). By using Msinga as a case study, we hope to gain more insight in the relation between manifestations of stigma, the underlying causes and mechanisms, their consequences, and ‘ways’ to address them.
6.3 Methodology

This study was conducted in Msinga, a poor, rural, traditional area in KwaZulu-Natal with a HIV prevalence of more than 20%. To explore stigma and discrimination, a study was conducted over a three-month period (April-June 2005). Focus groups and interviews were used to identify the perceptions and experiences of stigma from various perspectives (support groups, men and women, young and old). In Table 6.1 an overview is given of the characteristics of the participants in the focus groups and in-depth interviews.

In addition, in-depth interviews and informal conversations were held with home-based care (HBC) workers and representatives of the health care system throughout the process.

Participatory research methods, such as games, storytelling, and visualisation were used to allow discussion about the sensitive subject of HIV/AIDS-related stigma and discrimination (see Kidd and Clay, 2003). In-depth interviews were conducted within private settings. The research procedure took place in a phased fashion using a range of these methodologies with different target groups.
HIV/AIDS-related stigma and discrimination was first explored among members of support groups for women living with HIV/AIDS. Two focus groups were held to gain insight into their experiences of stigma and discrimination and the strategies they employed to cope with it. It was hypothesised that these women would be more open and free to talk about stigma and discrimination and provide insights that could be useful for framing other focus groups and interviews.

Stigma as expressed in the communities was further explored with women of one of the support groups for poor and HIV/AIDS-affected households. Four focus groups were held to get a better understanding of various manifestations of stigma amongst this group. In addition, in-depth interviews were held with three members of the support group. The privacy surrounding the in-depth interviews enabled them to tell their personal stories.

To examine the diversity of stigma, the information retrieved during the former steps was verified and discussed with HIV-infected men and youth of a local high school. A focus group with male patients from the local hospital aimed to gain insight in their experiences and perspectives. Male and female pupils were involved in a HIV/AIDS quiz to assess basic knowledge and to create and stimulate an atmosphere for sharing and discussing stories and experiences on stigma and discrimination.

In-depth interviews were conducted with three HBC workers in the participating village and the head of the antiretroviral (ARV) program of the local hospital in Msinga. Informal conversations were held with the social worker from the local community-managed health centre, one of the voluntary counselling and testing (VCT) staff, and

<table>
<thead>
<tr>
<th>Participants</th>
<th>Method</th>
<th># Part.</th>
<th>Age</th>
<th>M</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Support group for women living with HIV/AIDS</td>
<td>Focus group 1</td>
<td>7</td>
<td>26-53</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Focus group 2</td>
<td>5</td>
<td>26-50</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>(2) Support group for poor and affected households</td>
<td>Focus group 3a</td>
<td>5</td>
<td>24-72</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Focus group 3b</td>
<td>5</td>
<td>30-46</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Focus group 4</td>
<td>4</td>
<td>30-72</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Focus group 5</td>
<td>12</td>
<td>27-72</td>
<td>-</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>In-depth interviews</td>
<td>3</td>
<td>33-72</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>(3) Male HIV/AIDS patients</td>
<td>Focus group 7</td>
<td>6</td>
<td>24-55</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>(4) Youth</td>
<td>Focus group 8</td>
<td>20</td>
<td>14-21</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

Table 6.1: Research methods and characteristics of participants
the head of the HBC-program. The aim of the interviews was to gain more insight regarding their personal experiences and to get an indication of the role of stigma and discrimination in their work settings, as well as the wider health implications.

The research was conducted by a female researcher from the Netherlands in collaboration with a female and male translator. Before each focus group or interview, participants were informed about the background, aim, and procedure of the study and voluntary consent was obtained. Information of the focus groups were noted down and worked out directly afterwards. In-depth interviews were recorded on tape and transcribed in English. The transcripts were reviewed by the collaborators/translators. Drawing on the conceptual framework to stigma and discrimination outlined above, the data was subjected to thematic analysis.

The presence of project staff and researchers in the study area since the end of 2003 stimulated an atmosphere of trust and respect in interaction with participants, and ensured that information was well understood in relation to the context. To enhance validity, triangulation was used to compare data from various methods and informants. Direct observation and informal conversation were used to verify findings, while preliminary findings were presented for feedback to project partners and representatives of various groups involved in the process.

6.4 Results

In this section, we will link the diversity of manifestations of stigma in Msinga to the various social contexts in which they are produced and reproduced, and their consequences. It does not only provide a better understanding of the underlying causes and mechanisms, but also of the potential constraints and opportunities for action.

6.4.1 Manifestations of Stigma

Stigma is expressed in different ways and can be found across various levels of social interaction. Within traditional Zulu-cultural settings, families generally function as an important safety net on which one can fall back for care and support in difficult times (Swaans et al., 2008). However, within the context of HIV and AIDS, it may also become an important source for stigma and discrimination. The HBC workers mentioned some examples of painful events:

When the family sees me they say: ‘Aren’t we glad you are here! Please feed him for us’. Then he will start telling me the horrible things they do to him just because they found out he was HIV-positive. The person will tell they shut him up in the room alone.
He was staying in this room, isolated from other people. His mother would slide the food on the floor from the door like you would feed a dog once a day. He stayed only two weeks and died because of depression.

The exclusion from family life was considered by most respondents the rule, rather than the exception. However, social exclusion in the context of family takes different forms. Most dramatic is the loss of care, which was mentioned on more than one occasion by people living with HIV, members of affected and poor households, and HBC workers. Most families in the community only take care of their ill family members if they do not know their status. When someone’s status is known or when a disease gets worse, they do not want to touch the person anymore. One of the HBC workers said:

Sometimes you find that a person is suffering from diarrhoea and the family does not want to have anything to do with the person. (…) They tell us they are scared to touch the patient because they don’t know what the person is suffering of.

Social exclusion is not something that occurs solely in the context of family relationships, but also in friendships and relations with community members. One of the HBC workers recalled a recent experience in a taxi:

I was taking a person [infected with HIV] to the hospital in a public taxi. He had skin rash and sores in the mouth (…) People did not even want to look at him. (…) if there would have been other means of transport, they would have dropped off.

Gossip appears to be the most widespread form of discrimination in Msinga. As soon as a person is sick, people in the community entirely withdraw from that person, but at the same time set up an elaborate scheme to get as much information as possible about the person and his/her disease. A woman speaks of the fact that people no longer come to care, but to gawk:

When you are sick, people come to check what disease it is and they start to gossip that it is ‘that’ disease. The children are no longer allowed to play at or near that place. The people come in groups, no longer to care but to observe and to gawk and to find out that what they heard is true.

Name calling is a nastier version of gossip that is not concerned with getting information, but with actively trying to make a person feel bad. Even though derogatory words are sometimes used as euphemism to refer to HIV/AIDS-related diseases, these
words can also be used to refer directly to people who are living with HIV. Deroga-
tory words for HIV include, among others, ‘OMO’ named after a three letter washing
detergent brand, and ‘the three-letter disease’. This last word can also be visualised
by holding up three fingers. Even more degrading are the remarks that are made
concerning the way a person looks. Often there is a direct referral to the skeleton-like
appearance of a person with full blown AIDS. However, for people not yet that thin
but known to be HIV-positive are no longer considered human beings:

*Sometimes people will say that you are rotten, or they will say that you are dead
but that you are still walking.*

Gossip, taunting or name calling, often go along with expressions of blame, in which
those who are stigmatized are held responsible for their own infection due to their
alleged immoral (sexual) behaviour.

People who work with or are related to HIV-positive persons are often also the victim
of stigmatization and discrimination in the community. Some families even deny
HBC workers to come and take care of the sick person, as one of the women indi-
cated:

*People assume that if you are HIV-positive, than the HBC worker that is treat-
ing you will have to be positive too. So they will gossip about the HBC worker
and will not let her enter their house.*

However, formal and informal caregivers can also have stigmatizing beliefs. Some people
living with HIV reported that they were treated differently or badly by health care pro-
viders in clinics and the hospital. Stigma also transgresses into other institutions. Some
people indicated that they were often discriminated in the Church for being sinful and
not being good Christians and that the media portrayed them as sleeping around and
being irresponsible; some participants lost their jobs due to HIV infection.

HIV-positive people and those affected by HIV/AIDS may also fall victim to unintend-
ed structural discrimination, i.e. when existing institutional structures and processes
are insufficient to support them and protect their rights. For example, it was regularly
mentioned that widows and AIDS-orphans face the risk of loosing property to other
family members; many mentioned they lacked social and juridical protection.

The main manifestations mentioned in focus groups, interviews, and conversations
are summarized in Table 6.2.
Table 6.2: Manifestations of stigma in Msinga

<table>
<thead>
<tr>
<th>Family</th>
<th>Community</th>
<th>Institutions</th>
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</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>Social exclusion</td>
<td>Differential treatment by institutions</td>
</tr>
<tr>
<td>– Marking and separating</td>
<td>– Less visits from neighbours</td>
<td>– Church</td>
</tr>
<tr>
<td>eating utensils</td>
<td>– Less daily contacts and</td>
<td>– Health system</td>
</tr>
<tr>
<td></td>
<td>exclusion from community</td>
<td>– Orphans/children</td>
</tr>
<tr>
<td></td>
<td>activities</td>
<td>– Stigmatized at school</td>
</tr>
<tr>
<td></td>
<td>– Children not allowed to play</td>
<td>– Risk of losing jobs</td>
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<tr>
<td></td>
<td>with children/orphans of</td>
<td></td>
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<tr>
<td></td>
<td>HIV-positive people or near</td>
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<tr>
<td></td>
<td>their house</td>
<td></td>
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<tr>
<td></td>
<td>– Public rejection in taxi</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expressions of blame &amp; shame</td>
<td>Gossip</td>
<td>(Unintended) structural</td>
</tr>
<tr>
<td>– They did not care about the</td>
<td></td>
<td>discrimination</td>
</tr>
<tr>
<td>family and now they come to</td>
<td></td>
<td>– People living with HIV</td>
</tr>
<tr>
<td>die on us</td>
<td></td>
<td>and affected families</td>
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<tr>
<td></td>
<td></td>
<td>– Are disadvantaged as result of existing social inequalities and institutional</td>
</tr>
<tr>
<td></td>
<td></td>
<td>infrastructure</td>
</tr>
<tr>
<td>– The wife brings HIV/AIDS in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the household</td>
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<tr>
<td>Loss of identity/role within</td>
<td>Using derogative words or signs</td>
<td>Media</td>
</tr>
<tr>
<td>the household</td>
<td>– OMO (3-letter; detergent)</td>
<td>– Emphasizing negative images of people living with HIV</td>
</tr>
<tr>
<td>Withdrawal of care when</td>
<td>– You are dead, but still</td>
<td></td>
</tr>
<tr>
<td>disease gets worse</td>
<td>walking</td>
<td></td>
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<tr>
<td></td>
<td>– You are rotten</td>
<td></td>
</tr>
<tr>
<td></td>
<td>– They think/say you are</td>
<td></td>
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<tr>
<td></td>
<td>mentally retarded</td>
<td></td>
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<tr>
<td></td>
<td>– Showing three letter signs</td>
<td></td>
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<tr>
<td>Expressions of blame &amp; shame</td>
<td></td>
<td>Lack of (social) protection</td>
</tr>
<tr>
<td></td>
<td>– It is their own fault when</td>
<td>– Police</td>
</tr>
<tr>
<td></td>
<td>they are infected</td>
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<tr>
<td></td>
<td>– People who have HIV/</td>
<td>– Juridical court</td>
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<tr>
<td></td>
<td>AIDS sleep around or are</td>
<td></td>
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<tr>
<td></td>
<td>unfaithful</td>
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<tr>
<td>Loss of identity/role in the</td>
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<tr>
<td>community</td>
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</tbody>
</table>

6.4.2 Underlying Causes and Mechanisms

The diversity and omnipresence of HIV/AIDS-related stigma and discrimination across all levels in Msinga is overwhelming. It extends itself from people who are infected to people suspected of being infected and people associated with them. However, it does not arise in a vacuum, but is perpetuated and sustained by various factors and mechanisms. They are described below by placing the diverse manifestations in the various contexts in which stigma and discrimination occur and are reproduced.
Chapter 6

The Biomedical Context

People’s negative attitudes and behaviours seem underpinned by ignorance of the biomedical aspects of HIV infection and progression of the disease. One of the women said:

*It was scary when we first heard of this disease. When you met a person who had it, we did not know what to do. We felt like running for our lives. Even now there are people like that.*

Most participants view HIV/AIDS mainly as a ‘killer’ disease. It was often mentioned that the progress of the disease is fast and ‘eats a person alive’. The illness trajectory and symptoms have led to a strongly felt fear among participants that to be tested HIV-positive is to face a quick death. That HIV-positive people can recover from AIDS-related illness, with or without Anti Retroviral (ARV) treatment, does not seem to change this perception. This may be fuelled by the fact that in many cases, people who are infected with HIV only seek treatment when they already have full-blown AIDS – when chances to recover are severely reduced.

AIDS was usually not only perceived as deadly, but also as very contagious. Contact with people infected or suspected to be infected is seen as dangerous and needs to be avoided. Or as one of the women of the support group for poor and HIV/AIDS-affected households expressed:

*We do not know the cure, so we would like to better be safe than sorry.*

Most respondents mentioned that being ill immediately leads to suspicion of HIV infection. This suspicion of infection is not only reserved for people with symptoms that are associated with HIV infection, such as sores, Tuberculosis, and severe weight-loss, but also with common afflictions such as a cold or a headache.

Fear of infection may also be expressed in the myths that people hold about HIV/AIDS. Participants were generally afraid that people who are infected with HIV may infect others when they cut themselves while preparing food. Some thought that HIV-positive persons try to infect others. This notion seems to be reinforced by ‘known’ cases. In one of the focus groups, a HBC worker mentioned that an HIV-positive man in the area carried a great syringe filled with his own blood to infect other people. This story seems to be based on sensational media reports, which, combined with ignorance, triggers and justifies peoples own stigmatizing behaviours.
The exaggeration of risk and potential modes of infection seems closely related to people's knowledge. Especially among those who were not infected themselves, knowledge about HIV-transmission seems to be poor (see also Swaans et al., 2008b). In a quiz with women of the support group for poor and affected households, most were familiar with the general modes of transmission, but some of them also mentioned ‘saliva’, ‘sweat’, ‘faeces’, ‘vomit’, and ‘urine’ as modes through which the virus could be transmitted. Even casual contact as ‘sitting next to someone who is infected’, ‘eating food prepared by HIV-positive people’, ‘using the toilet after HIV-positive people’, ‘hugging’, and ‘sharing towels, clothing, and cutlery’ was perceived as risky.

Thus, people were not always sure about the exact conditions under which or how HIV is transmitted, how big the risk is, or more important, when it is not transmitted.

The Symbolic Context

Biomedical information may help people to better understand HIV/AIDS and their risk of infection, and hence reduce stigma and discrimination towards people living with HIV. However, health messages have to compete with other important beliefs, such as witchcraft, religious motives and myths on the origin and cure of HIV and AIDS. A woman in one of the focus groups said:

I saw it happening in the family of my neighbours. You cannot ask if it is HIV (…). If you suggest this person should go to the doctor, they deny that the person is really ill. They say that it is witchcraft or that she had something bad to eat.

Although some people seem to use witchcraft as an excuse not to talk about HIV/AIDS with others, many older people in Msinga believe that a person can be bewitched when someone is jealous or when that person does not appease the spirits of the ancestors. Some HIV-positive persons mentioned that Church leaders referred to AIDS as a punishment from God for people's irresponsible sexual behaviour, while one of the men explained that HIV was introduced by the white population as a way to control black Africans after the end of apartheid. It was also mentioned that some people in the area belief that sex with a virgin cures AIDS (see also Leclerc-Madlala, 2002). These examples do not only show that diseases and deaths may lead to misconceptions and myths, but also to accusations and blame.

In addition, participants often mentioned a gap between the information they received through health education and the applicability of this information to their own situation. For example, most women know that HIV is transmitted sexually, but many explained that cultural norms and values make it difficult to avoid risky behav-
Our. Sex and sexuality in this cultural setting are strongly entwined with concepts as fertility and procreation. One of the men said:

*My wife died last month. (...) I may marry again and with my new wife I like to have children. That is to say, she would like to have children. If I marry a woman, she expects me to give her children.*

In African families children are crucial. They help in the household and on the land. They provide social security when people reach old age. And most important, children ensure people’s personal ‘immortality’ through their lives and memories (see also Van Dyk, 1998).

Moral values on sex and sexuality directly interfere with perceptions of HIV/AIDS and attitudes to people living with HIV. Sex is not only seen as a means of procreation, but also as something bad or sinful when indulged in too much or when it is not in the context of a marital relationship. As HIV is transmitted sexually, most respondents link HIV infection with promiscuity, which is seen as a disgrace. Clothing, appearance and behaviour are all incorporated in the stereotype of a promiscuous person. When asked to identify which people are at risk of getting HIV-infected when showing pictures of different people, one woman said about a young girl in trousers:

*She is promiscuous, because of the way she looks (holds her legs). She is attracting boys. She will infect the whole nation. She is not married yet, so she can have many relations.*

As soon as someone is found to be HIV-positive, it is usually assumed that this person could not suppress his/her sexual desires. This is not only shameful for the person involved, but also for his or her family. Denial of the seropositive status of a family member by relatives can thus be considered an evasion strategy to prevent stigmatization, as one of the HBC workers mentioned in an interview:

*The parents are afraid to tell because they think that the rest of the family will laugh and say they also have this disease in their household.*

It can also result in discrimination, as illustrated by one of the HBC workers:

*A woman’s son came back from Johannesburg because he was ill. She said really hurtful things to him (...). When he asked for food, she would say ‘I was not with you in Johannesburg when you were getting this illness’. Maybe she will*
give him a small amount of food and say: ‘leave me alone because I was not there when you were feeding your sluts’.

**The Political Context**

Manifestations of stigma do not occur at random, but often follow existing inequalities in power. In Msinga, this was most visible across age and gender.

Younger people tend to be stigmatized more often than older people. This is due to several factors. The fact that young people are more sexually active, results in the general assumption among participants that young people have a higher risk to become infected. One of the women the community said:

*She is still young and she is still having children, so she has a high risk of becoming infected, because she has sex regularly.*

Generally, older participants blame young people for not living carefully enough and by contracting HIV putting a strain on the household. They try to convince them to take precautions and abstain from sex. However, the school children that participated consider this old-fashioned and do not want to be patronized. According to one of the women in the community, the young people say:

*We die through sex, because we arrived through sex.*

This indifference, although possibly exaggerated, expresses young people’s struggle with their own expectations and ideas about sexuality and the constraints HIV/AIDS impose on their sexual development.

Moreover, most of the older respondents find that young people are not too concerned with the cultural sexual norms. Marriage is seen as the correct way to engage in sexual activity. Men and women that are married appear to be less scrutinized than young people who are not yet married. One woman explained in an interview:

*Young boys and girls are at risk. But what happens is that the newly weds are the ones dying. However, they don’t gossip about those but about the ones who are not married yet.*

HBC workers mentioned that married older women can usually count on some form of care from family, neighbours or friends. Young people, however, are more often shunned and left to fend for themselves.
However, stigmatization also occurs in marital relations. There seems to be general consensus among participants that women are more at risk of becoming infected as they are less able to protect themselves. Their husbands often work away from home, leaving women in charge of the household for long periods of time. While women are frowned upon for having extra marital affairs, for men it is often seen as a sign of status when he has multiple partners. One of the women said:

Yes, we as wives are faithful, but men go to the city to work and they are faithful to the disease.

When a man is at home, his spouse generally has to comply with his wishes. One woman said:

It is easier to stay HIV-negative if you are not married, because then if someone proposes you can say no. But if a man has paid lobola [bride wealth], you are at his mercy and he can do whatever he wants.

Most female participants mentioned that suggestions for safe sex are seen as a sign of infidelity or that they do not trust their husband. They felt particularly vulnerable as men find it difficult to disclose their status to them. Some of the women stated that men might be afraid to lose their wives when they find out they are HIV-positive. According to the women in the village, some even take the diagnosis of HIV infection of their wife as a means to draw attention away from them:

If the woman finds out she is infected, for example because she is the one who falls ill first or because she was checked at the antenatal clinic, the man will blame her and ask: ‘where did you get it?’ Even if he has had a blood test and knows the result.

**The material context**

HIV/AIDS-related stigma is also intrinsically linked to poverty. Most households in Msinga depend on migrant labour for their income (see Swaans et al., 2008b). When a migrant labourer falls ill with HIV infection, this does not only result in the loss of identity and role within the family and the community as a productive member, but also in an extra burden on a household’s scarce resources. This often goes together with expressions of blame. One of the HBC workers mentioned:

Family members shout at the patients. If it is a girl they say ‘she went out and now she is coming to us with this disease’. If it is a boy they say ‘he went and came back to die on us and now he is our responsibility’.
Respondents associate HIV infection with an urban and wealthy lifestyle and a decline in sexual norms. Those who returned ill from the city are more vulnerable to stigmatization, as they were accused of being responsible themselves for being infected. One of them said:

*In urban areas the chances of infection are higher, because these people have more money which makes them more attractive and also because they often have a boyfriend or girlfriend on the side if their spouse is staying at home.*

According to most women, the more educated a person is, the greater the chance that he/she will become rich and work in an urban environment, thereby increasing the vulnerability to HIV infection.

Poor adult women, who get infected as a result of transactional sex to take care of the family, are still met with some sympathy from other women in Msinga:

*She is like my daughter. She is taking care of the children, but she falls in the trap of the boys to get money and that is where HIV lies. She will take a boyfriend to relieve the burden of care for the children. He will pay for things she needs, so she will sleep with him.*

**The Institutional Context**

Institutions can be a source of support, but they can also facilitate stigmatizing representations and practices. For example, Msinga has a relatively good infrastructure of health care facilities and social services providing a continuum of care for people who are living with HIV and their families. Stigmatizing behaviour of medical professionals is highly scrutinized in Msinga, but gaps between patient and care still exist – forming an extra hurdle to those that seek support. Moreover, several respondents indicated that specialised services, such as the Communicable Disease Control (CDC) clinic, or VCT-counselling, are so strongly associated with HIV/AIDS, that it renders a visit into a suspicious act.

For HBC workers the situation is somewhat different. They appeared not to be daunted too much by the psychological pressure of being stigmatized. In approaching their patients, however, they were fully aware of the stigma attached to their visits. One HBC worker explained how she went about visiting a new patient:

*I always visit the surrounding households first. I ask them if they need any help with medical problems. Then, I will go to the household of my client. I do this so people will not stigmatize my client for needing HBC.*
As mentioned before, stigmatization also occurs in the Church, at school and at the workplace. Often, negative remarks and differential treatment were directly related to moral values or to the fear of people to become infected themselves. Although these practices seem to take place on a case-by-case basis, community members may see them as confirming and justifying their own (stigmatizing) beliefs and attitudes. Moreover, HIV-positive people who were discriminated against did not trust, or could not always count on the department of police for protection. One of the health care professionals even mentioned that women who were raped, often lost their case in juridical courts.

Although no evidence was found of overt and systematic stigma and discrimination in policies and institutions, experiences from participants suggest that they do occur. For example, it was often mentioned by participants that rural areas lack good access to service and health care facilities, and that bureaucratic difficulties make it hard to access social grants. This will most likely affect those who are already marginalised, such as the poor and those who are infected or affected by HIV/AIDS. Female-headed and child-headed households are particularly vulnerable to discrimination due to their low social status in the community.

### 6.4.3 Consequences of Stigma and Discrimination

Given the magnitude of stigma and discrimination related to HIV/AIDS, it is hardly surprising that HIV-positive persons experience severe psychosocial consequences. Aside from having to cope with the fact that they are diagnosed with a life-threatening disease and the psychological consequences that stem from that, they are confronted with adverse and painful reactions from people in their immediate surroundings. Of particular concern is that it impedes disclosure. One woman infected with HIV said:

> Telling my family is what kept me awake at night and I think that is true for a lot of people that are diagnosed with HIV.

Often the reluctance to disclose stems from negative remarks that have been made by family members or friends.

There are indications that the experience and anticipation of stigma lead to internalized stigma. Many HIV-positive persons we spoke to often felt left alone and hopeless, and found it difficult to think about the future. Some felt ashamed and guilty; they think that they themselves are to blame for their infection, that they are dirty and do not deserve any attention or care of other persons. Internalised stigma is not only restricted to those who are infected. When asked what the impact of psychoso-
cial consequences was on the emotional and physical well-being of their patients, one HBC worker answered:

A woman I knew lost some weight and people started gossiping (...). I visited her and she cried and told me that people said she has AIDS. (...). I asked her if she had done a blood test. She said no. Then I asked how then do you know (...). She said that a person who is close to her was gossiping about her. I encouraged her to go for a blood test. At first she refused but then she went. The results came out negative, but she had to wait for another test in three months to be sure. She regained her weight and was beautiful by the time she went back for another test.

As social norms restrict people living with HIV from revealing their status and sharing their feelings, other aspects of their lives are impacted negatively also. HIV/AIDS can disrupt family or social relations. When combined with stigma, this can result in a situation where a person can be heavily discriminated by his/her own family members without the surroundings commenting or frowning upon it.

The struggle for acceptance and recognition by others, often results in a situation where persons living with HIV have to find their own ways to cope with being HIV-positive. The support groups initiated by the hospital enable HIV-positive people to talk about their fears and situation and to discuss problems that they encounter. One person of the support group for women living with HIV/AIDS said:

I started going to the support group and I felt welcome and at home. Here we can talk about everything, talk about our experiences and share our problems. This feels very comfortable. It feels really lonely without the support group, because here I can share.

On a more individual level, HIV-positive respondents often found solace in religion. Although some reverends stress in the church services that HIV-positive people are to blame for their infection, religious people were still able to separate the church services from their own ideas about religion and God.

The HBC workers appear to play an important intermediary role in this context. They did not only play a crucial role in signalling and mediating the psychosocial consequences of their patients, but also act as a link to the formal health care system and other services. Their role has become even more relevant since the recent provision of ARV medicines by the hospital. According to the physician in charge of the roll-out program of the hospital, the availability of ARVs has changed the stigma dynamics in Msinga.
It offers people who are infected a possibility to stay healthy and to engage in everyday activities. They may be able to gain their own income and relieve the burden of care in the family. It gives them a means to actively take responsibility of their own life (…).

The physician had seen an increase in couples coming together to the VCT-counselors to get tested and get counselling. Although some are afraid to go to the CDC-clinic in charge of the ARV program – as it is known as the HIV-clinic – it seems that for a person who takes the step to go to the hospital, the stigma decreases.

A factor that can mitigate stigma in a community, which has been mentioned by community members themselves, is a critical mass of non-stigmatizing people in the community. One of the women interviewed said in an interview:

There is nothing the families can do, but we as a community should hold a mirror up for these people to look in, to show them what they are doing and how they would feel if they were treated like that.

Although this is a hopeful sign to deal with disease as a community problem, when talking about HIV and AIDS people in Msinga hardly ever called it by its name. HIV and AIDS are taboo and not a subject to be talked about openly nor in public. This greatly impedes coping of the community with the disease. People are afraid to be associated with the disease and sometimes speaking one’s mind about the disease can result in discriminating actions such as gossiping or exclusion. The silence surrounding HIV is intrinsically linked with denial of the disease and the fact that HIV/AIDS is thought to be a disgrace. One of the women in the community even said:

There are even people that laugh at others here, but go to the CDC-clinic.

The silence surrounding HIV makes it easier for people to cultivate their own ideas about the disease, resulting in denial, myths, misconceptions and inaccurate knowledge. This is perhaps most clearly illustrated in the example of condom-use, which was often discussed in focus groups (see Box 6.1). However appropriate the guidance and counselling, men and women were reluctant to use condoms for a variety of reasons, e.g. loss of sexual pleasure, fear of getting infected through the use of condoms and most importantly, the suspicion raised concerning the fidelity of the partner. It illustrates the battle that is fought within relationships and communities, not only to secure protection from HIV infection, but also in making sense of health care messages from a cultural perspective. Moreover, it showed how condoms themselves have become the subject of associated stigma.
When discussing condoms as a preventive measure against HIV infection, reactions were ambiguous towards the effects this measure would have. First of all, there is a reluctance to use condoms, which is mainly confined to the loss of sexual pleasure. In the focus group with infected men, one of them said:

*People don't want to use condoms. They say that they miss out on the flesh on flesh feeling and they say that they need to feel that. Also they say that you cannot eat a sweet in a wrapper and that if you buy a sweet you always tear of the wrapper first before you eat it.*

In South Africa, condoms are also seen as a vehicle that actually carries the virus, as one of the other men explained:

*Some people say that the lubricant contains the virus (...). They also say that if you hold the condom up to the light that you can see little worms and that these little worms are the HIV-virus and that you will get infected like that.*

On a more personal level, especially in the context of marital or sexual relationships, the suggestion to use condoms often leads to conflicts. Some typical reactions by women in the focus groups were:

*If a wife says that she wants to use condoms, the husband gets really suspicious and says: ‘have you been checking my status behind my back?’ Also, men think that you are judging them if you want to use condoms, they will think that you are accusing them of sleeping around.*

*If a woman suggests using a condom, she is often beaten. The men will say, where did you learn to use a condom? You probably learned how to use them from one of your other boyfriends, so you must be sleeping around. Sometimes boys just get jealous if you say that you want to use condoms, because they think that you are unfaithful.*

However, during the focus group with infected men, men expressed that they have to fight their own struggle for the use of condoms.

*Ha, but that is not the way it is! If you suggest using a condom, they think that you think that they are sleeping around and that you want to use a condom to prevent yourself from getting infected. They will try and prove their faithfulness by insisting on making love without a condom. If you insist on using one, they will refrain from sex and say that you can move on to the next girl.*
Stigma, silence and denial have far reaching consequences for health care interventions. The fear of being associated with HIV leads to people not only denying the occurrence of HIV, but also ignoring their duties of care. It was often mentioned that the stigma surrounding HIV/AIDS has made it more difficult to seek financial and social support from close relatives, neighbours and friends. This results in families not seeking or accessing the support they need and puts a strain on relationships in the community. Moreover, it negatively affects testing, treatment, care, and prevention in general.

6.5 Discussion

This study shows that stigma and discrimination are embedded in complex social interactions. Women are more susceptible to HIV infection than men, and are more vulnerable to the impact of AIDS; young people are more at risk of HIV infection when exploring their sexuality, and face the risk of stigmatization as result of their low social status. People who are poor are more likely to engage in risky behaviour to gain money or food (see also Bryceson and Fonseca, 2006; Weiser et al., 2007); due to lack of money for transport to get ARV or buy healthy food (see also Swaans et al., 2008b), they are also less able to hide infections. In this way, biological factors directly interact with socio-economic ones.

When institutional factors occur in combination with traditional cultural norms and values, it may result in stigmatizing attitudes towards HIV/AIDS and persons living with HIV, for example in churches and health care settings (see also Ogden and Nyblade, 2005). Institutional structures and processes may also lead to limited access to services among the rural poor, and increased vulnerability to material stigma and discrimination. The study also showed that this is often related to a lack of political power. Women and youth are particularly vulnerable, as they often have fewer rights in traditional institutions and lack social protection. Poor people generally lack the knowledge and social networks to change the status quo (Swaans et al., 2008b).

The lack of power among women and youth may also explain why they are more vulnerable to stigmatization based on moral grounds. The older generation in Msin-ga seems to prescribe to traditional cultural norms and values, possibly exacerbated by fear to lose power as result of an ever more dynamic and open society (see also Campbell et al., 2005). It was interesting to see, though, that at community level, there was sympathy for those who are poor and engage in risky behaviour, indicating
that there is ‘space’ for competing values and norms, such as the responsibility to take care of one’s family. In the case of myths and witchcraft, the situation becomes even more complicated. They are often based on a mixture of biological facts, cultural norms and values, and social power. The example of condom-use in Msinga shows that this extends to the institutional setting and directly interferes with health care interventions.

The impact of stigma and discrimination on the psychosocial well-being of HIV-positive persons is severe. They have to fight a constant internal battle to keep their positive status a secret and/or an external battle to defend themselves against stigmatization and discrimination. This ultimately results in feelings of hopelessness and depression (see also Carr and Gramling, 2004; Kang et al., 2005). Moreover, former experiences of stigma, directed to people infected with HIV or those affected by the disease, results in anticipated stigma, which further contributes to the silence and denial surrounding HIV and AIDS.

This study does not only show that manifestations of stigma are perpetuated in various social contexts, but also that they are interlocked and united to support systems that mutually reinforce each other. This leads to internalized stigma and self-policing behaviour, and to a situation whereby existing social inequalities and social difference are maintained in a context of power (Parker and Aggleton, 2003; Campbell et al., 2005). It is not surprising that this affects the already vulnerable groups in society, i.e. women, youth and the rural poor. They are relatively far removed from service providers and additional support, while they lack the political power to counter existing inequalities.

6.6 Implications for Interventions

The question that rises after this study is what can be done to prevent or mitigate the impact of stigma on these vulnerable groups. First of all, it is important to realise that HIV/AIDS-related stigma and discrimination manifests itself not only in the different contexts, but also in the different domains of social interaction. Figure 6.2 shows the four different domains in which stigma and discrimination emerge and are shaped: the individual, the household, the community and the institutional. This figure can add to the analysis and discussion as well as shape recommendations for interventions.
Stigma and discrimination occur in each of the four domains. It can be active – for instance expressed verbally and in actions – or passive, for instance as result of anticipated stigma and unintended structural discrimination. Where it occurs in individuals, it is called internalized stigma. Stigma and discrimination also occur in the ‘interface’ of two or three domains and where all four domains overlap. Their particular form or expression is ‘shaped’ and ‘coloured’ by the particular domain or domain interface in which they emerge. Manifestations and consequences of stigma and discrimination in each of the domains can be summarized as follows:

- **Individual**: e.g. fear to disclose, denial, refusal to test and/or to seek support (medical, social, financial etc.);
- **Household**: e.g. fear to disclose that HIV/AIDS exists ‘in the house’, denial, anger, withdrawal of care and support to people living with HIV;
- **Community**: e.g. ridicule, gossip, isolation, discrimination of a known HIV-positive person, person working with HIV-positive people, group, or non-specific group of people living with HIV as a ‘category of people with negative characteristics’;
- **Institutional**: e.g. differential treatment and (unintended) structural discrimination as result of existing policies.

Interventions to address stigma and discrimination, thus, also need to target these domains and interfaces. The study gave various indications what these interventions should entail.
The study clearly demonstrates that the lack of in-depth knowledge contributes to stigma and discrimination. Furthermore, stigma and discrimination are embedded in social representations which are constructed in daily interactions in the community. In order to come to an effective approach, community members themselves need to be involved in group sessions for education and discussion on HIV/AIDS for reconstructing existing misconceptions on HIV/AIDS and people living with HIV and to challenge norms and values that underlie stigmatizing behaviour. The study also indicates that HIV/AIDS is a sensitive topic, and that discussions are most likely to be effective when they take place within the safe environment of peer groups related to age and gender.

Stigma is also related to social and economic factors and is often embedded in institutional relations. Therefore, the provision of safe-spaces for critical reflection should go along with material and institutional support for vulnerable groups (see also Cornish, 2006; De-Graft Aikins, 2006; Hartwig et al., 2006). The HBC-program and the roll-out of ARV medicines have the potential to make a difference in the stigma dynamics and this should be further explored and strengthened.

Finally, the ultimate aim lies in bridging the gaps in perspectives and stigma between various social groups. Although support groups have shown to be effective in increasing coping skills, particularly if structured around issues likely to be confronted in the local culture (Chesney and Folkman, 1994; Kelly et al., 1993), the wider impact on their communities is often limited (Van Woudenberg, 1998). This suggests that besides offering safe-spaces, interventions also need to build the power-base of HIV-positive people to engage actively and collectively with the wider community to raise awareness, and fight stigma and discrimination. It may be more difficult to approach those in the community who deny the existence of HIV/AIDS and to establish a relationship of trust. It may help to address what unites groups, rather than what divides them. In case of vulnerable households, a more general development focus seems more appropriate. They need interventions that help improve their livelihoods.

This could lead to the following interventions:

- Individual: counselling/therapy to overcome psychosocial problems; nutrition and health support (e.g. nutrition advice, food supplements, ARVs and managing HIV-related health problems); positive role models (e.g. celebrities and opinion leaders revealing their status);
- Household: family counselling/therapy to overcome psychosocial problems; nutrition and health support; financial/livelihood support (e.g. grants, food garden, income generation);
Chapter 6

- Community: awareness raising campaigns (including zero-tolerance of stigma and discrimination), peer education, VCT services at community level as a dual HIV/AIDS prevention and support intervention;
- Institutional: awareness raising among managers/directors and among employees or members, zero-tolerance of stigma and discrimination, review of existing regulations and policies in the light of HIV/AIDS and stigma.

However, the study also showed that power dynamics come into play when existing relations, e.g. in the family, community or institutions, are challenged. Therefore, specific interventions and strategies at each level are sub-optimal. It emphasises the need to look for synergy between them. It is likely that the most effective interventions and strategies simultaneously operate in all four domains.

Some of the lessons of this study are currently implemented in the overall action research project in Msinga to prevent and mitigate the impact of HIV and AIDS among poor and HIV/AIDS-affected households.
The Farmer Life School: Experience from an Innovative Strategy to HIV Education

“After that session I was happy, because we did not know each other. But now I know the people (…). We have something to talk about now when we meet.”

7.1 Introduction

The Farmer Life School (FLS) is derived from the Farmer Field School (FFS), a discovery-based learning strategy developed in the late eighties in Southeast Asia (du Guerny et al., 2002). FFSs help farmers to gain a deep understanding of ecological concepts, as well as their practical applications. Instead of passive receivers of information and services, farmers are viewed as capable, responsible and sensible entrepreneurs and decision makers. Although the FFS was originally developed for integrated pest management for rice farmers in Asia, it now exists in over seventy countries around the world, encouraging farmer learning in areas as diverse as dairy farming, conservation agriculture, and community forest management (Braun et al., 2006).

The FLS goes beyond the agro-ecosystem, and includes human ecology. The central idea is to develop farmers’ critical thinking on the relationships between human behaviour and important livelihood issues (Yech, 2003). The FLS method aims to strengthen farmers’ understanding of how their socio-economic situation leads to risk-taking behaviour, prevent adverse social and economic effects from HIV/AIDS and other threats, and establish a farmer network to better address local issues in the interests of sustainable livelihoods (Yech, 2003).\(^\text{16}\)

The FLS differs from other strategies used in HIV/AIDS education in that it combines health-related messages with identifying root causes of vulnerability to HIV/AIDS.

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\(^\text{16}\) In the literature the FLS is often referred to as an approach. However, in the context of the overall project of which this study was part, it was used as a method.
AIDS and increasing the resilience of farm households through agriculture-related activities (du Guerny et al., 2002). This may be particularly relevant in the case of HIV/AIDS. The shape of the epidemic is highly dependent on social processes created by people, not by the virus as such (Barnett and Whiteside, 2002; Loevinsohn and Gillespie, 2003). The spread of HIV infection is rooted in poverty and inequality (Farmer, 1999), while consequences of AIDS-linked illness and death are shaped by features of agricultural and livelihood systems (Loevinsohn and Gillespie, 2003). It is perhaps through analysing farmers’ livelihoods that strategies can be developed to prevent HIV infection and mitigate the impact of AIDS.

Despite promises and high expectations, however, there is very little (evaluated) experience with the FLS (Braun et al., 2006). Especially in sub-Saharan Africa, with some of the highest infection rates in the world, its potential and applicability are largely unknown. Although the FLS can serve as an educational setting for farmers to shape their future in the context of HIV/AIDS, HIV/AIDS itself may have a negative impact on participants and the social dynamics of the group, and prevent this approach from being such a setting.

The aim of this study was to gain insight in the strengths and weaknesses of the FLS method, by piloting an adapted FLS in Msinga (KwaZulu-Natal), a rural and HIV high-prevalence area in South Africa. As empowerment of farmers through a process of participation and learning is central to the FLS method, the following research questions were raised: to what extent did the pilot have an impact on participation, learning, and empowerment; which factors affected the relation between the pilot and its impact; and how was this related to HIV/AIDS?

### 7.2 Methodology

The FLS took place in the context of an action research project, initiated by an agricultural NGO, in partnership with a community-managed health centre, and a university institute specialised in participatory methodologies. Role players in agriculture and health were brought together to improve food security and well-being among poor and HIV/AIDS-affected farmer households in Msinga, a poor, rural, traditional Zulu area with an HIV prevalence of more than 20%. A pilot study was conducted with three groups of community gardeners, which were geographically spread across the sub-district. Each group elected a committee for daily organisation. As this was an exploratory study on the strengths and weaknesses of the FLS method in a HIV high-prevalence area, qualitative methods were found to be most appropriate.
7.2.1 Delivery of the FLS Intervention

Although the pilot in South Africa was designed according to the main principles and guidelines of the FLS (Chhaya et al., 2004; du Guerny et al., 2002), it was adapted to the local context for practical implementation. The main characteristics of the pilot are presented below and summarised in Table 7.1.

Table 7.1: Main characteristics of the Farmer Life School in Msinga, South Africa

<table>
<thead>
<tr>
<th>Size of class</th>
<th>Maximum 25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of participants</td>
<td>Between 20 and 80 years</td>
</tr>
<tr>
<td>Gender</td>
<td>Predominantly females</td>
</tr>
<tr>
<td>Recruitment of participants</td>
<td>Participation was open to members of three garden groups. They were selected by HBC workers and one of the partner organisations, based on socio-economic conditions and impact of HIV/AIDS. The FLS was explained in meetings with each group</td>
</tr>
<tr>
<td>Facilitator profile</td>
<td>Both men and women:</td>
</tr>
<tr>
<td></td>
<td>– two came from the same area, not same community</td>
</tr>
<tr>
<td></td>
<td>– various backgrounds</td>
</tr>
<tr>
<td></td>
<td>– all had training in participatory approaches; two had experience as facilitator; two visited a Junior FLS</td>
</tr>
<tr>
<td></td>
<td>– good interpersonal and literacy skills</td>
</tr>
<tr>
<td>Duration of FLS</td>
<td>One session a week for 6 weeks (+ follow-up visits and support during remainder of growing season)</td>
</tr>
<tr>
<td>Time for each session</td>
<td>All participants agreed on a session in the morning or afternoon</td>
</tr>
<tr>
<td>Number of facilitators</td>
<td>The team consisted of two community facilitators and two researchers. Local professionals were invited to facilitate specific topics</td>
</tr>
<tr>
<td>Venue</td>
<td>Most sessions took place in the gardens. Before planting, sessions with two groups were held in a clinic and a church (session 1 and 2), respectively</td>
</tr>
<tr>
<td>Attendance</td>
<td>Participants were requested to come to all sessions. Rules were made to create commitment. ‘Catching’ up was done in a way of mutual agreement as a rule. No one could be excluded because of lack of attendance</td>
</tr>
<tr>
<td>Negotiables and non-negotiables</td>
<td>Non-negotiable: basic structures/processes of the FLS; every garden member was welcome in the sessions</td>
</tr>
<tr>
<td></td>
<td>Negotiable: topics covered (broader topics were suggested by facilitators)</td>
</tr>
</tbody>
</table>

Participants Members of two garden groups were recruited and selected by home-based care (HBC) workers and one of the partner organisations, based on socio-economic characteristics and impact of HIV/AIDS. Group sizes were determined at 64 (group A) and 35 (group B) members. One already existing garden group with 47 members (group C) was included, mainly on the basis of socio-economic characteristics. Most households belonged to the poorer segments of their communities. The way in which the members were affected by HIV/AIDS varied. Some
were HIV-positive or had experienced illness or death in the family, others were looking after HIV/AIDS orphans. Members were predominantly women between 21 and 80 years old, with a majority (74%) between 30 and 60 years of age (Swaans et al., 2005). Mainly women were selected, as they are responsible for the production of food and the household. Due to poverty and the impact of HIV/AIDS, this increasingly involves young women whose husbands have died and grandmothers taking care of orphans (Walker et al., 2004).

Setting and rules The maximum number of participants in FLSs is set at 20-25 per ‘class’. Since two groups were relatively large and showed high interest, they were split into a morning and an afternoon group. The groups met once a week for approximately three hours. Although the FLS usually takes place in the community (e.g. church, clinic), most sessions were held in the garden, as it played a central role in the curriculum. Principles of the FLS were respected at all times. Participation in the sessions was on a voluntary basis. Once someone had decided to participate, he/she was asked to come every time, so that the group would be consistent.

Curriculum The FLS usually builds on former experiences with the FFS, but in this case the approach was new to participants. Therefore, a relatively ‘short’ curriculum was developed, inspired by the main concepts of the FLS method, but with an emphasis on group building through participation and (discovery-based) learning. It was based on a livelihoods perspective, gradually shifting the focus from agriculture to health and HIV/AIDS, while emphasising linkages between them. The topics of the sessions were: introduction; vision and organisation; sustainable agriculture; nutrition and health; illness and care; and experimentation. The main elements of each session are summarised in Table 7.2.

Facilitation The team consisted of two community facilitators and two researchers. The community facilitators came from Msinga and had good interpersonal and literacy skills; one had expertise in sustainable agriculture. The researchers facilitated parts of the sessions. All had extensive training in participatory approaches. For the facilitation of specific topics, (local) professionals were invited. They were relatively free to address what they wanted, but in the case of HIV/AIDS, it had to be done openly, without blaming certain groups or stigmatising particular behaviours.
Table 7.2: Sessions and main elements of the Farmer Life School in Msinga, South Africa

Session 1. Introduction
- Getting to know each other: a card game was introduced as energiser and tool to get to know each other
- The FLS and rules: the FLS and the overall program were presented and rules were designed by the group
- Things going well/not well: participants were asked to evaluate, in groups, the progress made in the project so far

Session 2. Vision & organisation
- Vision: members were asked to all think and express their wishes and dreams for the future and to build a shared vision of the garden
- Organisation: different options for organising the group and the garden were discussed, such as farming in individual plots versus communal plots and home consumption versus marketing
- Experimentation: the principle of experimenting was explained, visualised by ‘pictures’ from a Junior FLS

Session 3. Sustainable agriculture
- Agro-ecological system analysis: an extensive garden walk was made for agro-ecosystem analysis; constraints and opportunities were identified and discussed
- Farming techniques: while exploring people’s knowledge and experiences, one of the community facilitators presented and discussed alternative farming techniques such as mulching, kraal manure, compost making, organic pesticides, and crop varieties
- Experimentation: options for experiments with ‘new’ crops/techniques were put forward by the groups and prioritised

Session 4. Nutrition & health
- Nutrition and health: relations between agriculture, nutrition and health were explored with support of a dietician from the local hospital; nutrition was discussed in relation to food, (indigenous) crops, health, and HIV/AIDS
- Experimentation: ideas for experiments related to nutrition were put forward; the first experiments with ‘new’ crops/techniques were initiated

Session 5. Illness & care
- Illness and care: a social worker from the local community-managed health centre spoke about the relation between health and agriculture and specifically about the stigmatisation and exclusion of people living with HIV and care for ill people; questions concerning HIV and AIDS and social grants were also answered
- Experimentation: last experiments were set up

Session 6. Experimentation
- Experimentation: progress of experiments was discussed with one of the community facilitators; together with the garden members the seed beds were prepared for the experimental crops
- Concluding: the session ended with a Christmas lunch with the whole group
Implementation From October to December 2004, a 6-week trial was conducted with each group. A typical session comprised three key elements: the garden, group dynamics, and a specific topic. A garden walk was organised according to the FFS/FLS way of working: members would go to the garden, collect samples of what they observed, and later discuss these observations with the whole group. Time was allocated to talk about the well-being of the group, attendance at meetings, work that had been done, and performance of the committee, while dynamic exercises were included to stimulate social interaction. Specific topics were presented and discussed by (local) professionals. Each session ended with a short evaluation. The FLS, including sessions and follow-up visits, was organised for one growing season.

7.2.2 Research Methods and Tools

Review of FLS sessions and field data Between October and December 2004, extensive reports were drawn up of the FLS sessions for post-hoc analysis. These contained detailed descriptions of the methodology, setting, conditions, attendance, presentations, discussions, group dynamics, experiments, and progress. In addition, field reports were maintained for the remainder of the season.

Follow-up interviews In January 2005, experiences from participants were captured by semi-structured interviews, to obtain more insight into the influence of HIV/AIDS on participants and the garden groups. Interviews were restricted to group A, an average performing group that was expected to provide insights into both aspects that went well and aspects that did not go well. In total, 14 people (13 women and 1 man, between 26 and 67 years of age) were selected, who varied in their degree of participation during the FLS sessions, personal situation and HIV/AIDS impact (see Table 7.3). Questions were related to the effectiveness of the FLS sessions and influencing factors.

Reflection with garden groups In May 2005 the overall design, content, expectations, and outcomes of the project in general, and the FLS sessions in particular, were evaluated. Discussions were held with each group and interviews were conducted with key persons. In group A, 9 people joined the group discussion, including the chairperson. In group B, 12 members joined the discussion, and an interview was held with the HBC worker. In group C, 23 members participated in the group discussion, while the secretary was interviewed. In addition, a discussion was held with the facilitation team and the overall coordinator of the project.
Table 7.3: Characteristics of participants in follow-up interviews regarding age, gender, FLS sessions attended, and personal situation

<table>
<thead>
<tr>
<th>Person</th>
<th>Age</th>
<th>Sex</th>
<th>No. of sessions visited</th>
<th>Personal situation*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>34</td>
<td>F</td>
<td>0</td>
<td>Takes care of sister-in-law (HIV-positive) and her children; income R400-500 pm</td>
</tr>
<tr>
<td>2</td>
<td>48/49</td>
<td>F</td>
<td>0</td>
<td>HIV+ (very ill); husband died; income R500-600 pm</td>
</tr>
<tr>
<td>3</td>
<td>42</td>
<td>F</td>
<td>1</td>
<td>HIV+ (very ill); polygamy; income R500 pm</td>
</tr>
<tr>
<td>4</td>
<td>50</td>
<td>F</td>
<td>1</td>
<td>Takes care of sister’s child; polygamy; husband died (tribal war); income R300-400 pm</td>
</tr>
<tr>
<td>5</td>
<td>40-45</td>
<td>F</td>
<td>1</td>
<td>HIV+ (very ill); polygamy; husband died (tribal war); income R150 pm</td>
</tr>
<tr>
<td>6</td>
<td>33</td>
<td>F</td>
<td>2</td>
<td>HIV+; first husband died after long illness; income R1900 pm</td>
</tr>
<tr>
<td>7</td>
<td>39</td>
<td>F</td>
<td>2</td>
<td>HIV+; sisters and cousin died of AIDS; cares for orphans; income R750-850 pm</td>
</tr>
<tr>
<td>8</td>
<td>42</td>
<td>F</td>
<td>2</td>
<td>HIV+; husband died after illness; income R200 pm</td>
</tr>
<tr>
<td>9</td>
<td>67</td>
<td>F</td>
<td>2</td>
<td>One son sick, daughter-in-law died; takes care of two orphans; income R800 pm</td>
</tr>
<tr>
<td>10</td>
<td>47</td>
<td>F</td>
<td>3</td>
<td>Sister-in-law and husband died; takes care of four orphans; income R740 pm</td>
</tr>
<tr>
<td>11</td>
<td>49</td>
<td>F</td>
<td>4</td>
<td>Husband died; income R60 pm</td>
</tr>
<tr>
<td>12</td>
<td>26</td>
<td>M</td>
<td>5</td>
<td>Parents died (due to AIDS); looks after brothers and sisters; income R1000 pm</td>
</tr>
<tr>
<td>13</td>
<td>47</td>
<td>F</td>
<td>5</td>
<td>Brother died (stroke); left with four orphans; income R1200 pm</td>
</tr>
<tr>
<td>14</td>
<td>66</td>
<td>F</td>
<td>5</td>
<td>One daughter died; takes care of two orphans; income R900-1000 pm</td>
</tr>
</tbody>
</table>

* Data based on questionnaire completed by garden group members in May 2004.

7.2.3 Data Process and Analysis

The researchers of the facilitation team produced detailed reports of each FLS session, which were validated by the other team members. Field reports were maintained by the community facilitators and discussed with the overall coordinator. Follow-up interviews were conducted by one of the researchers with the help of a translator. Interviews were recorded and subsequently transcribed into English. A freelance researcher conducted the reflection process; findings were presented in an internal report. Information obtained was codified so that confidentiality was maintained.
A basic analytical framework was used, drawing on the key elements of the FFS/FLS method: participation, learning, and empowerment (Braun et al., 2006; du Guerny et al., 2002; Pontius et al., 2000). Generally speaking, participation means ‘taking part’ and ‘getting involved’ (Pretty, 1994). However, in the case of poverty and HIV/AIDS this may be problematic. HIV/AIDS impoverishes and demoralises people (Swaans et al., 2005). For this reason, the study focussed mainly on participants’ attendance (i.e. attendance per session, sessions attended per participant) and engagement (i.e. involvement, enthusiasm, motivation).

Learning is a ‘broad’ concept. The FFS/FLS method differentiates between technical, practical, and emancipatory learning (Pontius et al., 2000). The technical domain relates to knowledge and skills to control the physical and social environment (i.e. concerning gardening, nutrition, health and HIV/AIDS). In the practical domain the concern is with understanding and meaning. It refers to knowledge and skills needed to communicate and act effectively in interaction with others. The emancipatory domain is concerned with self-reflection and critical thinking about internal and external factors that constrain people’s lives.

Finally, empowerment refers to increased control over inhibiting factors (Carney et al., 1999; Pontius et al., 2000). In this case, we are talking about the empowerment of a group of women who agreed on a common goal and undertook action to reach that goal. However, it would not be easy to mobilise them as long as they continued to perceive themselves as powerless and played the subordinate role that was ‘culturally’ expected of them (Crawley, 1998; Mayoux, 1995). Therefore empowerment is evaluated and discussed in relation to its psychosocial, socio-economic, and political dimensions (Page and Czuba, 1999). The psychosocial dimension deals with aspects such as ‘freedom to speak out’, ‘(access to) knowledge and skills’, ‘self-esteem and confidence’, and ‘a positive outlook’ (Van Woudenberg, 1998). Socio-economic aspects of empowerment refer to access and control over food, finances, education, health, safety, and shelter (Carney et al., 1999). The emphasis in this study was on food security as it featured as one of the main problems in a former study (Swaans et al., 2005). Within the political dimension the main focus is on the influence on (institutional) structures and processes (Carney et al., 1999; Pijnenburg, 2004).

Qualitative data were subjected to thematic content analysis (Flick, 1992), using the three key elements of the analytical framework and respective subdivisions as the core categories of our coding frame (see Table 7.4).
Participant observation, informal talks and meetings were used to verify findings. To enhance validity, triangulation of the various sources and methods was used. Preliminary results were presented to representatives of garden groups and partner organisations, and peers were asked to react to emerging findings. In all data collection methods, researchers were involved who were independent from the overall action research project. They stayed in the research area during the study, so that what took place was encountered first hand and was well understood in relation to the context.

7.3 Results

Taking the analytical framework as a starting point, the study examined the impact of the FLS method on participation, learning and empowerment, and the influence of HIV/AIDS on each of these elements. These constitute the section headings under which our findings are presented below.

7.3.1 Participation

Attendance

In the reflection exercises, participants were positive about the sessions and appreciated their regularity. According to them this established consistency and
encouraged participation. However, when we look at attendance throughout the program, as indicated in Table 7.5, the number of participants fluctuated greatly. Moreover, only half of the participants (59 out of 115) attended 3 or more sessions. Attendance in the already existing group (C) was more frequent than in the newly formed ones (A and B).

**Table 7.5: Number of participants per FLS session and frequency of participation**

<table>
<thead>
<tr>
<th>Group</th>
<th>Members</th>
<th>Participants per session</th>
<th>Frequency of participation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>A***</td>
<td>64</td>
<td>15</td>
<td>18</td>
</tr>
<tr>
<td>B</td>
<td>35</td>
<td>18</td>
<td>13*</td>
</tr>
<tr>
<td>C***</td>
<td>47</td>
<td>21</td>
<td>29</td>
</tr>
<tr>
<td>Total</td>
<td>146</td>
<td>54</td>
<td>60</td>
</tr>
</tbody>
</table>

*Session 2 and 3, on ‘vision & organisation’ and ‘sustainable agriculture’ merged for practical reasons
**Session 5 on ‘illness & care’ actually took place after session 6 on ‘experimentation’
***Groups were sometimes split into morning and afternoon groups (numbers refer to total participants)

From the interviews and group discussions, it became clear that in each group there was a core group of ‘committed’ members who were consistently present. However, there were also many members who did not come often. The ‘committed’ members suggested that this was due to institutional problems, such as the delay in ploughing and lack of access to water. However, it may also be linked to specific needs. Initial expectations, especially among newly formed groups (A and B), were higher than could be achieved through the pilot with the FLS. Some expected that orphans would be provided with food, clothes, social grants, and/or access to education, while the FLS is mainly aimed at capacity building.

However, there were also other factors that made participation, even among ‘committed’ members, difficult. In general, participants were struggling to come to sessions or the garden due to domestic activities, such as taking care of children and sourcing and preparing food. Although gardening seems to be a straightforward way of improving food security, many people chose to become or remain engaged in other jobs or part-time construction work on local roads, where they received regular wages.

Some were not able to attend due to poor health. One of the HIV-infected members said:
I have never been in the garden since it has been planted. Sometimes I do not hear that we have to be there. Sometimes I do, but I am sick and not able to go. I usually suffer from diarrhoea and right now I do not know how big the maize is. I told myself that since I am not able to work in the garden I was going to withdraw.

Others had to take care of ill people in their household. It is usually women who face the extra burden of care. A few members passed away due to AIDS just before or during the course of the pilot.

Local traditions related to death also affected participation. When someone in the community dies, relatives and neighbours are expected to comfort the family of the diseased. On the day of the funeral no one in that area is allowed to work in the field, while family members are not allowed to work for a week. Widows are particularly affected as they cannot work or be in the garden for as long as they mourn – this period varies from 3 to 6 months (Swaans et al., 2005). Some sessions had to be postponed, as people died almost every week.

Some members left the groups due to stigma. In the communities of the newly formed groups (A and B), the gardens were referred to as ‘AIDS gardens’. One woman said:

When this garden was initiated, people refused to join. Others withdrew, because it was said to be for HIV-infected people. We stayed on, because we wanted help. Men walked out of the meeting. They said that those who stayed are HIV-positive.

However, resilience to stigma varied across groups. One group (A) was more resolute to continue and seemed less concerned about the gossip. Some members who left the group returned when the garden was doing well. In the other group (B), however, some became too scared to come to the garden, after rumours became hostile and community members tried to damage the crops.

Violence was another common fear and concern. Many interviewed women felt unsafe on their way to and from the sessions; robbery and assaults were feared around and after sunset. This meant that sessions had to start and end on time, especially considering the fact that some members had to walk for up to 3 hours to get back home. Although some women wanted to leave their area for reasons of safety, they often lacked the means or possibilities to do so.
Finally, members were not always well informed about the sessions and garden activities. Lack of electricity, absence of cell-phones, or unreliable networks, made communication over long distances complicated. This was especially a problem for the newly formed groups (A and B). Their members were selected from a relatively large area and they did not know each other well.

**Engagement**

Those who did attend sessions were in general very motivated and involved. After a few sessions, most of them actively participated. In the evaluation after each session, the participants were enthusiastic about the topics and the methods. In relation to the introduction game, one of them recalled:

(…) the game was very much fun. If it was not fun you would never have seen me again.

Especially methods using song, dance, visualisation and imagination played a crucial role for moral support and encouraged participants to speak out. Also the personal attention and support by the facilitation team was highly appreciated. Some later regretted that they missed some of the sessions. Despite their often difficult personal situations, most members remained active in the garden for the whole season.

Nevertheless, the emotional impact of illness, death and violence cannot be underestimated. It sometimes directly affected the group dynamics. The chairperson in one of the groups (B) stated that with the loss of members, their determination to participate also dwindled. In one of the other communities (A) a few people were murdered during the time of implementation. One of the members said:

This is not a safe place to be in. We close our doors in the afternoon because we are scared. A woman was staying there (pointing at the household opposite her). They killed her in the early evening when she was cooking. (…) She was found decayed. A lot of things are happening here (sighing heavily) (…). It is new, it never happened before and it continues. (…) You do not even know if it is coming to you.

At the time of the study, one of the group members was killed. This did not only have an emotional impact, but the brutality also created dismay, unrest and fear among members of the group.
7.3.2 Learning

Technical Domain

As expected from adult learning principles, participants tended to remember specific knowledge better when they already used it in practice (Pontius et al., 2000). In the reflection exercises, organised 4 months after the last session, most members still remembered methods of dealing with pest infestations, information on nutrition, compost making, and other farming techniques. Especially experimenting gave them the opportunity to try out new techniques or different crops, and to sustain newly acquired skills, as some typical reactions show:

*Manure and compost are better in the garden. We saw that in the experiments we did with spinach, pumpkin and tomatoes.*

*I did not believe it when you were saying that the spinach could be planted in summer. That is why I wanted to try it. And it has proven you right.*

However, observational and discovery-based learning became more complex when the impact was not immediately visible, local traditions were challenged or when practices depended on others. For instance, it proved more difficult to change consumption patterns or cooking practices within households than to change agricultural practices in the garden. When one of the women reduced the cooking time of vegetables to preserve vitamins, her children complained that they did not like the food. Another woman, being aware that saturated fats may cause high blood pressure, still bought such foods, as she was not doing the cooking.

In the case of HIV/AIDS, this became even more problematic. People were eager for information, but not all of them wanted to talk about it in the group. As HIV/AIDS is related to sex and death, it is considered a taboo. While the social worker got many questions about social grants, more specific questions, e.g. on ‘*how you get it*, ‘*the cause of the disease*’, ‘*about blood tests*’, ‘*how to take care of another person*’, ‘*treatment*’, ‘*how to behave when infected*’, were more easily expressed in individual interviews than in groups. When people did speak out in group sessions, it was not always appreciated by others:

*I was not comfortable at all, not at all. She should not have disclosed the cause of the death of her son.*
Although HIV/AIDS remained a sensitive topic, the participants mentioned in the reflection exercises that the practical and informal nature of the sessions and its relation with nutrition and care helped them to start talking about the topic in general terms.

**Practical Domain**

The FLS enhanced a range of skills that enabled participants to work together more effectively. For instance, many were initially shy to speak out, but soon they became more communicative. Referring to the first session, one of them said:

> After that session I was happy, because we did not know each other. But now I know the people (...). We have something to talk about now when we meet.

The sessions did not only help members to get to know each other, but also created an atmosphere in which they could discuss and challenge each other’s perspectives. Participants learned to come to an agreement on rules, organisation and vision. They especially appreciated sessions that included visualisation (‘pictures’), games (‘get to know each other’), song and dance (‘vision’), observation (garden walks) and discovery-based learning (‘experimenting’). These methods stimulated group work and creativity, and increased enthusiasm, unity and respect. Participants indicated that this helped them to drive the decision making process and the activities in the gardens.

Still, the variation in age made it difficult for some to take part in discussions. For example, very young women remained more silent than others, respecting traditional norms and values. Older women sometimes lost their concentration or did not always comprehend the topics that were discussed. However, the younger ones were appreciated for their ability to write and their good memory, while the older women were valued for their motivation and positive influence on relations. In addition, older women usually play a central role in families (Swaans et al., 2005), which may be important for getting wider support within the community.

In one group (C), members initially relied on their leaders. Strong leadership in this group seemed to have a negative impact, but at the end it gave them a clear direction and unity. For example, participation was relatively good and problems were easily solved. Many members in this group were at first reluctant to talk about HIV/AIDS, but this changed during the course of the program. It seems that the emphasis on farming and nutrition and good relations allowed them to discuss HIV/AIDS at their own pace.
In the two newly formed groups (A and B), relations and trust were undermined by irregular participation, as a typical reaction showed:

*Some have never been to the garden (...). They don't know how the garden looks like, but sure they will be there when it is time to harvest.*

HIV/AIDS may have put relations further under pressure. Although some infected members praised their group’s tolerance when they were sick, some suspected them of being lazy. Others were afraid of being associated with HIV/AIDS, which may be another reason why relations were not always optimal.

**Emancipatory Domain**

Critical reflection helped participants to identify various constraints, such as limited access to water, pest infestations, damage by goats, unhealthy diets, limited access to markets, lack of money, and problems with governance and participation. Structural solutions were proposed, such as techniques for soil and water conservation, compost making, and the cultivation of vegetables. Other suggestions referred to social aspects, such as saving money as a group, monitoring systems for participation, distribution systems and ideas for marketing, as well as working in smaller groups. Although the analysis and suggested experiments remained rather superficial, it showed the potential synergy between farming, nutrition, and social aspects.

The reflection on HIV/AIDS remained restricted to practical issues, such as access to social grants or how to take care of people who are ill and infected. This is not surprising. As most participants did not know each other well, they were afraid of gossip and of being stigmatised. Moreover, perspectives on HIV/AIDS varied from biomedical explanations to witchcraft (Swaans *et al.*, 2005). This made it difficult to start a constructive discussion and to challenge values and relations.

**7.3.3 Empowerment**

**Psychosocial Dimension**

The involvement of (local) professionals gave participants access to knowledge and skills on farming and nutrition and ‘up-to-date’ information on HIV/AIDS. Even though HIV/AIDS was hardly discussed in a personal way, participants opened up and raised questions about the prevention of HIV/AIDS and its consequences. Some who were infected or affected mentioned in interviews that they were happy
they finally had someone to talk to. In general, the sessions enhanced confidence and raised consciousness, as shown by some of the statements made:

A person should talk about this (HIV status), not to die because of stress of knowing you have the disease and not talking about it.

When we talk about it (HIV/AIDS) in the garden, there is no stigma. We even encourage each other to go and have a blood test so that we know where we stand.

Some indicated that they would like to challenge those who wanted to join the garden again by reminding them that it was the HIV/AIDS garden, showing signs of a careful ‘discussion’ of HIV/AIDS as a communal problem. Others said that the sessions provided them with a positive outlook towards the future.

However, not everyone felt free to speak out. Apart from the sensitivity of the topic, negative attitudes or remarks in the groups about those who were infected or affected made some reluctant to speak out. Moreover, even though the FLS provided a platform for women to discuss HIV/AIDS-related issues, many women felt powerless regarding prevention. It is men who make the sexual and contraceptive decisions in this cultural setting (Swaans et al., 2005). In one of the interviews a woman said:

Ah! I try to tell him that “because you like women, you should do like this and this”, but he will say that I am jealous. But I took a good look at him now. He is not well at all and he had sores all over (…). I was not comfortable to be with him. I know the after-effects of unsafe sex. That is why I went for blood test. They said that I should come back after three months. Haai! (…) HIV/AIDS is a disease that is there. I cannot run away from it.

Women need not only to be free to express themselves, but also to be aware of the choices they have. Inspired by the sessions, some women asked the facilitators to come and talk on HIV/AIDS during the holidays when their husbands were around. This is a clear indication of becoming more assertive – implying in public that they wanted to change their situation, but recognising they could not without reaching out to their husbands.

Socio-economic Dimension

In general, members and facilitators perceived the gardens as a success. All groups produced maize and beans as the main crops in the garden, while they experimented with other crops on small plots. It was also encouraging that groups de-
developed their own distribution systems. When asked how they sold and shared the harvest, the chairperson in one group said:

Together with the HBC workers, I monitor the sharing and selling. Those members who can walk to the pension pay-out are advised to come and buy the maize from the garden at lower cost and resell it for their profit. Members have a discount (…). About the sharing, I was marking the book of those who came to work as they were planting till the weeding. I am marking the book again for those who have received their share.

They took into account that some members were not always physically able to participate:

When people are sick it is understandable when they cannot come to the garden (…), when we harvest we will take some portion to them as a group.

Despite differences in production, all groups managed to produce food for home consumption and to sell some of it on local markets. One group (C) even succeeded in saving a substantial amount of money.

However, throughout the season, the groups also faced ‘technical’ problems, such as the lack of easy access to water, insect infestations, theft, and lack of equipment. Especially water access was a major problem, which demoralised participants. Most proposed solutions, such as irrigation systems, better conservation, security, and organic pesticides, required money or time to develop and apply effectively.

Working together enabled participants to share resources and get access to draft power, seeds, fertilisers, and perimeter fencing. However, it also put a bigger claim on social organisation and was a source of conflict. Especially in the newly formed groups (A and B), there was confusion about decisions made. For many members it was not clear how much was kept for home consumption, how much was sold, or what happened with the money of sold surplus. This was partly related to problems with participation, but committees were not functioning well either.

Under circumstances of scarce resources and malfunctioning groups, external factors can easily destroy success and morale, as one of the facilitators remarked:

The members of this group have not managed to grow the beautiful crops like the others. Looking at the beans and maize you can see that they weeded late,
the maize looks yellowish and the beans are not in good condition. Maybe it is because of the hail. (...) The group is presently not well motivated. They were destructed by the gossip that the garden was for AIDS.

In this group (B), a combination of bad weather and destructive social processes seem to have undermined their initial success. Also in this group, the impact of AIDS was most apparent and sessions were cancelled or postponed because of funerals.

Due to the vulnerability of participating households, it is not surprising that they mainly focused on food production. Alternatives related to nutritional value, year-round production, other sources of income, and social organisation remained largely unexplored. Although these aspects were mentioned during the sessions, it takes time and focused experimentation to adapt a production system to such alternatives.

In addition to food production, some families with orphans were assisted to a point where they received a social grant or got access to education. However, the time frame was too short to address aspects of health, education, and/or social welfare in a structural way. Nonetheless, the discussions during the sessions and individual cases showed the scope for improvement, as bureaucratic rules and institutional formalities made it complicated to take full advantage of various services.

**Political Dimension**

Power is characterised by domination, authority and influence, but it can be influenced through social solidarity, i.e. through collaboration, sharing and mutuality (Kreisberg, 1992). This was particularly relevant within the context of the FLS. People’s motivation, confidence and self-esteem were positively correlated with the overall functioning of the group and the garden. All groups wanted to continue with the garden and the FLS sessions. Some individuals saw the pilot as a first step toward other activities, such as chicken farming and selling produce to supermarkets.

However, when it came to decision making and action, the newly formed groups (A and B) still depended on the project partners. Material funding and former experiences with subsidised programs may have contributed to this. It needs to be realised though, that most members did not know each other well, as they move in with their husbands’ family when married (Swaans et al., 2005). This makes it difficult to establish independence based on unity and respected leadership. That this is not impossible, however, was shown by the group of women that already existed before the project started (C). Good leadership and internal motivation enabled them to expand and improve social cohesion.
So far, however, the influence of participants on (institutional) structures and processes has been limited. Male-dominated structures, lack of access to information and money for transport, as well as the top-down operation of service providers, made it difficult for women to act upon their needs. Stigmatisation of the garden in two of the communities (A and B) made it even more complicated, although it is positive that people in one of the communities (A) wanted to join again.

The involvement of local professionals was a first step toward establishing contacts and relations between participants/groups and service providers. Networking by the community facilitators with a variety of organisations also enabled them to refer members and groups to others when necessary. Although members may have recognised the opportunities for better contacts with service providers, it is questionable whether they realised their potential and were willing to challenge established structures or existing (cultural) norms and values.

7.4 Strengths and Weaknesses

The study revealed various strengths of the FLS method regarding participation, learning and empowerment. Many people, who are usually not reached by service providers, were not only able to participate, but were also very engaged and committed. The practical and informal ‘nature’ of the sessions made it easier for them to contribute meaningfully. In addition, working together on agriculture and nutrition enabled them to get to know each other, and enabled them to explore and learn more about HIV/AIDS at their own pace. Especially group-based methods using song, dance, visualisation and imagination encouraged participants to open up and speak out among others, while experimentation boosted people’s confidence and enthusiasm. The practice of conservation agriculture helped them to grow crops with limited means. The pilot with the FLS showed that a welfare-oriented project for women, where they were involved in sharing agricultural and other activities, provided them with emotional support – being a first step towards empowerment, while they produced food and saved some money. The group that was formed beforehand became an example of group cohesion and visionary leadership that resulted in positive outcomes.

However, various weaknesses can also be identified. The group-based character and intensity of the program made it difficult for some members to participate as a result of poverty and HIV/AIDS-related illness and death (see also Sokunthea, 2002); this was often further constrained by stigma, gender relations and violence. It is well known that individuals and households affected by HIV/AIDS often struggle to cope
Labour shortages, exacerbated by HIV/AIDS, combined with declining household incomes are compounding food and livelihood insecurity (Topouzis and du Guerny, 1999). Moreover, HIV/AIDS often leads to confusion, denial and depression, resulting in withdrawal from social activities (Swaans et al., 2005; Van Woudenberg, 1998). The general set-up seems rather rigid and not flexible enough to deal with these circumstances.

Furthermore, the FLS relies very much on discovery-based learning. In the FLS manual, human ecosystem analysis is explained as a process whereby farmers research issues related to their daily lives (Chhaya et al., 2004). They prioritise them, and select families for further investigation in smaller groups to achieve a holistic understanding of the way people live and the factors that contribute to or detract from a healthy life. However, in the case of HIV/AIDS this remains problematic. For example, it remained difficult for participants to reflect critically on HIV/AIDS, despite signs of more openness and willingness to share experiences. This was especially prevalent where groups were newly formed, and could not build on pre-existing relations between their members. In addition, in a social environment in which stigmatisation of HIV/AIDS and violence are common, moving beyond the FLS group may even put participants and their families at risk (Walker et al., 2004). Although the results seem to confirm the general belief that FLSs can only be implemented successfully when participants are already familiar with agro-ecosystem analysis (Müller, 2005), in the context of HIV/AIDS, other concepts, such as common ground, trust, safety, confidentiality and respect, seem at least as important.

Moreover, while setting up an FLS, complex social dynamics come into play. Many HIV/AIDS-related problems, such as stigmatisation, social exclusion, and gender inequality, are ‘expressed’ through institutionalised rules and behaviour (Douglas, 2004). Douglas argues that the way people assess risks is rooted in notions of social organisation and solidarity, and that change is mediated only through shifts in or challenges to collective values. This would imply that the poor respond to danger not on a risk-by-risk basis, but through adapting group values and commitments. This may explain why efforts to tackle AIDS and related problems on an individual basis have so far been rather ineffective (Walker et al., 2004). However, despite its group-based character, the main focus of the FLS is on individuals, and not on the underlying values and relations between them (du Guerny et al., 2002). Especially in the context of HIV/AIDS this seems to be a missed opportunity.

And finally, structural changes to improve people’s lives have been limited, although one has to realise that one FLS season is very short to have a profound impact on
economic and institutional aspects of empowerment. It takes time to acquire agricultural knowledge and skills and to apply them successfully to reap the benefits. Some suggest that this may take three to five years (Barnett and Grellier, 2003; Bishop-Sambrook et al., 2004). Vulnerable households do not only lack the money and time to invest in this, but also lack access to necessary services. In a recent review of FFSs, Braun et al. (2006) emphasise that sustainable, local level, institutionalised gains, can be negated or diminished when surrounding conditions are unsupportive. It seems even more difficult to change practices in relation to HIV/AIDS. Root causes of HIV/AIDS are related to gender and social inequalities, which are deeply ingrained in social norms and values and embedded in institutions and policies (Parker and Aggleton, 2003).

7.5 Conclusion and Implications

Several lessons can be drawn from this study. Firstly, HIV/AIDS-related illness and death, and factors that drive the epidemic and its impact, such as poverty, gender inequality, stigma and violence, also undermine people's participation in development processes. Rules and recruitment of participants may unintentionally lead to the exclusion of the poor and people infected or affected by HIV/AIDS. Although agricultural NGOs, development organisations and public services have increasingly integrated HIV/AIDS as an important component of their focus (Gillespie, 2006), it has hardly led to fundamental changes in the methodology to include, rather than exclude, people who need it most. It requires a flexible approach that is better adapted to people's personal situation.

Secondly, the study shows the importance of developing trust relations and social cohesion. It requires a 'safe' environment in which participants feel free to express themselves and support each other. A group-based approach can help participants to get to know each other, build trust and stimulate learning. It provides the opportunity to challenge underlying values and relations between them (Welbourn, 1995). The issue of safety and confidentiality deserves specific attention. Talking about HIV/AIDS provokes strong emotional reactions, positive and negative. It requires sensitive methods and competent process facilitation.

Thirdly, the case study shows the importance of achieving successes that others are 'envious' of, such as a thriving garden. An intervention must bring some kind of 'reward' to the participants, which in turn makes them stronger, as it helps to create a positive self image, and a project image of which they want to be part. Conservation agriculture has the potential to contribute to food security and income (see also Bish-
op-Sambrook et al., 2004). However, innovations have to go beyond labour-saving technologies to be effective. At least as important are shared activities and a feeling of ‘togetherness’, to reverse the destructive impact of HIV/AIDS on institutions. A small successful group can pave the way for a larger initiative that can sway others to get involved.

Fourthly, to achieve impact and innovation over the longer term, changes are required in larger sets of relationships or institutional arrangements than can be established by the FLS alone. Interventions such as the FLS need to be integrated into an overall program on HIV/AIDS and food security, taking into account the specific needs of individual households, while creating a supportive environment at community level.

Last, but not least, when life more than livelihood comes under threat, the effectiveness of the FLS becomes questionable. In that case more immediate support is needed. This requires a technical, social and medical response, whereby individuals can be referred to other service providers when necessary. However, it is difficult to think of any approach being effective in fighting the epidemic and its devastating impact if poverty, inequalities and injustices are not seriously challenged.

Overall, we can conclude that the FLS has great potential to improve food security, while providing safe spaces to address HIV/AIDS. However, interventions aiming to mitigate the impact of HIV/AIDS need thorough understanding and where possible adaptation to the (social) context, in order to facilitate processes that reverse, rather than reinforce, social inequalities, stigma and discrimination.
Chapter 8

Promoting Food Security and Well-being in the Context of AIDS: Lessons from an Interactive Approach

“I am happy to see my crops growing. I never thought of planting crops, but the sessions and the work in the garden opened my eyes.”

8.1 Introduction

Food security is one of the most important issues in the context of care and support of families affected by HIV/AIDS (Barnett and Whiteside 2002; Gillespie, 2006; Gillespie and Kadiyala, 2005). The international community, governmental, and non-governmental organisations, have tried to prevent and mitigate the impact of HIV/AIDS on individuals and households using various strategies, such as food relief programs, social and financial support, food-for-labour programs, and gardening projects (see Barnett and Grellier, 2003; Gillespie, 2006; Gillespie and Kadiyala, 2005; Harvey 2004). However, they are unlikely to be the most appropriate and sustainable solution for the majority of African families, since they usually have a narrow focus on food and food production, without addressing the factors that drive the HIV epidemic and its impact.

Recently, participatory and interdisciplinary strategies have been promoted to mitigate the impact of HIV/AIDS on food security and well-being in a more structural way (FAO, 2003; Gillespie, 2006; Gillespie and Kadiyala, 2005; HSRC, 2003). These interactive approaches emphasize a close collaboration between relevant stakeholders to gain access to knowledge, insights, experiences, needs and/or creativity, and generate required involvement and ownership (Leeuwis, 2004). It is, however, one thing to acknowledge the power and validity of these approaches, yet another to apply them sensitively and consistently.

Although evaluated experience from interactive approaches at the interface of HIV/AIDS and agriculture is rare, published case studies show remarkable similarity in what they consider as crucial principles for agricultural innovation, i.e. a central role
of farmers, a shared vision, enhancement of trust relations, the facilitation of social
and experiential learning, integration of knowledge, capacity and coalition building,
scaling out and up, and institutionalization (Broere and Bunders, 2000; Guijt et al.,
2000; Hagmann et al. 2002; Lizares-Bodegon et al., 2002). HIV/AIDS does not seem
to change these conditions, but target group specific characteristics, the sensitivity
and silence surrounding HIV/AIDS, and the diversity of relevant stakeholders do
pose additional challenges (Swaans et al., 2006).

The main aim of this chapter is to describe and evaluate a methodology that attempts
to realize effective participation and interaction of vulnerable households with other
relevant stakeholders in order to improve food security and well-being in the context
of HIV/AIDS. It is based on earlier experiences with participatory and interactive ap-
proaches within the context of agricultural innovation.17 Below, a short description of
this interactive methodology is given. It has been applied in three support groups for
poor and HIV/AIDS-affected households in Msinga, in the Province of KwaZulu-Natal
in South Africa. Next, we elaborate on a framework to evaluate the effectiveness of
the participation and interaction accomplished. We subsequently present the evaluation re-
sults and close with some concluding and reflective remarks and suggestions for the im-
provement of interactive methodologies at the interface of HIV/AIDS and agriculture.

8.2 HIV/AIDS and Food Security in Msinga, South Africa

Msinga is a traditional Zulu area with a HIV prevalence of more than 20%. In 2003,
a local community-managed health centre mobilized almost 150 people – mainly
women – from HIV/AIDS-affected and poverty stricken households into support
groups around HIV/AIDS and food security.18 Since most rural households – es-
pecially the poor – partly depend on agricultural production for their livelihood,
strengthening the agricultural production capability was identified as an entry point
to prevent and mitigate the impact of HIV/AIDS. As access to water for irrigation is
limited in the area, land was acquired from traditional authorities near water sources
(e.g. river, water dam, or spring) for communal gardens.

Households were identified by HBC workers; assessment was mainly qualitative. Es-
pecially households taking care of orphans were invited to participate. It was ex-

17 The concept of ‘innovation’ in this chapter is broadly defined and refers to any technical, social or organisational
adaptation in practice which is new to the practitioners involved.
18 The community health centre was financially supported by the Department of Health and the Department of
Social Development in Msinga.
pected that a focus on women as care takers and child minders in the family would not only lead to improved food security, but to improved well-being of households as well. There was no age restriction. Members were between 21 and 80 years old, with a majority (74%) between 30 and 60 years of age. Two groups of 35 and 64 members were newly formed, while one existing garden group of 47 members was included. Most had limited to basic farming skills, while some had received previous training in sustainable agriculture.

An agricultural NGO and a Dutch university institute established a partnership with the health centre. An action research project was designed to promote secure access to food and increased well-being among households participating in the support groups through farming. The specific objectives were:

a) to improve insight into the relation between HIV/AIDS, agriculture, food security, and rural livelihood at the individual and household level among (support) group members and stakeholders;

b) to identify, test and evaluate innovations in farming to prevent and mitigate the impact of HIV/AIDS, and to develop strategies to stimulate and sustain these innovations;

c) to strengthen capacity in sustainable farming among (support) group members;

d) to stimulate learning between stakeholders; and

e) to improve the conceptual and methodological framework.

8.2.1 The Interactive Learning and Action Approach

The interactive methodology selected for the project was based on the Interactive Learning and Action (ILA) approach (Bunders, 1994). The ILA approach is a rather well elaborated and tested methodology that has proven to be successful in involving small-scale farmers in decision making on agricultural research and development in developing countries (Broerse and Bunders, 2000; Zweekhorst, 2003). Recently it has been successfully applied in the health sector to include patients, citizens, health professionals and other stakeholders in decision making on health policy and research (Abma and Broerse, 2007; Caron-Flinterman et al., 2006). Key characteristics of the ILA approach are the enhancement of trust relationships, mutual learning, and knowledge integration between

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19 These three organisations are referred to as ‘partners’ or ‘partner organisations’ for the remainder of the text unless otherwise indicated.

20 The main part of this process was commissioned by the International Food Policy Research Institute (IFPRI).

21 For the remainder of the text the term ‘stakeholder’ is reserved for institutions, organisations and/or groups involved; in case of (support) group members, the term ‘participant’ is used.

22 It resembles other participatory methodologies for innovation development in agriculture and rural resource management (cf. Guijt et al., 2002; Van Veldhuizen et al., 1997).
relevant stakeholders in a carefully guided process around a shared vision that is facilitated by an interdisciplinary team. Specific attention is paid to the role of stakeholder groups that have previously been neglected in decision making, while coalition building is stimulated throughout the process to ensure support and availability of resources.

The ILA approach is roughly structured along four phases:

1) Initiation and preparation: a project team is established, a first assessment is made of the local setting, contact is made with the local community, and agreement is reached between stakeholders on general issues and procedures for collaboration;

2) Collection, exchange, and integration of information: information is collected in relation to the constraints, needs, and interests of different stakeholders involved. The team organizes dialogues with key stakeholders, and analyses and integrates information and knowledge;

3) Priority setting and planning: stakeholders address conflicts and seek consensus on priority issues, common goals and plan of action;

4) Project formulation and implementation: participants determine and take action, monitor progress and evaluate results in continuous learning cycles (Broerse and Bunders, 2000).

These phases can be broadly distinguished on the basis of their chronology, the outcome of the previous phase being the input for the next. After the first two phases (i.e. so-called reconnaissance), a spiral of activities keeps recurring: planning, action, observation, reflection, re-planning, etc. (see Figure 8.1). In this way an interactive and iterative, instead of linear, process evolves. It includes a varied toolkit of methods and techniques for knowledge generation and interaction.

The ILA methodology should not be regarded as a blueprint; within the boundaries of the key characteristics it needs to be adapted and specified to the context of application. A few decisions were made for application in the context of HIV/AIDS. To overcome the diversity of perspectives and values between relevant stakeholders, it was decided to establish a core-team for mutual learning and joint collaboration. The marginalized position of women and the silence surrounding HIV/AIDS were seen as a major concern. Therefore, the project emphasized capacity building and organisational development among women through a process of group-based learning, while the concern for safety and confidentiality was taken seriously.

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23 Women are not only more susceptible than men to contract HIV, but they also more vulnerable to the impact of AIDS, e.g. as care taker, but also in the sense that widows are more vulnerable to property grabbing) (see Barnett & Whiteside, 2002; Swaans et al., 2008b).
8.2.2 Implementation

The activities and main outcomes of the different phases in the project are presented in Table 8.1.

The first period covered the first three phases of the project and took place from November 2003 to September 2004. Activities undertaken during this period were a context analysis, a base line study, priority setting and planning of activities. Data was collected among support groups and stakeholders to assess the impact of HIV/AIDS on people’s livelihoods. In almost a third of the households (29%) someone was chronically ill, while in almost half of them (48%) someone died in the last five years; many households (43%) were taking care of orphans. Even though other diseases and violence were common, AIDS had a profound impact. The study did not only confirm food insecurity as one of the main problems, but it also revealed the multiple ways in which HIV/AIDS perpetuates the poverty cycle and decreases resilience (Swaans et al., 2008b). A further investigation into the role of HIV/AIDS-related stigma and discrimination showed that it was widespread, enacted through a variety of expressions at the family, household and institutional level, and exacerbated people’s fear to test or disclose their positive status (Spanjers et al., 2005).
<table>
<thead>
<tr>
<th>Activities</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1: Initiation and preparation (November 2003-February 2004)</strong></td>
<td><strong>Phase 2: Data collection, exchange and integration (March-June 2004)</strong></td>
</tr>
<tr>
<td>- Exploratory interviews and group discussions with key persons in relation to farming, health, HIV/AIDS, and social aspects.</td>
<td>- HIV/AIDS impacts on all resources (human, financial, social, natural, and physical); many households live in fear, denial, and hopelessness; misconceptions and myths around HIV/AIDS are rife; food insecurity featured as one of the main problems.</td>
</tr>
<tr>
<td>- Partnership and project team were established.</td>
<td>- Results showed diversity between and within categories of households with chronically ill members and those that cared for terminally ill or for orphans; the impact also depends on access to medical, financial and social support, which is especially a problem among women.</td>
</tr>
<tr>
<td>- Meetings with authorities to get permission.</td>
<td>- Stigma is widespread, enacted through gossip and social exclusion; lack of knowledge, stereotyping, and discrimination in the household and by other institutions, exacerbate people's fear to test or disclose; women feel powerless to protect themselves in a male-dominated culture.</td>
</tr>
<tr>
<td>- Ethical approval was obtained from Social Ethics Committee of University of KwaZulu-Natal.</td>
<td>- Support group members were consulted regarding their living situation and impact of HIV/AIDS, using focus groups, questionnaire, and in-depth interviews.</td>
</tr>
<tr>
<td>- Support groups and members were informed and asked to participate and give verbal consent.</td>
<td>- Interviews were held with partner organisations, governmental departments and authorities to explore views on HIV/AIDS and potential role in the project.</td>
</tr>
<tr>
<td>- A joint proposal was developed and submitted to the RENEWAL program of the International Food Policy Research Institute (IFPRI).</td>
<td>- Role of stigma &amp; discrimination was further investigated using focus groups and interviews.</td>
</tr>
<tr>
<td>- Funding awarded by IFPRI in April 2004.</td>
<td>- Information retrieved was exchanged within each support group and in monthly meetings with representatives of partner organisations and support groups.</td>
</tr>
<tr>
<td>Activities</td>
<td>Outcomes</td>
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<tr>
<td>------------</td>
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<tr>
<td><strong>Phase 3: Priority setting and planning (July-September 2004)</strong></td>
<td><strong>Phase 4: Project formulation and implementation</strong></td>
</tr>
<tr>
<td>– Results of the base line study were discussed with partner organisations and the support groups, and options for further action were considered.</td>
<td><strong>1st learning cycle (October 2004–September 2005)</strong></td>
</tr>
<tr>
<td>– Although the need for a diversified and holistic program of development interventions was acknowledged, it was decided to focus first on the need to restore a household's resource base, while addressing psychosocial issues.</td>
<td>– A curriculum was developed based on discussions with partners and support groups, literature review, expert advice, and a visit of a Junior FLS.</td>
</tr>
<tr>
<td>– The project identified the Farmer Life School (FLS) as a potentially appropriate approach.</td>
<td>– The curriculum was based on a livelihoods perspective, including farming, health and social aspects; it incorporated field observation and analysis, group dynamics and discussion.</td>
</tr>
<tr>
<td><strong>Phase 4: Project formulation and implementation</strong></td>
<td>– FLS (season 2004/05). Weekly sessions with each group (mainly in garden). Topics: introduction, vision &amp; organisation, sustainable agriculture, nutrition &amp; food, illness &amp; care, experimentation; with follow-up visits.</td>
</tr>
<tr>
<td><strong>1st learning cycle (October 2004–September 2005)</strong></td>
<td>– The FLS has the potential to improve food security and well-being, while allowing participants to explore issues around HIV/AIDS; but illness, death, poverty, stigma, gender inequality and violence, undermine the ability to participate and realize safety and trust required for learning and empowerment.</td>
</tr>
<tr>
<td>– A Mid-term evaluation among groups (May-June 2005).</td>
<td>– Various institutional problems were identified.</td>
</tr>
<tr>
<td>– Participants and key stakeholder were engaged in a planning process; institutional cooperation with the Department of Agriculture and the Department of Health were strengthened, while a new coordinator was appointed.</td>
<td>– Various technical innovations were identified and tested to reduce costs and enhance nutritious intake. In addition, groups came up with ways to stimulate participation, improve communication and share produce more equally and fairly.</td>
</tr>
<tr>
<td>– FLS (season 2005/06). Similar to 'pilot', but stronger focus on innovation. Topics: vision building, problem identification &amp; ranking, strategy development (technical/social), nutrition, indigenous crops, HIV/AIDS. Groups continued to meet to review decisions.</td>
<td></td>
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</tbody>
</table>
Although the need for a diversified and holistic program of development interventions was acknowledged by the support groups and the partner organisations, it was decided to focus first on the restoration of the household’s resource base and to address psychosocial issues. The Farmer Life School (FLS) was identified as a potential appropriate approach. The FLS is derived from the Farmer Field School, a discovery-based learning method involving groups of farmers, aimed at improved decision making in sustainable farming. The FLS goes beyond farming to include people’s livelihoods.

The second period covered the implementation phase. The first learning cycle bridged the period October 2004 to September 2005. Garden activities were started using the FLS. A curriculum was designed in interaction with key stakeholders and participants and after consultation of FLS manuals and experts. The following topics were addressed: introduction, vision & organisation, sustainable agriculture, nutrition & food, illness & care, and experimentation. Each session included field observation and analysis, group dynamics, and discussion. The practical focus on agriculture engaged participants actively, while allowing them to explore issues around HIV/AIDS in a relatively non-threatening way. However, analysis also showed that HIV/AIDS-related illness and death, and the factors that drive the epidemic and its impact, undermine people’s ability to participate, the safety and trust required for learning, and the empowerment process (Swaans et al., 2008a). Furthermore, a mid-term evaluation indicated various institutional problems.

Participants and key stakeholders were then engaged in a planning process for the second learning cycle, which was conducted from October 2005 to June 2006. Institutional cooperation with the Department of Agriculture and the Department of Health was strengthened, while a new project coordinator was appointed. The FLS method continued to be used, but with a stronger emphasis on innovation development to address technical and social problems. Topics were vision building, problem identification and ranking, strategy development, nutrition, indigenous crops, and HIV/AIDS. Various innovations were identified and incorporated into participatory experiments (see Box 8.1). Participants continued to meet regularly to discuss and review their decisions, thus continuing to improve their life skills related to health and agriculture.

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24 At the onset of the project, two members of each group participated in a training program on sustainable farming that the agricultural NGO conducted in the area. Trainees were expected to share their knowledge with the other members with further support of the community facilitators.
i. New crops and techniques Innovations were sought to reduce production costs (e.g. organic pesticides instead of chemical ones, compost-making to reduce inorganic fertilizer requirements, open-pollinated maize and sorghum varieties (OPVs) whose seed can be retained for replanting) and to improve water conservation (e.g. seedbeds, mulching). In addition, various options were introduced to enhance nutritious intake throughout the year. These included planting of new vegetable varieties (e.g. butternut, garlic), or the growing of vegetables in a different season than traditionally (e.g. spinach).

ii. Maize Variety Evaluation Support groups decided to compare a Maize OPV with a hybrid and a traditional variety using multi-criteria analysis. Hybrid maize was preferred because of its high yields, early maturity and white flour; the OPV was preferred for the possibility of storing the seed, its ability to dry quickly and its white flour; the home variety was preferred for its low cost, resistance to lodging, better taste and the possibility of retaining the seeds. The varieties performed differently across the sites.

iii. Sorghum Red sorghum is grown in the area for sorghum beer and is recognized for its tolerance to drought. Because farmers prefer white flour for food, a white OPV sorghum was planted as a more nutritious and drought-tolerant alternative for maize – their main staple food. Two impediments confronted the groups. The early planted sorghum was eaten by birds before maturity, while the grain filling stage of the second sorghum crop coincided with the encroachment of frost. The members realized that to grow sorghum, it has to be planted early. They are exploring ways of protecting the grain from birds during dough stage.

iv. (Traditional) vegetables Vegetables were grown at various times in the community gardens. The trials were evaluated using multiple self-identified criteria. The groups prefer vegetables that produce seeds for replanting, can be planted all year round, harvested at all times, and which are resistant against insect and diseases; quick maturity, taste and nutritional value were also mentioned as important; also crops that could be eaten raw or draw consumers’ attention were valued. Groups recalled knowledge about traditional vegetables, and want to plant them in the garden on a trial basis.

v. Social innovations In addition to technical innovations, the groups came up with various ways to stimulate group participation, to share harvested produce equally, improve communication etc. Communal farming and the FLS method were also new to the groups involved. One group preferred to work on individual plots, but another preferred communal gardening as it provided new opportunities for knowledge sharing and marketing produce. The FLS was perceived as an important strategy to this.
The partner organisations and the support groups – each represented by an elected committee – participated in monthly meetings to discuss and decide on project design and implementation. Since July 2005, the Department of Agriculture joined regularly. A project team composed of staff from the agricultural NGO and the university institute facilitated the activities, often in close collaboration with the HBC workers and the support group committees. To initiate activities in the garden, the health centre provided draft power, seeds, fertilizers and perimeter fencing. Throughout the project the support groups planted staple crops in the garden, while plots were reserved for experiments. Produce was sold or kept for home consumption, while money earned was saved in a bank account. The university institute played a key role in the design of the project and conducted studies on the implementation process.

The project was embedded within the local context via a platform on HIV/AIDS, which consisted of representatives of governmental departments, the health centre, and the municipality. In addition, a ‘think tank’ was initiated, involving professionals from provincial and national level, to generate strategic advice on HIV/AIDS and food security based on the project in Msinga.

8.3 An Evaluation Framework

The main objective for joint collaboration between the support groups and service providers and researchers is their enhanced involvement with and rationality of the innovation process, and hence enhanced ownership and quality of resulting innovations. The evaluation framework should thus contain both process and outcome criteria. These are introduced and further explained.

8.3.1 Process Criteria

Process criteria track how well principles and guidelines are operationalised in practice. In an evaluation study of the ILA methodology in health research agenda setting, Caron-Flinterman et al. (2006) described three sets of criteria to ensure a rational process, which are also appropriate in the context of this project, i.e. stakeholder representation, process structure and process management. In addition, specific attention is given to capacity building and coalition building.

- **Stakeholder representation** Interactive approaches depend on effective collaboration between relevant stakeholders with different backgrounds (Abelson et al., 2003; Rowe and Frewer, 2000; Webler and Tuler, 2000). Therefore it is important to know who participated during the various stages in the project and who de-
cided on what. As intended beneficiaries, special consideration has to be given to the role of support groups and the extent to which they represent poor and HIV/AIDS-affected households.

- **Process structure** An effective participatory process has to be transparent. All participants have to be aware of the main objective, the tasks and roles of each participant, which steps the process consists of and how decisions are made (Rowe and Frewer, 2000; Webler and Tuler, 2000). Moreover, the various views, priorities and needs have to be incorporated (Abelson *et al.*, 2003, Rowe and Frewer, 2000; Webler and Tuler, 2000). This deserves specific attention for the support groups, as they are often less well organised and confident to speak out. In addition, the decision making process has to be structured, based on relevant information and gained insights (Rowe and Frewer, 2000).

- **Process management** Coordinators and facilitators must be competent in leading or facilitating the processes. They must have skills and sufficient knowledge of the main issues (i.e. agriculture, health, social aspects). They must be independent from parties involved and indifferent to outcomes (Rowe and Frewer, 2000). They have to be responsive in a way that they facilitate mutual respect, openness, and constructive interaction (Abelson *et al.*, 2003; Driessen *et al.*, 2001; Webler and Tuler, 2000).

- **Capacity building** To enable support groups to play a prominent role, a training methodology has to mobilize their members and address identified needs and wishes (Hagmann *et al.*, 2002). Learning is required in the technical (e.g. farming, nutrition, health and HIV/AIDS), social (e.g. communication, organisation & management) and reflexive (e.g. norms and values on HIV/AIDS) domain. This requires appropriate methods and tools, which cover knowledge, attitudes and skills (Guston, 1999; Irvin and Stansbury, 2004).

- **Coalition building** Effective innovation depends on appropriate support (endorsement, backing-up, approval, and legitimacy) (Moens *et al.*, 2007) and access to resources (knowledge, funds, material, and time) (Abelson *et al.*, 2003; Rowe and Frewer, 2000; Webler and Tuler, 2000). This seems especially important within a context of stigma and discrimination.

### 8.3.2 Outcome Criteria

The outcome criteria are based on the objectives of the project. A distinction is made between direct and indirect outcomes.

- **Direct outcomes** The ‘quality’ of innovations is determined by their contribution to food security and well-being among poor and HIV/AIDS-affected households
and the extent to which they reflect stakeholders’ perspectives (Driessen et al., 2001; Irvin and Stansbury, 2004). The degree to which groups are self-managed and are part of a stakeholder network indicates the sustainability of the process (Moens et al., 2007).

- **Indirect outcomes** Indirect outcomes are related to learning and ownership. This comprises personal and mutual learning on technical matters (farming, livelihood, nutrition, health & HIV/AIDS), social matters (social interaction, methodology and management), and/or in a reflexive way (perspectives and roles) (Guston, 1999; Irvin and Stansbury, 2004). Ownership is an important aspect for sustainability and refers to aspects as identification, responsibility, initiative, and independence (Moens et al., 2007).

Effectiveness is defined as the relation between the achieved result and the intended result. As intentions are often not articulated fully, may change over time, and may differ based on personal and political perceptions and stances, contentment or accept-

### Table 8.2: Evaluation criteria for effective multi-stakeholder interaction to improve food security and well-being among ‘vulnerable’ households through agricultural innovation

<table>
<thead>
<tr>
<th>Processes</th>
<th>Stakeholder representation</th>
<th>Adequate and balanced representation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>A central role for intended beneficiaries</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inclusion of poor and HIV/AIDS-affected households</td>
</tr>
<tr>
<td>Process structure</td>
<td></td>
<td>Transparency on objectives, roles/tasks and procedures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Incorporation of different views and perspectives</td>
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<td></td>
<td></td>
<td>Structured decision making</td>
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<tr>
<td>Process management</td>
<td></td>
<td>Independent and unbiased management</td>
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<tr>
<td></td>
<td></td>
<td>Facilitation of mutual respect, openness, and constructive interaction</td>
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<td></td>
<td></td>
<td>Competent facilitation and coordination</td>
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<tr>
<td>Capacity building</td>
<td></td>
<td>Mobilize participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Address needs and wishes</td>
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<tr>
<td></td>
<td></td>
<td>Appropriate tools and methods</td>
</tr>
<tr>
<td>Coalition building</td>
<td></td>
<td>Appropriate support</td>
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<tr>
<td></td>
<td></td>
<td>Access to resources</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Direct</td>
<td>Food security and well-being</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Innovations</td>
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<td></td>
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<td>Self-managed groups</td>
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<td></td>
<td></td>
<td>Stakeholder network</td>
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<tr>
<td></td>
<td>Indirect</td>
<td>Learning (technical, social, reflexive)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ownership</td>
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</tbody>
</table>
Promoting Food Security and Well-being in the Context of AIDS: Lessons from an Interactive Approach

tance by the parties involved was taken into account (Rowe and Frewer, 2004). Since the study concerns an explorative study to improve the conceptual and methodological framework, cost-effectiveness was not included as one of the criteria. The criteria are summarized in Table 8.2.

8.4 Research Methods for Evaluation

The study was conducted from March to May 2006. The method of ‘responsive evaluation’ was applied to evaluate the interactive methodology on the extent it realized effective participation and interaction (Greene and Abma, 2001). In a responsive approach, evaluation is reframed from the assessment of interventions on the basis of initial goals to an engagement with and among all stakeholders about the value and meaning of their practice. It is not only qualitative but also participatory, including views from all relevant stakeholders. To include information and experiences of the various stakeholders and to facilitate a reflection process, a stepwise process of data-collection, analysis and validation was initiated.

The first step concerned data collection. Data has been collected by means of a triangulated approach, involving various stakeholders and methods. Research was conducted on project documents to reconstruct important activities and events. To gain information on perspectives and experiences, semi-structured interviews were held with: a) members of the project team (two facilitators and the coordinator from the agricultural NGO, and a researcher from the university institute); b) representatives of project partners (the director of the agricultural NGO, the researcher from the university institute, and the manager and a social worker from the health centre); c) members of the support groups (chairperson, HBC worker, two active members, two less active members); and d) other ‘relevant’ stakeholders (the head of the ARV program from the Department of Health and an extension worker from the Department of Agriculture). Questions addressed the evaluation criteria as well as the interviewees’ experiences and feelings. Interviews were recorded and interview reports were analysed by coding (Flick, 1992).

Responsive evaluators have to be sensitive to power relations. Therefore, the photo-voice method was used to add and validate the information gained from support group members. Photo-voice is a participatory action strategy to enable people to identify, record, and represent their own perspectives on important issues in their life, and is an innovative way to access information about the impact of development interventions.25 Two active and two less active members of each support group were

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25 see http://www.photovoice.com

introduced in taking pictures with a disposable camera after the semi-structured in-
terviews. They were asked to make ten pictures; five representing what had changed for them since the start of the project and five what according to them still has to change. A facilitator interviewed the twelve support group members (four from each group) about the stories behind the pictures.

Based on the analysis of the interviews, separate validation sessions were held with the project team and each support group. To stimulate reflection and discussion in the support groups, the members that participated in the photo-voice method were asked to present a selection of their pictures. Detailed notes were made during the sessions and newly derived insights and information was integrated in the overall analysis. Preliminary results were presented for feedback during one of the monthly meetings. The evaluation process was facilitated by a Dutch Master-student in collaboration with two staff members from the agricultural NGO.

8.5 Results

Below we describe the findings according to the criteria of the evaluative framework. Where possible and relevant, we have illustrated findings with verbatim quotes.

8.5.1 Evaluation of the Process

As mentioned in the evaluation framework, stakeholder representation, process structure and management, as well as capacity and coalition building are important aspects to consider in an interactive process. They will be discussed below.

Stakeholder Representation

Throughout the project, there was an adequate and balanced representation of stakeholders in terms of expertise, knowledge, and institutions. The key stakeholders, i.e. the partner organisations and the support groups, were represented in monthly meetings for decision making, combining experience and expertise on agriculture, health, methodology and local knowledge. In addition, the health centre had good local contacts with governmental departments, the municipality and traditional leaders, making it relatively easy to consult and involve them during the various stages of the project. Some, however, were disappointed about the participation of the health centre. The centre represented HBC workers, VCT counsellors and a social worker, but was not always able to provide the required input due to capacity problems.
The role of the support groups was substantial. The project evolved around the activities of the groups, while each was represented by two members in the monthly meetings, usually the chairperson and the secretary. Logistical constraints to participate in these meetings were largely solved through the availability of cell-phones and compensation of travel costs.

The base-line study showed that most households in the support groups belonged to the poorer segments of their communities, while the impact of HIV/AIDS-related illness and death among participating households was high. The health centre told the communities that it amongst others wanted to help families with orphans. However, not all partners were happy with the way members were selected, as it raised expectations that could not be met. The new coordinator said:

*Those people wanted to get something for their children, the orphans, but this is not part of the project. Maybe that caused unfulfilled expectations. (...) even when they don’t turn up at the meetings or work in the garden they think they have the right to get food.*

Moreover, it created diversity within the groups. HIV/AIDS impact varied from taking care of orphans or someone chronically ill, to the experience of recent death or no direct impact at all. Due to poverty and the impact of HIV/AIDS, it involved young women whose husbands had died and grandmothers taking care of orphans. Some participants were infected themselves as they did not have someone else to work for them in the garden. As this study will show, it is especially those that got sick during the course of the project and those being very old, who had difficulties to participate.

**Process Structure**

In general, the process structure was transparent. The overall objective, work plan and procedures were defined at the start of the project and laid down in a project proposal. This was presented among participating organisations, while the overall program and plans were regularly explained and discussed in meetings and FLS sessions.

Among partners there was consensus on the overall objectives of the project. However, they had different interpretations how best to address these. Where the agricul-

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26 Based on data from May 2004, most households depended on 300-1200 Rand (45-180 US$) per month. For comparison, 40 % of the South African households in the year 2000 earned less than 1104 Rand per month, while 20% earned less than 666 Rand (Statistics South Africa, 2002)
tural NGO and the university institute emphasized capacity building and food production for home consumption, the health centre stressed the importance of saving money as groups through communal gardening and marketing of produce in order to sustain themselves. This had consequences for the expectations regarding roles and tasks. The agricultural NGO and the university institute expected a more active role of the health centre:

*We expected them to provide services with regard to VCT, raising awareness, and psychosocial support, also outside sessions.*

The health centre acknowledged their importance, but saw it as their main task to provide direct (material) support to the groups they initiated.

Raised expectations and the provision of inputs also had their reflection on the support groups. Although each group was relatively free to decide on their own work plan, in practice they mainly followed the suggestions made. For example, all groups engaged in communal gardening in order to get material support, but the chairperson in one group said:

*Some people did not want to work as a communal group; they wanted individual plots within the garden.*

In addition, it was initially not clear to everyone where the process would take them. This was not only a problem among support group members, but also among facilitators and partners. ‘Finding out as you go’ is partly inherent in an interactive approach, which depends on intermediate outcomes and may change its direction over time. However, the confusion was also related to inexperience of the project team.

Despite these problems, partners and support groups indicate that stakeholders’ views, priorities and needs, were taken into account. They were satisfied how feedback from consultations and experiences were discussed between partners and support groups at the end of each phase to optimize decision making.

**Process Management**

An effective interactive process requires independent, responsive and competent coordination and facilitation. These tasks were mainly in the hands of the agricultural NGO and the university institute. There are no indications or reports that this led to biased decisions.
Mutual respect, openness and constructive interaction were stimulated during the monthly meetings by changing the language into Zulu, and giving everyone equal opportunity to speak out and present their progress. The representative of the university institute said:

*The partner organisations and support groups would report in turns what happened since the last time they met (...). I am quite satisfied with that. The way people have changed. The way the people are speaking up (...)*

The support groups were happy with the way the process was facilitated. At the start of the FLS, the facilitators and the members established rules regarding respect and confidentiality, while members were given equal opportunity to express their feelings and ideas. In the validation sessions, it was regularly mentioned by group members that the facilitators were different from other service providers:

*They showed real interest in our lives by visiting us at home, sleeping overnight in our communities, and in helping us to access social grants and schools (...)*

Also the progress made in gardening contributed to good relations and trust. Together with the HBC workers, the facilitators were often the first ones to be approached by community members with personal problems.

Although the support groups never questioned the competencies of the team, some partners were of the opinion that the initial project coordinator lacked the visionary leadership and time for this type of approach. This improved when a new coordinator with more research experience joined. In addition, the diversity of topics put a large claim on the facilitators and made the involvement of local ‘professionals’ on health, nutrition and HIV/AIDS necessary. The character of the work was also very emotional, not only for the support group members, but also for the facilitators:

*(...) you get confronted directly. Like: “I am HIV-positive myself, my husband, my last-born”. I really have to respond to that. Not saying, this is the end of the world and cry. You have to look for something to say, not lying, or saying: “ok you are dead”.*

This does not only ask for a well-balanced team, but also for psychosocial support for both participants and facilitators.
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Capacity Building

Knowledge, attitudes, and skills have implications on planning, problem solving, and sustainability. Hence, capacity building was considered crucial. However, it was not easy to mobilize members from the two newly formed groups. While they had a core group of ‘committed’ members, who actively participated in the FLS sessions and the garden activities, there was also another segment that did not show commitment. Lack of easy access to water for irrigation, communication problems, and too highly raised expectations – that could not be met – affected participation. But also other factors, such as health, stigma, violence, and gender relations played a role (see also Swaans et al., 2008a). Maybe even more important is poverty. Many participating households were struggling and faced numerous short-term decisions. One of the facilitators indicated:

They have to do so many things. They prefer doing things that have an immediate outcome. They don’t understand investment, that you have to invest in time and then you get something out of it. People go for quick cash (...)

Holding sessions once a week established consistency and encouraged participation. However, a balance is required in the frequency of sessions, recognizing the need to keep the activity vibrant and yet not stifling the activities that women have to accomplish within their households.

Early success seems to play a pivotal role in bridging up expectations. Activities in the gardens stimulated attendance and ran parallel to the discussion forum in the FLS. People who left the groups wanted to return when the gardens started to produce food. However, dependence on the garden as focal point also meant that the momentum of the program could not be maintained off-season when there were no crops in the garden.

Overall, the partners and support groups were very satisfied with the FLS. In addition to the base line study, visioning helped to identify needs and wishes. The curriculum ensured that the broad array of issues influencing poor and affected households was taken into consideration. Still, most partners felt that not enough attention was paid to organisational development. At the same time, they realized that many underlying problems to food insecurity are structural and related to limited access to resources, particularly among women. This can not be solved by the participants of the FLS alone, but has to be addressed in collaboration with other relevant stakeholders.

The methods and tools seem very appropriate. The combination of discovery-based learning, with group dynamics and discussion, were highly appreciated by the group
Promoting Food Security and Well-being in the Context of AIDS: Lessons from an Interactive Approach

members. With the exception of some older people – who had difficulties to remain concentrated during sessions – engagement was high, even though many were illiterate. The focus on agriculture made it possible to build confidence and trust and to create a safe environment to discuss more sensitive issues. However, despite creative methods and techniques, some remained afraid of gossip and stigmatization and did not feel comfortable to discuss HIV/AIDS in a group setting.

**Coalition Building**

Although it was relatively easy to consult and involve local stakeholders, contacts were often too informal and ad-hoc to create strong commitment. The local platform on HIV/AIDS hardly met after some of its key persons left due to other commitments or jobs. On a more strategic level, the ‘think tank’ meetings had a positive impact, but it proved difficult to involve professionals from the provincial and national level based on one particular project. One of the main problems, though, was stigma and discrimination at the local level. Despite the endorsement by traditional leaders, in two communities the garden was known as the ‘AIDS-garden’. Some people left their group as a result of this.

Access to resources was mentioned by the partner organisations as another key issue. The research budget provided by the international donor was insufficient for implementation, while the health center had to go through a complicated and time-consuming procedure to get money for materials from the Department of Social Development. It did not only demotivate participants, but also staff. Staff turnover at the health center was high and replacement difficult. Referring to the Department of Health and the Department of Social Development, the social worker indicated:

_They are lazy with employing the VCT-counsellor. Now, that I am leaving, there won’t be a social worker for a long time._

The representative of the Department of Health mentioned that it was difficult to acquire motivated and competent staff to work in rural areas, especially with the high level of HIV/AIDS prevalence.

8.5.2 Evaluation of the Outcomes

Although the partners and support groups were in general satisfied with the achievements, several aspects need improvement. Some of these are reflected in the results of the photo-voice method (see Box 8.2).
### Box 8.2: Results of photo-voice method as expressed by support group members

<table>
<thead>
<tr>
<th>What has changed?</th>
<th>What still needs to change?</th>
</tr>
</thead>
<tbody>
<tr>
<td>– They acquired farming implements.</td>
<td>– In one garden there are too many stones, which make it difficult to plough.</td>
</tr>
<tr>
<td>– They have planted crops; they used the produce for selling and home consumption; they saved money as a group.</td>
<td>– The fence is still not safe; goats/livestock may get into the garden and there is a risk that people steal produce.</td>
</tr>
<tr>
<td>– Some gained skills, which they also use for home gardening.</td>
<td>– Gardens are too small for everyone; for some they are located too far away; however farmers are willing to form groups and to make a garden closer to their home when it can be fenced.</td>
</tr>
<tr>
<td>– Some women saw their children happy when they got food and something to eat; they try to transfer their knowledge and skills to their children, who help them with gardening.</td>
<td>– One group still has to open a bank account.</td>
</tr>
<tr>
<td>– Since the garden started, people have become aware that they can derive a livelihood from gardening; it has also opened their eyes to other things they can do themselves.</td>
<td>– Markets to sell are limited.</td>
</tr>
<tr>
<td>– They enjoyed the work; they are happy and proud, also on the role of women in society and traditional ceremonies (people used to fight, but now they come together).</td>
<td>– Not everyone is working together well; some do not do their work and are lazy; others cannot participate when they are sick.</td>
</tr>
<tr>
<td>– One group took the initiative to extend the garden and it is thinking of building a dam for irrigation.</td>
<td>– Lack of water for irrigation is a main problem; farmers do not have resources to address this problem and for those who are sick/old, it is difficult to fetch water; one group draws water from a dam, but livestock owners are not happy with that.</td>
</tr>
<tr>
<td>– They got access to varied support through the project.</td>
<td>– Infrastructure is bad, but development is coming. They get electricity (to schools) and roads are improving.</td>
</tr>
<tr>
<td>– There are fewer worries as they are succeeding in fighting poverty.</td>
<td></td>
</tr>
<tr>
<td>– Many emphasized that HBC workers have been very important for people who were sick.</td>
<td></td>
</tr>
</tbody>
</table>
Promoting Food Security and Well-being in the Context of AIDS: Lessons from an Interactive Approach

**Direct Outcomes**

Direct outcomes refer to food security and well-being, innovations, self-managed groups, and the establishment of a stakeholder network.

The main aim of the project was to improve *food security and well-being* among participating households. The term food security relates to increased access to nutritious food throughout the year. This is also linked to income generation by selling produce. Food security improved among households during summer time – when water was available – while the growing of vegetables was stimulated during the winter. Also the financial situation of the groups improved through money earned from selling surplus of the garden produce.

However, some support group members felt that the project had no impact as they only received food seasonally, while others received little or no food at all. Members also mentioned that they did not get any of the money that the group had saved. They did not see the money accruing at group level as positive impact as it did not directly translate into benefits at the household level. Especially, people who got sick were excluded, as a typical reaction showed:

*When I was sick and not in the garden, I got nothing. (...) It is just that I was not fit to walk to the garden. It is too far.*

Despite their illness, these women like to have another possibility to participate in the project. Some already started with their own home garden close to their household, hoping to be supported through fencing or seeds.

The project partners considered the impact on well-being as limited. Some households got access to social grants and access to schools through substantial support by the community facilitators. Some mentioned that they derived strength from working in groups as they could share their experiences related to poverty or HIV/AIDS. Others indicated that they are happy, because they were able to gain a lot of knowledge through the project, or that they do not have to worry about hungry children. Reasons for the limited impact on well-being among households might be the strong focus on agriculture and capacity building, and the short duration of project implementation.

In view of the adverse consequences of the HIV/AIDS pandemic, the project aimed to stimulate and sustain *innovations* to improve food security and well-being. The impact of HIV/AIDS on human and financial resources necessitated changes in agricul-
tural practices to reduce production costs, e.g. by using organic pesticides, compost-making, open-pollinated maize and sorghum breeds, and seedbeds. Various options were introduced to enhance nutritious intake throughout the year. These included planting of new vegetable varieties or the growing of vegetables in a different season than traditionally. One group successfully planted sorghum, as a more nutritious and drought-tolerant alternative for maize – their main staple food.

However, the groups have not been able to try out and develop the innovations further. Lack of time and insufficient expertise of the project team were mentioned as reasons for the slow progress. However, according to one of the partners, the groups were not ready for it when they started due to a lack of cohesion, confidence, and experience.

The inexperience in farming and lack of familiarity with trying out new practices did not only make it difficult to set up ‘structured’ experiments, but also to recognize ‘innovations’ and come up with ‘creative’ ideas. The first learning cycle showed that farmers can be stimulated through ‘pictures’ of examples from other areas, but there is a tendency – even among facilitators – to describe innovations as a new ‘thing’ or ‘technique’. Although groups came up with various strategies to address more social problems, the university representative indicated that different ways of working together, e.g. in sub-groups, combining individual and collective elements, etc., need further exploration.

The transformation of the support groups into self-managed collectives was one of the main strategies to empower women in the area, and to address the social breakdown of relations in the community. All partners agree that it is a success that the three groups still exist. However, they also said that only one of them is sustainable. The other two have problems with participation and governance, reflecting tensions between members and resulting in lower production. One member said:

*People do not want to do something that is being directed by someone in the group. We don’t listen to one another (...) it is lack of respect.*

Some members explain the problems in their groups as a ‘lack of togetherness’. According to respondents, some members who took care of orphans even gossiped about those who were sick, resulting in inactivity and drop-out.

The lack of solidarity might be related to the patriarchal setting. When women move in with their husband’s family, they often do not know other women in their ‘new’ area. Various respondents argued that the groups are too big and diverse. The limited
effectiveness of two of the groups has been attributed to the fact that some committee members did not know what was expected from them, but lack of strong leadership seems more important. The group that is doing well is an example of a group of women that started small and grew bigger over the years under visionary and respected leadership. Moreover, it confirms the importance of an internal drive to participate.

Despite the organisational strengthening of the groups and institutional collaboration, it is too early to talk of an effective stakeholder network. There has been a clear improvement in exchange of experiences between the groups, not only on technical issues, but also in relation to participation and governance. The groups managed to access support they did not receive before. However, this has not yet resulted in concerted action by relevant stakeholders at the local level. Most partners advocate the re-establishment of a platform to integrate and coordinate HIV/AIDS-activities. It is encouraging that the Department of Health wants to intensify cooperation with existing groups or start a food security project with groups of infected people only, with support of HBC workers and VCT counsellors.

**Indirect Outcomes**

Indirect outcomes refer to personal and mutual learning (i.e. technically, socially, reflexive), as well as ownership. They are not only important in relation to empowerment of the participants involved, but also form an indication of the sustainability of the innovation process.

Interviews and validation sessions indicate that individuals and stakeholders gained new knowledge, attitudes and skills. On a technical level, support group members learned through the FLS sessions and the garden work. One of the women said:

> *I am farming at home. I am happy to see my crops growing. I never thought of planting crops, but the sessions and the work in the garden opened my eyes.*

The FLS allows them to learn from each other. During interviews and validation sessions it became clear that members shared knowledge and skills with less experienced members, while some taught their children. When asked what members learned exactly, common replies were: ‘how to fight insect infestations’, ‘how to make seedbeds’, ‘how to plant various crops and vegetables’, ‘how to use kraal manure instead of fertilizer’. Farmers considered trials carried out in the gardens as particularly useful as they allowed them to try out things and use newly acquired skills. This emphasizes the importance of carrying out practical exercises in conjunction with theoretical training exercises.
Chapter 8

They also learned about nutrition, health and HIV/AIDS. Especially on HIV/AIDS, people want to know more. One of the facilitators expressed:

*When we started with the project, only one group was able to speak with us openly about HIV/AIDS. It was because the HBC workers were already there. (…) And now, you can just go to the groups and talk about it. You don't have to beat around the bush. You can't find that in other communities.*

At a social level, several respondents indicated that they learned from the set-up and methodology. Members indicated that they gained confidence to drive the decision making process and the activities in the garden. The chairperson of one of the groups said:

*I learned how to manage people and to have patience with people (…) and when there is a problem in the garden (…) we know what to do.*

The FLS allowed them to participate in planning and implementation, thus enhancing their capacity to deal with development issues, regardless of the low literacy rates within the groups. Also the facilitators reported that they gained more confidence and experience to deal with a variety of organisations and with sensitive issues. The interactive and participatory way of working was new to the support groups and highly appreciated. Some of the partners were especially enthusiastic about the FLS:

*The group needs to have space. So that people can come together to talk and reflect (…). How AIDS impacts on their lives and what the project can do to strengthen them. This school model is definitely something that we should pursue (…)*

However, the partners also realized that farming may not be the most appropriate strategy for everyone. The FLS has to be flexible and create a range of options for people to choose from, e.g. cropping, gardening, livestock production, craft and tourism, both on individual and group level.

*At a reflexive level, various partners stated that they learned about their own and each other's perspectives. In general, support group members have a better insight in the relation between food security, agriculture and health. They became aware of what they can do themselves to improve their lives, but also of the constraints. In one of the communities, women asked the facilitators to organize activities with their husbands during Christmas, showing signs of increased awareness that they can only change some of their practices when their husbands are involved. Leaders of support groups also mentioned that the groups became more tolerant towards people who are sick.*
Also the partners gained more insight in each others’ perceptions. Especially the agricultural NGO learned from the support groups. Their director expressed:

_I have learned about the different ways HIV/AIDS impacts on households. Stigma and discrimination was definitely great. I was blown away by the severity of discrimination, the ignorance of people. (...). Now I can speak to authorities about that issue._

The representative of the Department of Agriculture showed increased awareness during the course of the project of the relation between agriculture and HIV/AIDS. Also the representative of the Department of Health indicated that it helped him to develop concrete plans to improve food security among infected people.

With regard to ownership, it is too early to be conclusive. This is partly related to tensions between on one side the Agricultural NGO and the university institute, and on the other side the health centre. Moreover, the provision of resources created dependency. Only one group – which already existed for several years – showed regular initiative, e.g. they tried to acquire land to extend their garden and had plans to build their own water dam for irrigation purposes. They also made it clear, when they did not agree with the partner organisations. It is positive, however, that many members in other groups showed their commitment and enjoyed working together, showing signs of an emerging group identity. All groups indicated that they would like to continue.

**8.6 Conclusion and Discussion**

With respect to the effectiveness of the ILA methodology, we can conclude that, in general, the methodology provided a rational process that resulted in actual influence from poor and AIDS-affected households, as well as other role players in agriculture and health. Facilitation and coordination created an atmosphere for constructive interaction. Especially group-based learning seems appropriate for capacity building, although a stronger institutional embedding is required to address structural problems. In addition, some knowledge sharing between stakeholders has taken place, resulting in changes of thinking among participants and stakeholders that might facilitate future innovation processes.

However, there were also several aspects that were less positively evaluated. One of the sub-optimal aspects was the lack of a common vision on strategy, tasks and roles between the organisations of the partnership. Organisations have specific backgrounds,
cultures and traditions, which may come to the surface in interactions (Jasanoff and Wyne, 1998). Especially the organisations representing agriculture and health were different in various respects: 1) they supported the groups from a different perspective; 2) they depended on different kinds of funding; and 3) they used a different type of approach. They expected each other to perform specific tasks yet these were not mutually agreed upon. The lack of clarity by the institutions regarding the division of tasks created lack of confidence in each other. This was further frustrated by the lack of capacity among the local partner.

Another suboptimal aspect was the mobilization of poor and affected households to participate and to overcome stigma and discrimination. The study showed that a cooperative group can reduce poverty and improve people’s health through the production of healthy food, selling of produce, sharing knowledge, and improved relations. Success rates are higher when groups start small and are initiated by themselves. However, the study also showed that effective cooperation takes time, is fragile and subject to erosion. Some have indicated that the poor may be less likely to form groups and make it successful (Thorp et al., 2005). It seems especially difficult in the context of HIV/AIDS due to the reluctance to discuss personal and sensitive issues openly. Moreover, we observed that those who are infected themselves or take care of others who are infected, may be too ill or busy to commit themselves to commonly agreed upon rules and agreements. And even if an open and respectful environment among members is created, there still is stigmatization and discrimination emanating from the broader community.

Several lessons can be drawn from this study. First, more attention is required for institutional collaboration. The diversity of impact needs to be matched by a diversity of researchers and service providers, working collaboratively. However, since role players from different sectors, such as agriculture and HIV/AIDS, are likely to have no history of interaction, the level of trust is initially low as routines, procedures and protocols are lacking. This may raise uncertainty, anxiety and defensive behaviour. The ILA approach emphasizes the importance of responsive facilitation and shared activities to improve mutual understanding (Broerse, 1998), but negotiation processes may initially be necessary to overcome the various differences (see Leeuwis, 2004). It also requires capacity building among participating organisations, possibly in combination with more effective collaboration with other (strong) stakeholders.

Secondly, in an environment of social inequalities, poverty, diseases, deaths, and violence – all common in the area – it becomes less likely that people are willing to take risks and engage themselves in a process with uncertain outcomes (see Woolcock,
1998; Campbell et al., 2005a). Hence, early success seems to be pivotal for participation. This requires a balance between risk (experiments) and safety (‘conventional’ agriculture) and innovative ways for a year-round program. A group-based approach may have to be combined with interaction with individuals, particularly women, in the vicinity and privacy of their own home through gardening and counselling. This would minimize the scenario where members who fall sick are excluded.

In addition, the stigma and discrimination attached to HIV/AIDS requires a safe environment so that people can speak openly about it. The practical focus on farming allowed people to explore more sensitive issues as HIV/AIDS at their own pace and terms, but some people still felt uncomfortable. The possibility of setting up small sub-groups of either infected members or poor households should be explored; activities and content could be adapted to their specific characteristics and needs. It is interesting to note that some members, who left their groups due to stigmatization, returned when they started to produce crops (see also Swaans et al., 2008a). This suggests that concrete positive results may help to overcome stigma and discrimination. However, interactive approaches are unlikely to succeed without an enabling environment (Campbell et al., 2005a). It needs the active involvement and support of authorities and key persons in the community, as well as awareness and education activities in the area, e.g. through the establishment of an interdisciplinary platform on HIV/AIDS.

Finally, the participation of the poor and HIV/AIDS-affected households requires a broader focus. This may include a shift in focus from farming to other income generating activities, but also holistic programs, including short-term food assistance (e.g. for those with several orphans and few productive adults), linked with agriculture and income-generating activities at both household and community level. In addition, options should be identified for supporting people who are too sick or old to participate. The challenge lies in identifying the most appropriate interventions, targeting the right individuals and households, and providing it at the right time for the right duration. In food insecure and resource-poor settings, a livelihoods approach based on vulnerability and risk may be more appropriate for this purpose than selection based on poverty indicators and HIV/AIDS impact (see Drimie and Mullins, 2006; Swaans et al., 2008b).

Interactive methodologies that focus on the facilitation of mutual learning and constructive interaction overcome many inadequacies of other strategies in the context of HIV/AIDS; especially communities, with their advantages of local knowledge, may represent an untapped resource to explore the livelihood system and develop ap-
appropriate solutions in joint collaboration with service providers and researchers. It is too early to say whether the ILA presents an effective way of mainstreaming HIV/AIDS into farming systems research and development efforts. The labour intensity and the ongoing requirement for external funding seems to make it difficult to scale up activities, although substantial gains can be made through self-financing mechanisms and the introduction of micro-credits and saving schemes (Kim et al., 2002; Okoth et al., 2003). Other studies have shown that scaling up is feasible with adequate institutional support and political commitment (Hagmann et al., 2002; Zweekhorst, 2003). Considering the labour-intensity of the approach future applications will have to take its cost-effectiveness into account. But first, we need more experience and experimentation with the lessons learned in order to come to a more mature conceptual and methodological framework.
9.1 The Main Research Question Revisited

HIV/AIDS poses one of the main challenges for the 21st century. It threatens human development in sub-Saharan Africa, and increasingly beyond (Müller, 2005). The progress that has been made in many African countries during the past decades has been diminished by the impact of the HIV epidemic (Barnett and Whiteside, 2002). Some have argued that without more effective strategies, it will be impossible to reach the Millennium Development Goals, with the overall objective to cut world poverty by half by the year 2015 (UN, 2004; UN General Assembly, 2000).

Food insecurity is an important factor influencing both susceptibility and vulnerability to HIV/AIDS. The vicious relation between malnutrition, HIV infection and AIDS impact drives individuals, households and communities in a downward spiral of impoverishment (Gillespie et al., 2001; Loevinsohn and Gillespie, 2003). Especially in rural and semi-urban areas, HIV/AIDS is exacerbating food insecurity as people are weakened and unable to engage in production activities, while poverty and food insecurity may fuel the epidemic when people engage in more risky strategies to ensure a livelihood. Although scientists and development practitioners have stressed the importance of integrated and interactive approaches to prevent and mitigate the impact of HIV/AIDS on agriculture and rural development, sustainable implementation is far from easy and straightforward.

The objective of this study is to contribute to the (further) development of a conceptual and methodological framework for interactive approaches to agricultural innovation in the context of HIV/AIDS in order to realize better informed, more sophisticated and effective intervention programs dealing with improvement of food

Synthesis and Reflection

“A new paradigm is asked for, a paradigm that combines social protection and development, is based on people’s own perceptions and priorities, and addresses key structural factors driving the epidemic.”

(Kim et al., 2002)
security and well-being among poor and HIV/AIDS-affected households. The main research question addressed in this thesis is:

*Which key issues and strategies can be identified to realize effective interactive approaches to agricultural innovation in the context of HIV/AIDS?*

To be able to answer this question, it was divided into two sub-questions that determined the outline of this study. The first sub-question referred to a more conceptual study on the key issues in the design and implementation of interactive approaches at the interface of HIV/AIDS and agriculture. The second sub-question concerned the practical application of a ‘tentative’ framework for agricultural innovation in the context of HIV/AIDS – in this case a rural high-prevalence area in the Province of KwaZulu-Natal in South Africa. It consisted of a descriptive-analytical study to characterize the selected problem situation, and a more action-oriented study, whereby identified innovations/strategies were implemented and tested in practice.

In this final chapter the main findings and conclusions of the study are summarized and placed in a broader perspective. Based on the findings the main research question is addressed. Subsequently, the main conclusions and lessons are discussed in relation to the theoretical framework. Finally, the validity of the research findings and some research implications are reflected upon. The chapter concludes with some suggestions for further research in the field of HIV/AIDS, agriculture and interactive approaches.

### 9.2 Conclusion

#### 9.2.1 Key Issues in Design and Implementation

A conceptual study was conducted to gain insight into the main lessons and challenges with respect to the design and implementation of interactive approaches to agricultural innovation in the context of HIV/AIDS. As evaluated experiences of interactive approaches at the interface of HIV/AIDS and agriculture are rare, main lessons were derived from agriculture and natural resource management, while challenges in the context of HIV/AIDS were identified through personal experiences from researchers, development practitioners and extension workers in South Africa. The findings, presented in chapter 4, indicate that each specific local situation requires its own context-specific approach, which needs to be adapted continuously as the process proceeds. Nevertheless, many scientists and practitioners of participatory and
interactive approaches suggest that it is important to be aware of certain principles and guidelines at the process level.

Published case studies in agriculture and natural resource management show remarkable similarity in what they consider as crucial factors for success: a central role of farmers; commitment to a shared vision; enhancement of trust relationships; facilitation of social and experiential learning; integration of knowledge; enhancement of coalition building; capacity building; and scaling out, scaling up and institutionalization. It requires the application of an action-spiral, in which planning, action, monitoring, and reflection keep recurring; a variety of methods and tools; participatory monitoring and evaluation, and process facilitation.

Although interactive approaches have been applied in resource-poor settings before, agricultural innovation in the context of HIV/AIDS confronts researchers, development practitioners and extension workers with new and unforeseen problems:

1) *Poverty* A household affected by HIV/AIDS faces enlarged constraints on time and resources, while vulnerability to other shocks/stresses increases. It requires a flexible approach, a livelihood focus, and a long-term commitment of service providers.

2) *Diversity* Not all people are equally at risk for HIV infection or AIDS impact, while risk changes over time. A diversity of services is needed to support people in various stages in the disease trajectory and/or personal situation. It involves qualitative and ethnographic methods over longer time frames to explore underlying factors and mechanisms, and the potential for synergy between social groups in the community.

3) *Stigma and gender* HIV/AIDS is a taboo and deeply ingrained in cultural norms and values and triggers stigma and discrimination. This particularly affects women; they are not only more susceptible to HIV infection than men or boys, but also more vulnerable to the impact of AIDS. This requires emotionally safe spaces for peer education in conjunction with sexuality education. Credit and enterprise development programs have been suggested to improve women’s socio-economic independence.

4) *Mobilisation of stakeholders* As HIV/AIDS is a sensitive issue and a taboo; the initiative for interventions often relies with outsiders, while other stakeholders may not ‘see’ their potential contribution. It underlines the need to build trust relations at the personal and institutional level through honest and transparent communication and follow-up on ethical guidelines. Social organisation of user groups may stimulate ownership and action.
5) **Integrating different perspectives** The wide variety of relevant stakeholders implies increased differences in knowledge, ideas, beliefs, meanings, discourses and practices. It requires social learning and joint problem solving, although clear-cut strategies were not identified.

6) **Innovation(s) in response to HIV/AIDS** The increased number of orphans, middle-aged widows and elderly requires low risk strategies and a focus on food security and livelihoods. New partnerships around local innovation and HIV/AIDS are required, with a focus on the aspirations and constraints of those affected by HIV/AIDS.

7) **Hope, optimism and self-initiative** The uncertainty and fear of illness and death and impoverishment lead to despair, helplessness, and depression. Emotionally safe spaces, counselling, and interactive approaches that match individuals’ potential with broader development goals were suggested. ARV treatment in particular may have an impact on the well-being of those who are infected and reduce stigma.

8) **Additional competencies of facilitators** The variety of topics and new partnerships puts a high demand on the knowledge and skills of facilitators. They have to be trained in variety of topics and work according to ethical guidelines. Not all skills need to be embodied in one person; a team approach may be preferred.

Overall it was concluded that key principles and guidelines for process design derived from agriculture and natural resource management remain unconditionally valid, but that target group specific circumstances, the sensitivity of HIV/AIDS, and the variety of relevant stakeholders pose extra challenges.

### 9.2.2 Identified Challenges in Practice

The descriptive-analytical study of the problem context in Msinga, described in chapter 5 and 6, shows that the HIV/AIDS epidemic is an additional burden on already vulnerable households. Although it is difficult to differentiate the impact of HIV and AIDS from other shocks and stresses (see also Gillespie, 2006; Müller, 2004, 2005), an ethnographic study on people’s lives revealed how HIV/AIDS exacerbated poverty and food insecurity. The epidemic touched not only upon ‘human capital’ (health), but also on financial, social, natural and physical resources; food insecurity featured as a main problem among the HIV/AIDS-affected households in this study. Moreover, many households seemed to live in fear, denial, and hopelessness, while misconceptions and myths around HIV and AIDS were rife. The psychosocial impact of HIV/AIDS has so far not received much attention in the livelihood-literature (see Seeley, 2002), but it may severely limit the options people may consider. Although changes in money and time allocation, and altered gender and age roles, are impor-
tant for poor households to cope, most responses were based on ad-hoc decisions, with negative consequences in the long term.

However, not everyone is affected to the same extent. Case descriptions in chapter 5 show that the impact and associated coping strategies, as well as prevailing power relations and exclusion from social-exchange networks – which are not (readily) available factors in the sustainable livelihoods framework – affect people’s lives in different ways and depend on the specific situation of the individual or household concerned. Not only were there large differences between households with orphaned children, chronically ill members, or recent experience of an adult death (see also White and Morton, 2005; Wiegers et al., 2006), but also within these categories. The diversity between households is often insufficiently recognized in impact assessments, thereby obscuring differences in vulnerability and needs (see Wiegers, 2008).

Three key issues were identified as critical areas for concern: gender, access to social grants and access to ARVs. The findings indicate that gender-based inequalities are a main obstacle in terms of access to resources and control over sexual behaviour. Local social status and economic dependence prevents many women and young people from controlling their own risks, which make them often unable to insist on safer sex. And as society’s traditional care-givers, women carry the main psychosocial and physical burdens of AIDS care. Yet they have the least control over and access to the resources they need to cope effectively. In addition, the findings suggest that due to economic constraints, social grants are a vital source of income for poor and HIV/AIDS-affected households, but not always easy to access due to bureaucratic regulations. Relatively new in South Africa is the free provision of ARVs, which can make a crucial difference in the lives of people who are infected with HIV, not only with respect to improved health, but also in reducing stigma and discrimination. But access is limited, while efficacy may be compromised due to poor nutrition and poor treatment adherence. Access and control over resources seem even more problematic in a rural and resource poor setting, due to limited infrastructure, lack of information, high illiteracy rates, and traditional customs, norms and values. Structural factors may not only affect the impact of HIV/AIDS, but also shape risk-environments for HIV-infection (see Kalichman et al., 2006; Pronyk et al., 2007).

What stood out in this study was the omnipresence of HIV/AIDS-related stigma. Findings presented in chapter 6 indicate that stigma in Msinga was widespread and enacted through a variety of expressions at the family, community, and institutional level. The lack of in-depth knowledge, the association with immoral behaviour, stereotyping, active and structural discrimination exacerbated people’s fear to test or
disclose their positive status, and resulted in internalised stigma and self-policing behaviour (see also Thomas, 2006). Although the form and content of stigma varied from one context to another, this study demonstrated how various forms of stigma were interlocked and united to support systems of social inequality and enforced social control. It is not surprising that this affects the already vulnerable groups in society, i.e. women, youth and the rural poor. They are relatively far removed from service providers and additional support, while they lack the political power to counter existing inequalities.

Extended families and kinship networks are generally regarded as the main source of social, economic and practical support for individuals. However, in the context of economic hardship and stigma, they may not be able or willing to provide this any longer. People become increasingly dependent on weak linkages and ties. Households in crisis are assumed to rely on friends and neighbours, but social fabric is breaking down as result of the impact of HIV/AIDS, often exacerbated by violence and accusations of witchcraft (see also Nombo, 2007). HBC workers played a crucial role in the communities of Msinga to cope with the impact of HIV/AIDS and the consequences of stigma and discrimination. They did not only provide care and psychological (or even financial) support, but they also functioned as a link between people who were ill or infected and other service providers, such as the Department of Social Development, the CDC clinic (including ARV treatment), and support groups for people living with HIV. In this way, they enabled HIV-positive persons to build up new support networks.

The ability of households and communities to meet their members’ increasing needs is limited; there is a need for external support from government and NGOs to help communities to respond to other shocks and new demands created by HIV/AIDS impacts. The loss of income and assets and social marginalization and disruption of social networks undermines the outreach of HIV interventions into affected communities. The study confirms the need to restore a household’s resource base and to address psychosocial issues. While acknowledging the importance of individual based information and education approaches and structural interventions, the study also shows that an interactive and participatory approach is needed to renegotiate underlying norms and values and existing power relations in the context of HIV/AIDS. An interactive program needs to be sensitive to differentiation of households and challenge the inequalities that drive HIV/AIDS susceptibility and vulnerability, while restoring social relations and community institutions. This requires not only an etic or outsiders perspective, but also an emic perspective based on people’s own perceptions and worldviews.
When considering HIV/AIDS mitigation in relation to agriculture-based livelihoods in rural South Africa, women and their dependents need to be central to any intervention aimed at tackling the social and economic impact of HIV/AIDS (see also Müller, 2005). Women play a major role in ensuring food security, while taking care of the sick and of children. Given the importance of agriculture in the lives of the rural poor in Msinga, agriculture seems to be a logical entry point to address other aspects of the HIV/AIDS impact spectrum; it can play a catalyzing role to reduce susceptibility and vulnerability to HIV/AIDS. It may help to provide food, to combat loss of knowledge through groups-based learning and sharing, to improve social relations and trust, to address weaknesses within agricultural extension services, and to rebuild support structures.

9.2.3 Addressing the Experienced Challenges

The action-oriented part of the study shows that an interactive approach to agricultural innovation has potential to improve food security and well-being among poor and HIV/AIDS affected households in the context of HIV/AIDS (see chapter 7 and 8). The ILA approach provided a rational process for agricultural innovation that resulted in actual influence from poor and AIDS-affected households, as well as other role players in agriculture and health. Facilitation and coordination created an atmosphere for constructive interaction. In addition, some knowledge sharing between stakeholders had taken place, resulting in changes of thinking among participants and stakeholders that might facilitate future innovation processes. Building ‘trust’ at the personal and institutional level was a key factor to responsive facilitation.

The FLS is a promising method for application within the ILA approach in order to introduce conservation agriculture in combination with health education and capacity building among members from poor and HIV/AIDS affected households. Various strengths of the FLS method were identified regarding participation, learning and empowerment. The practical and informal nature enabled people – who are usually not reached by service providers – to participate actively, while working together on agriculture and nutrition allowed them to explore HIV/AIDS at their own pace and terms. Especially song, dance, visualisation and imagination encouraged participants to open up and speak out among others, while experimentation boosted people’s confidence and enthusiasm. The findings indicate that the practice of conservation agriculture helped the support group members to grow crops with limited means. The group that was formed beforehand became an example of group cohesion and visionary leadership that resulted in positive outcomes.

The study also revealed various weaknesses. The group-based character and intensity of the program made it difficult for some members to participate as a result of pov-
erty and HIV/AIDS-related illness and death, often further constrained by stigma, gender relations and violence. Literature has often focused on the importance of labour-saving technologies to counter the impact of HIV/AIDS, however, conservation agriculture seems especially promising due to its ability to make efficient use of available local and ecological resources. But technological change has its initial costs; raising additional questions on suitability and sustainability (see also Müller, 2005). Already vulnerable households do not have start up costs, nor are they willing to face additional risks. This requires external funding and long-term commitment (see Barnett and Grellier, 2003).

Moreover, despite signs of more openness and willingness to share experiences on HIV/AIDS, it remained difficult for participants to reflect critically; especially where groups were newly formed, and could not build on pre-existing relations between their members. And even if an open and respectful environment among members is created there still is stigmatization and discrimination emanating from the broader community. The reconstruction of community institutions and social capital seems crucial to prevent and mitigate the impact of HIV/AIDS at community level, but the underlying values and relations between members of the group and/or other community members are not the main focus of the FLS method. In addition, structural changes to improve people’s lives were limited, although the period of implementation was too short to have a profound impact on economic and institutional aspects of empowerment.

Furthermore, the study reveals that effective cooperation among participants and stakeholders at the interface of agriculture and HIV/AIDS takes time, is fragile and sensitive to erosion. One of the sub-optimal aspects was the lack of a common vision on strategy, tasks and roles between the organisations of the partnership. Especially the organisations representing agriculture and health had different backgrounds, cultures and traditions, leading to lack of clarity regarding division of tasks and confidence in each other, and further frustrated due to differences in capacity. It also took time and a continuous effort to make other relevant stakeholders aware of the impact of HIV/AIDS and the potential role they could play in the process. Their involvement was often based on personal interest and motivation, as in the case of the Medical Doctor in charge of the ARV program in Msinga.

The limitation to address structural factors through the FFS/FLS approach has been acknowledged before and has resulted in a stronger focus on the structural involvement of other relevant stakeholders (see Braun et al., 2006). The ILA approach provides a methodological framework to involve service providers and researchers as actors in an interactive process to explore the livelihood system and develop ap-
propriate solutions in joint collaboration with resource users. Although such an approach seems especially relevant in complex issues in specific contexts, it has to be adapted to be cost-effective beyond the group or community level. The ILA approach puts a high demand on participants and stakeholders and is rather labour intensive. Jayne’s work in Zambia (2006), points to the fact that for many affected households labour is their only asset and therefore there is a need to use such strategies with care. The study also emphasized the importance of ethical guidelines. As mentioned in the overall research design of this study, working in areas, such as agriculture, where information given by respondents seems less sensitive, the ethical aspects of research have often been taken less seriously in practice. In a context of HIV/AIDS, a project or its activities may – unintentionally – contribute to the stigmatisation of participants. Working in the context of HIV/AIDS requires an approach that is sensitive to the risk of participants involved in the process and a continuous reflection on ethical implications of its design.

9.2.4 Lessons Learned

Overall it can be concluded that an interactive approach is needed to prevent and mitigate the impact of HIV/AIDS on the lives of poor and HIV/AIDS affected households. The diversified and gendered vulnerability among households and the deterioration of ‘social fabric’ requires an interactive approach that addresses the underlying factors that drive the epidemic and its impact. The adapted version of the ILA approach provided a robust process for mutual learning and knowledge integration within the context of HIV/AIDS, and has the potential to improve food security, while providing relatively safe spaces to address HIV/AIDS. However, the secrecy and stigmatization in relation to HIV/AIDS raise concerns about the feasibility of interactive and integrated approaches in a situation of high HIV/AIDS prevalence. Interventions aiming to mitigate the impact of HIV/AIDS need thorough understanding and where possible adaptation to the (social) context, in order to facilitate processes that reverse, rather than reinforce, social inequalities, stigma and discrimination. Even though a process-oriented approach based on trust and learning has high potential to explore the livelihood system and develop appropriate solutions together with small-scale farmers, it can only do so in a supportive environment. In addition, the ILA approach seems particularly relevant in complex problem situations and in specific contexts. However, it is rather labour and cost intensive, which makes it difficult to implement beyond the group and/or community level.

To make interactive approaches to agricultural innovation in the context of HIV/AIDS more effective, the following lessons regarding key issues and strategies should be considered:
1. In the context of HIV/AIDS, motivation is a key factor for participation

In an environment of social inequalities, poverty, diseases, deaths, and violence it becomes less likely that people are willing to take risks and engage themselves in a process with uncertain outcomes (Woolcock, 1998). Under these circumstances motivation is a key factor for participation. Various factors have been identified that stimulated motivation among support participants of poor and HIV/AIDS affected households: (early) success, learning and social dynamics, and a future – but realistic – vision. Something similar is true for other stakeholders. Not all actors immediately see why they should be involved in a ‘domain’, which they do necessarily consider their ‘own’; moreover, the government sector faces financial and human constraints and may not be able or eager to play an active role (see Gillespie, 2006).

2. Group-based, discovery learning, is important to engage (illiterate) people in a learning process, but it needs diversification in activities to include, rather than exclude, poor and HIV/AIDS affected households

The combination of discovery-based learning, group dynamics and discussion seems very appropriate to engage (illiterate) participants actively in a learning process. The practical focus on farming allowed people to explore more sensitive issues as HIV/AIDS at their own pace and terms. Success rates were higher when groups started small and were initiated by themselves with respected leadership. However, some people still felt uncomfortable and some exclusion occurred. Therefore, a flexible approach is needed that is better adapted to people’s personal situation. Sometimes it may be more appropriate to form more homogenous subgroups; this can either take the form of mitigation strategies for specific vulnerable groups (gender/pro-poor) or be targeted to people living with HIV in particular (Drimie and Mullins, 2006; Müller, 2005). Also the possibility for individual action, e.g. home-based instead of communal gardens could be included. This would minimize the risk that members who fall ill are excluded.

3. Gender plays a key role in the susceptibility and vulnerability to HIV/AIDS and needs to be central to any approach to prevent and mitigate the impact of HIV/AIDS

Women continue to bear the brunt of the epidemic and to be highly vulnerable to infection. Reducing their risk of infection demands gender-based responses that focus on how the different social expectations, roles, status and economic power of men and women affect and are affected by the epidemic (see Commonwealth Secretariat, 2002, Müller, 2005; Wiegers, 2008). This involves analysis of gender stereotypes, re-definition of male and female relationships and roles, promotion of cultural beliefs and values supporting mutually responsible behaviour and exploration of ways to
reduce inequalities between women and men. The data suggest that peer groups for education and discussion on HIV/AIDS to reconstruct existing misconceptions and to challenge norms and values are most likely to be effective when they are based on age and gender. Eventually, though both men and women, young and old, need to be involved in an interactive process in order to come to a shared understanding and agreement on underlying factors and strategies to address these (Tallis, 2002). A lack of reflection over power differentials can lead to disempowering outcomes even after achieving a seemingly participatory process (see Chung and Lounsbury, 2006).

4. In resource-poor settings, ARV treatment needs to be part of an interactive and integrated approach focussing on strengthening food and nutrition security

ARV treatment can strengthen resilience and recover capacity of people who are infected with HIV in the long term. ARV may give other strategies the chance to work (Barnett and Grellier, 2003). Apart from saving lives, ARV treatment enables people to remain economically and socially productive. It helps them to continue to care for their children, to participate in their communities. It also has a psychological effect. The quality of life of an infected person improves considerably; a future living can be anticipated again. This may indirectly affect prevention strategies and reduce stigma. The ARV component was not linked to the project in Msinga. However, the potential synergy between a project focused on food and nutrition security and ARV treatment is obvious. Firstly, HIV-infected members who have access to treatment become stronger and healthier again. Secondly, healthy food is needed for effective treatment (Castleman, 2003).

5. The variation in HIV/AIDS impacts among households requires a diversified and holistic program of development interventions

As most African livelihoods rely (partly) on agriculture, farming seems an appropriate focus for improving food security and well-being in the context of HIV/AIDS (DFID, 2003). This study shows, however, that a broader focus needs to be considered. This may include a shift in focus from farming to other income-generating activities (e.g. crafts, sewing), but also programs that include social and money aid, and short-term food assistance (e.g. for those with several orphans and few productive adults) (see Barnett and Grellier, 2003; Harvey, 2004; Gillespie, 2006). The challenge lies in identifying the most appropriate interventions, targeting the right individuals and households, and providing it at the right time for the right duration. In food insecure and resource-poor settings, a livelihoods approach based on vulnerability and risk is more appropriate for this purpose than poverty indicators and HIV/AIDS impact (see also Drimie and Mullins, 2006).
6. For programs to be effective in the context of HIV/AIDS, simultaneous and coherent activities and strategies are required at four levels: the individual, the household, the community, and the institutional level

For a highly contextualized issue, such as HIV/AIDS, it is important that interactive approaches not only take into account the specific needs of individuals and households, but also create a supportive environment at community level (see Campbell et al., 2007; Walker et al., 2004). It requires safe spaces for discussion to renegotiate underlying norms and values and existing power relations in the context of HIV/AIDS. It needs material and institutional support, and awareness/education campaigns in the communities on HIV and AIDS (preferably with local organisations, e.g. schools, churches, local clinics, etc.). However, the study also showed that power dynamics come into play when existing relations, e.g. in the family, community or institutions, are challenged (see also Gruber and Caffrey, 2005). This does not only require specific interventions and strategies at each level, but it also emphasises the need to look for synergy between activities. The institutional network plays a crucial role, not only to support these development efforts, but also to reconsider – and when necessary adapt – their policies and activities in the light of the HIV/AIDS epidemic and its impact.

7. Institutional cooperation in the context of HIV/AIDS is problematic due to the differences in background, culture, and tradition; this requires more attention for factors that constrain or enable institutional collaboration

The diversity of impact needs to be matched by a diversity of researchers and service providers, working collaboratively. However, differences in background, culture and tradition may raise uncertainty, anxiety and defensive behaviour, while differences in capacity, knowledge and skills between organisations in a partnership may cause tensions about each other’s roles (see also Nair and Campbell, 2008). The various stakeholders are likely to have no history of interaction and the level of trust is initially low as routines, procedures and protocols are lacking. The ILA approach emphasizes the importance of responsive facilitation and shared activities to improve mutual understanding, but negotiation processes may be necessary to overcome the various differences (Leeuwis, 2004). It also requires capacity building among participating organisations, possibly in combination with more effective collaboration with other (strong) stakeholders. To achieve impact and innovation over the longer term, changes may be required in larger sets of relationships or institutional arrangements. This involves coalition building and advocacy at the policy level.
8. Interactive approaches in the context of HIV/AIDS need competent process facilitation and management; it requires ethical guidelines, sensitive methods, and management of relations at the network level

Interactive approaches are not easy and need good process facilitation for enhancing learning, trust relationships and local ownership. Facilitators need to steer the process, not the outcomes (Groot and Maarleveld, 2000). They have to be respectful, empathizing, responsive, and show interest, compassion and trustworthy behaviour. They have to operate as mediators between the participants, between the group and community members, and between stakeholders in the process, which requires a good overview of the overall process and vision (see also Hagmann et al., 2002). They also need good technical skills on (sustainable) agriculture and experiential learning, and a basic understanding of health and HIV/AIDS. Not all skills have to be embodied in one person. The involvement of (local) professionals to provide technical back-up and information (e.g. in relation to nutrition and HIV/AIDS) is encouraged to create awareness and commitment within the institutional network. The sensitivity and emotional impact of working in a high HIV prevalence area did not only emphasise the importance of ethical guidelines and sensitive methods to identity factors and mechanisms that could make people more resistant and resilient to the impact of HIV/AIDS, but also the need for additional psychological support for participants and members of the project team (see also Van Dyk, 2001).

9. In order to implement interactive approaches beyond the group and/or community level, cost-effectiveness factors cannot be ignored during the development stage of its design

Interactive approaches to prevent and mitigate the impact of HIV and AIDS should be sensitive to factors that affect the cost effectiveness of the approach and which may have consequences for its design. Participation, from both participants and stakeholders, is a scarce resource (Leeuwis, 2004). Attention is needed to measure costs and benefits (direct and indirect ones). Moreover, financial resources are limited and need to be allocated in the most efficient way. An interactive approach seems most effective in complex situations in specific contexts, but for purposes of up-scaling, out-scaling and institutionalisation, more experimentation is needed with technical and social innovations (e.g. related to self-organisation and management) and self-financing mechanisms and micro-credit/savings schemes (Kim et al., 2002). In addition, it requires a stronger emphasis on embedding of interactive approaches within existing programs and structures (Hagmann et al., 2002; Zweekhorst, 2003). In the context of HIV/AIDS, a combination of interactive and instrumental forms of interventions – within an integrated framework – may be most effective and efficient at higher levels of social aggregation.
Chapter 9

9.3 Theoretical Implications

Interactive approaches at the interface of HIV/AIDS and agriculture are complicated; more systematic data is needed on key issues and strategies to improve their effectiveness. The lessons learned in this case study are important for future work of this kind. However, for the further development of interactive approaches at the interface of HIV/AIDS and agriculture, it is important to put these lessons into a broader theoretical perspective. When we relate the lessons of this study to the three main concepts of an interactive approach – as described in the theoretical framework of this thesis, i.e. participation, interdisciplinarity, and a system perspective – some interesting issues emerge. Here, we like to discuss these issues according to the three elements and introduce concepts such as motivation, ‘liberation’, conflict management, and managing uncertainty; these concepts may not be completely new, but they have not received specific attention within the ILA approach and in interactive approaches in general. They appear to be, however, very relevant in this context.

Participation

The study raises various questions about ‘participation’. What type of participation is most effective in the context of HIV/AIDS? True participation may be strived for, but this may not always be feasible, realistic or appropriate (Leeuwis, 2004: 251-259). Especially at the start of an activity or intervention this may be difficult. People need technical back-up and guidance, and may require material support. Active participation is especially difficult among those who are old and too poor or sick, which requires mitigation strategies that include relief and social support (see also Barnett and Grellier, 2003). The study also described the efforts to mobilize stakeholders around an interactive approach to agricultural innovation in the context of HIV/AIDS, a domain they may not necessarily consider as ‘their own’. The step towards participation presupposes a minimum level of ‘motivation’. This is why ‘motivation’ is such a key issue for participation in interactive processes. A shared vision in itself is often not sufficient to participate in activities; it requires an explicit motivation or a ‘cue to action’. Several additional elements, such as ‘early’ success, learning and positive group dynamics, were identified as key elements for the functioning of the support groups; also the provision of ARV medicines can be seen as a motivation factor for participation among those who are infected. However, motivation needs to be seen in a broader perspective; it refers to the involvement of a variety of actors in activities of an intervention; the project as a whole facilitates motivation.

What does this imply for the ILA approach and other interactive methodologies? Two elements are important. Firstly, specific attention needs to be paid on what activities
will motivate various stakeholders to participate. Secondly, the outcomes of a particular activity can act as a motivation factor for subsequent activities. This results in an interesting and stimulating iterative process of action and reflection, with a stronger emphasis on feasible intermediary and ‘measurable’ (self-evaluative) outcomes, which can be followed up and taken further in a continuous cycle of refinement and improvement. In this way, the action-spiral becomes a motivation-spiral for change, whereby each activity has an effect on the next activity.

Tuveri and Koelen (1998) come to a similar conclusion in relation to community-based action programs on health in the Netherlands. They found that learning from each other and the enthusiasm of the partners in action strongly stimulates and provides motivation for continued participation in collaboration. However, they also mention that it is difficult to arrive at a balance between community participation and intersectoral collaboration, and stress the importance to ensure ‘visibility’ of results since it is one of the major stimulating and driving forces to stay on track. ‘Visibility’ may, however, not be enough. In this respect it may be useful to look at what it is that makes people ‘tick’, what drives people, and how can we link that to broader development goals. Salomon (2004) calls this ‘from participation to transformation’ and links this to ideas of transformational leadership, whereby participants become change agents in their community. In a similar way, we need to look more closely at institutions and organisations, what makes them ‘tick’, and what more do we need to do to motivate and inspire them to become involved.

**Interdisciplinarity**

Differences in perceptions and views among support group members and between various stakeholders are the challenges that lie ahead in order to realize a shared understanding of the problem context and strategies to address this. Effective knowledge integration does not only require integration of perspectives, but also of cultures and practices (see Jasanoff and Wynne, 1998). Knowledge is embodied and contextual. It might be better to speak of co-creation of knowledge where by various stakeholders are actively involved as part of a ‘community of practice’ (see Wenger, 1998). This requires interaction and shared experiences in order to build up trust, confidence, and a common understanding; this demands a safe and ‘liberating’ environment that allows sensitive and conflicting issues to be addressed.

The study suggests that it might not always be the best strategy to discuss and address HIV/AIDS primarily within the context of health. It may be better to take up the discussion within the context of other domains, in this case agriculture through the establishment of food gardens. The study shows that the new setting and the practical
nature of the activities make it possible to explore and discuss more sensitive issues such as HIV/AIDS and stigma. Agriculture provides a safe environment for people to work together and talk about their daily life; this may not only help to produce food, but also to build trust and relations among people, who may not know each other very well. This does not have to be restricted to agriculture. Other examples could be the establishment of businesses, or joint activities such as collecting water at a far located irrigation pump, or exchange visits to other areas and projects etc. Although the domain of agriculture as an entry point is related to motivation (because the activity delivers something concrete, such as vegetables), the activity as such has a more fundamental ‘liberating’ character, as it offers people an opportunity to escape from their daily problems and obstacles. It does not matter so much what the other domain is, as long as it contributes to people’s livelihoods and creates ‘space’ for discussion of HIV/AIDS.

Shared (embodied) experiences of success and failure may facilitate the co-creation of knowledge. However, this may not always be easy given the diversity among participants and between stakeholders. Therefore a relevant concept in the context of interdisciplinarity is that of ‘conflict’. Interactive processes that are only centred on consensus building are unlikely to succeed (see Leeuwis, 2004). This study shows – as well as other studies in the field of interactive research and decision making (Caron-Flinterman, 2005; Hagmann et al., 2002; Zweekhorst, 2003), that it is very important to pay systematic attention to ‘conflict management’. An example of a conflict is contested knowledge and framing of a problem. In the ILA approach, it is common to make the following steps in a group session (dialogue): (a) what do we agree upon; (b) in what respect to we disagree; (c) what is based on misunderstandings; (d) what can we explain to each other (mutual learning – whereby empathy is created), and finally, (e) the sharing of priorities in order to come to acceptable ‘agendas’, ‘action-plans’, etc. Remaining conflicts of opinion will be solved on the basis of a general agreed plan for the future. This may include straightforward negotiation.

Thus, within the ILA approach there is an aspect of conflict reduction, but so far this has not been made sufficiently explicit. Transcending boundaries is not only about one group versus other groups, one sector versus other sectors, but also about overlap and conflict. The ILA approach does not start with the clarification and reduction of conflicts, but searches first for common values and a shared vision in order to strengthen them. Only after the search for commonalities, enough momentum may have been created to constructively deal with a conflict, to negotiate, and to explore and exploit the ‘room for manoeuvre’. In this respect, the study shows the importance of a process facilitator (or broker/mediator), who is perceived as independent, and
can manoeuvre between the various interests of stakeholders (see also Hagmann et al., 2002; Bueren et al., 2003). Especially, the community facilitator plays an important role to mediate and align between community interests and service providers, who could re-direct the overlap-conflict spiral in a positive turn.

**The System**

The study confirmed the complexity of the system. The impact of HIV/AIDS is determined by many underlying, interacting, factors and mechanisms, which continuously change over time (see also Gillespie et al., 2007). For interventions to be effective and reactive, a flexible action oriented approach seems most appropriate. However, it also asks questions about who should be involved, when and how. This stretches beyond the farming system and reaches for a wider livelihoods perspective; this does not only require the active involvement of community people, but also of a variety of actors from different domains and levels.

The thesis focuses on the ‘actors’ of a project in Msinga (i.e. the university, the researchers, the agricultural NGO, the community-managed health centre, the community members and support groups), while there is explicit consideration of government departments and officials in health, agriculture and social development. However, one of the main findings is a lack of concerted effort and commitment to change the institutional procedures amongst these agencies. Government agencies can constitute an obstacle to the implementation of an interactive approach. In South Africa, there is a wide gap between government policies that promote ‘integrated’ development programs and ‘multisectoral’ interventions and actual practice by government agencies. These issues cannot be avoided, however, in an interactive approach.

Several features of the local public-sector have been identified that are detrimental to effective community empowerment, such as a rigid hierarchy, poor communication between senior and junior health professionals, lack of social development skills and the demoralisation and/or exhaustion of public servants dealing with multiple social problems in under-resourced settings (Nair and Campbell, 2008). Currently, much emphasis is placed on the private sector’s potential to contribute to social-development programs (Nishtar, 2004; Richter, 2004; Rosen, 2007; UNAIDS 2006), but some studies conducted in South Africa suggest that businesses tend to shift the economic burden of AIDS to households and governments, raising scepticism about the potential of the private-sector’s contribution in remote areas (Nair and Campbell, 2008; Rosen & Simon, 2002).
Thus, at the level of institutions and organizations, there is often a sense of rigidity and ineffectiveness. This makes it difficult to realize a successful interactive approach with these institutions and organizations. In such a situation, the search for collaboration has to take place on the basis of the degree of flexibility. In first instance it makes most sense to start small and work together with those who are prepared to operate in a flexible way in a process of mutual learning. Complex problems may be characterised by ‘uncertainties’ related to a lack of knowledge, differences in problem perception and it solutions, and the lack of rules for cooperation at the institutional level (see Bueren et al., 2003). There is a need to pay attention to these underlying systemic factors and mechanisms that may prevent or hinder effective stakeholder collaboration. Joint problem solving through a process of mutual learning, cooperation and interaction, is a way to reduce these uncertainties. When enough momentum has been created it may be easier to involve other organizations. At the system level the management of a positive momentum spiral is crucial for success.

AIDS is entwined with a range of other stressors in rural South Africa and it is difficult to separate out the issue of the disease from other negative factors (Collins and Rau, 2000; Loevinsohn and Gillespie, 2003). A holistic response includes thinking and approaching HIV/AIDS and food insecurity within an integrated rural development strategy – this is sorely lacking in South Africa and would mitigate many of the associated issues around HIV and AIDS. A more focussed and explicit attention to concepts as the motivation spiral, the overlap-conflict spiral, the momentum spiral may help in the discussion to improve interactive approaches in the context of HIV/AIDS. In this way, the interactive process becomes a more dynamic and ‘breathing’ process. It creates good-will, motivation, shared ideas and values, enabling to tackle tensions and conflicts; tensions and conflicts in turn, can help to clarify issues, in order to develop better informed and more sophisticated interventions and policies in the context of HIV/AIDS.

9.4 Validity of the Findings and Research Implications

This section reflects on internal and external validity of the research findings and some research implications. In relation to internal validity, the following topics will be discussed: the risk of researcher bias, the risk of a respondent bias, the relatively short time frame of the project and the relation between food security and HIV/AIDS. Subsequently the research findings will be discussed in relation to its validity in other areas, beyond the context of HIV/AIDS, and the value of ‘sociological data’. Some final remarks will be made about research implications.
**Internal Validity**

Since the PhD-fellow actively participated in the project that was evaluated in the action-oriented part of the project, the research could be interpreted as a kind of self evaluation with a danger of researcher bias. Various validity checks were built in to prevent this: (1) other researchers, who were not (or to a very limited extent) involved in the design and management, were invited to conduct the evaluative research; (2) all participants were involved in the evaluation process in an open way; (3) triangulation of evaluation methods and sources was applied; (4) member checks were obtained from participants on interpretations of results; and (5) research peers were asked to react on findings. To further avoid bias of interpretation, primary data were extensively documented, e.g. through verbatim transcripts and detailed reports – so called ‘rich data’ – to ensure that findings would be interpreted within their specific context and for further reference; since different team members were involved in the evaluation studies, there was also triangulation through checks and balances among investigators.

The study also faced the risk of a respondent bias. The study mainly focused on women from the support groups of poor and HIV/AIDS-affected households. They were also involved in the studies on the impact of HIV/AIDS, and the underlying factors and mechanisms. This may lead to skewed interpretations. However, as the marginalised position of women emerged as a key challenge in the conceptual study, this study aimed in first instance to explore how women themselves perceive the impact of HIV/AIDS and the constraints they face to address it. To be able to generalise data to the overall context, key persons and representatives of various social groups, service providers, and authorities were interviewed about their perceptions and experiences. In the study on HIV/AIDS-related stigma and discrimination, men infected with HIV and youth from a local high-school were involved to check and validate findings of interviews and discussions with women. In addition, the members of the project team stayed in the research area for longer periods. Informal conversations with men, women, young and old, as well as observations during household visits and overnight-stays, helped to check the data and to validate the findings.

It was not expected that after two and a half year of field work (two growing seasons) full insight would have been obtained on the methodological framework for interactive approaches to agricultural innovation in the context of HIV/AIDS. However, as the action-oriented part took place as from late 2004, including two learning cycles – while the activities concerning the descriptive-analytical part started early 2004 – practical experience on the conceptual and methodological elements was obtained.
over a period of more than two years. Therefore, we are confident that this generated sufficient lessons to contribute meaningfully to the (further) development of a conceptual and methodological framework for interactive approaches to agricultural innovation in the context of HIV/AIDS. At the same time, it enabled the project team and partners to improve the design and implementation of the project in Msinga.

However, two learning cycles proved to be too short to have a profound impact on food security and well-being. A few remarks need to be made in respect of this. First, food security, knowledge and well-being were mainly assessed in a qualitative way. Quantitative data may not only be more convincing for stakeholders involved, but also for the members of the support groups themselves; practical tools could be developed by and for people to measure their own progress (see Hagmann et al., 2000). Secondly, the relation between food security and HIV/AIDS is complex and multiple factors play a role; including factors beyond the scope of the project (Collins and Rau, 2000; Gillespie, 2006). The complexity emphasises the importance of an interactive approach, but it requires high quality process indicators to prove that actual progress is related to the project and not due to other external influences (see Hagmann et al., 2002).

It is difficult to predict to what extent the approach is able to prevent and mitigate the impact of HIV/AIDS – the ultimate aim of the project. However, food security, knowledge and psychological well-being have been mentioned as key issues for individuals and households to cope with the impact of AIDS (see Campbell et al., 2007; Gillespie et al., 2006). A recent quantitative study on women in Botswana and Swaziland confirmed earlier qualitative studies that food insecurity in sub-Saharan Africa is directly associated with high-risk sexual behaviour (Weiser et al., 2007). Other studies have shown that HIV incidence in rural South Africa is particularly high among women of low education and that education may be more effective to reduce risk-taking behaviour than poverty reduction (Bärnighausen et al., 2007; Hargreaves et al., 2007). This seems to indicate that an interactive approach to agricultural innovation in combination with health education and training could have an impact on the prevention and mitigation of HIV/AIDS in the long term. We need to realise, however, that this depends on many other factors as well and that multi-level and integrated approaches are required to be effective.

External Validity
The study was conducted in a specific local area in South Africa. This raises questions to what extent results can be generalized to similar contexts and other countries. The research method which was used is a case study. This means that social events are
studied within their social and natural context. Extrapolation is based on the validity of the analysis rather than the representativeness of the events which are studied. The case study of Msinga was ideal for the purpose of this research in the sense that it provided a HIV high-prevalence area and a rather typical rural (traditional) area in Southern Africa in terms of farming-livelihoods. Many households (partly) rely on agriculture. Men are often working elsewhere, while women are responsible for food security and taking care of the children. The case study in South Africa is in some aspects different from many other African countries in terms of a relatively well established health care infrastructure, the provision of the social grants and the recent roll-out of ARVs in many areas, including Msinga. Experiences in a setting like this, however, may provide interesting insights for prevention and mitigation strategies for other countries in sub-Saharan Africa that face the social and economic impact of HIV/AIDS.

Since the start of this study, various initiatives in sub-Saharan Africa have looked more closely at the role that agriculture can play to ensure food and nutrition security in the context of HIV/AIDS. Several studies have been published on the impact of HIV/AIDS and people’s livelihoods and their responses, which support our findings. The systemic impact, of HIV/AIDS on rural households in Msinga, which has been mentioned in chapter 5, has been demonstrated in other qualitative and quantitative studies in Africa (e.g. CHGA, 2004; Haddad and Gillespie, 2001; Stokes, 2003); food and nutrition insecurity has been reported as one of the main problems (Bryceson and Fonseca, 2006; Gillespie and Kadiyala, 2005; Loevinsohn and Gillespie, 2003; Steinberg et al., 2002). Furthermore, as mentioned in chapter 6, similar psychosocial impacts of HIV and AIDS on poor rural households have been reported for other countries in sub-Saharan Africa where there is significant misinformation about HIV and AIDS, and stigmatisation and discrimination of people living with HIV (see Nyblade et al., 2003). Stigma and poverty are mutually reinforcing, as HIV-positive persons are considered by some as a burden (Bond, 2006). Depending on the social environment, disclosure of HIV status may lead to stigma, or – when there is openness – it may be a gateway to community support (Norman and Chopra, 2005). To ensure food and nutrition security in the context of HIV/AIDS, there is a growing consensus on a three-pronged strategic approach. It has to strengthen household and community resistance and resilience, preserve and augment livelihood opportunities for affected communities, and ensure that there are safety nets in pace for those who need them (Gillespie, 2006). These findings support our conclusion of the importance to address psychosocial, social and economic aspects of livelihoods among vulnerable people, as well as structures and processes that can support them. Therefore, we expect the findings to have a more general scope and validity.
More in general, one may question to what extent the results and lessons from this study on agricultural innovation and local innovation are specific to the context of HIV/AIDS. One may claim that HIV/AIDS merely exacerbates people’s poverty and has brought ‘old’ inequalities to the fore. To a certain extent this is supported by literature. Scientists and development practitioners in the field of agriculture and rural development have mentioned similar problems, e.g. difficulties of farmers to participate in participatory processes and challenges of stakeholder collaboration (see Leeuwis, 2004); power relations in the community (Chambers, 1997); and the lack of access among rural poor to resources and the need for stronger institutional collaboration (Braun et al., 2006). HIV/AIDS is different, however, in the sense that it deprives households from the most productive members, while it requires a stronger emphasis on gender inequality and stigma. In addition it undermines the institutional capacity to respond to it (see also Gillespie, 2006). Exclusion from social networks, however, is not new, and a better understanding to what extent commonly accepted participatory methodologies lead to the inclusion or exclusion from intended beneficiaries may lead to adaptation and improvement in their design and implementation.

**Some Research Implications**

The argument is made in this study that there is a need to recognize the value of, and to develop means to obtain, data of ‘sociological significance’ in counterpoint to the general valuation of data of ‘statistical significance’. This does not mean that statistical data are not relevant. The collection of quantitative data through surveys and questionnaires are an efficient way to show correlation between various factors and the representativeness of certain phenomena. However, this study showed that the vulnerability to HIV/AIDS varies, not only between categories of affected households (e.g. chronic illness, death, or caring for orphans), but also within these categories. Differences in vulnerability to HIV/AIDS can be due to multiple factors that are difficult to disentangle from the effects caused by the epidemic; moreover, people’s livelihoods are influenced by a complex set of interacting factors that impact households differently. In addition, individuals and households make decisions from an emic perspective, which varies among men and women, and the personal situation of the households. Indicators from an emic perspective, may not always correspond with the indicators selected from an etic perspective. This poses various challenges in terms of sample size and selection of respondents (see also Hosegood et al., 2007; Wiegers, 2008). Therefore, in-depth qualitative data are especially important to enhance our understanding of quantitative data (see Seeley et al., 2008) and to reveal the factors and mechanisms that determine the susceptibility and vulnerability to HIV/AIDS; including ways to address them through interventions.
Community-based research in the context of HIV/AIDS raises, however, also some ethical concerns (see also Wiegers, 2008). For example, visiting households or implementing a project on HIV/AIDS and agriculture, may ‘unintentionally’ contribute to stigmatisation of individuals and households concerned. It also raises questions to what extent HBC workers are allowed to inform you about someone’s status without given consent. Also the requirement of a ‘written’ consent does not seem to comply very well with people’s experiences with signing documents; in an area which has been suppressed for a long time, it may create an uncomfortable feeling and even lack of trust. Ethical standards which may be common in the context of research and medicine, are not always very well suitable at the community level – with many illiterate people – or in the context of action research that is based on creating trust.

Concluding, the study described in this thesis contributes to scientific knowledge production on interactive strategies at the interface of HIV/AIDS and agriculture. It has resulted in increased insight in the relation between HIV/AIDS and people’s lives, and in the conditions and procedural elements that facilitate the process of developing ‘appropriate’ agricultural innovation(s) through joint collaboration. Since social and physical phenomena become increasingly interwoven, it is expected that some of these insights could probably be generalized to other contexts of complex stakeholder interaction.

9.5 Further Research

We would like to conclude with some ideas for further research.

Firstly, considering the short time frame of the project studies, first more experience and experimentation is needed with the lessons learned in order to come to a more mature conceptual and methodological framework. This especially refers to: gaining more experience and insight with the effectiveness of interactive approaches with various social groups, such as people living with HIV and vulnerable (pro-poor/gender) households; exploration of technical innovations to improve food security (quantity, quality, stability, access to), as well as a stronger focus on social (organisational and cultural) aspects of innovation to prevent and mitigate HIV/AIDS; the integration of micro-credit/other models to improve financial sustainability; a broader focus than agriculture alone, including a stronger integration of health, social and technical components – and in case of HIV-positive persons, integration of an ARV-component. At the moment some of these lessons are being implemented in a follow-up project in Msinga.
In addition, further research and experimentation is needed on aspects such as ‘motivation’, conflict management and the constraints and opportunities for institutional collaboration. At the same time, additional research could comprise more experimentation and thorough investigation with creative methods and tools. This may relate to tools for measuring progress in terms of food security and well-being, tools for discussing sensitive issues within the context of HIV/AIDS, methods that improve leadership and tap into the potential of individuals and link that with wider development goals, but also tools at the network level that deal with conflict management and managing uncertainties.

Other research could focus on the applicability of the presented interactive approach within other contexts. In first instance this would refer to similar rural contexts in Southern Africa and other countries in sub-Saharan Africa. To what extent do these settings differ and what are the conceptual and methodological implications. Given the predominance of the rural poor and the increasingly precarious nature of rural livelihoods in much of the region, food insecurity is widely recognized as one of the highest-priority problems. This situation is only exacerbated by the HIV/AIDS crisis that is decimating the most productive segments of society and creating vast numbers of orphans. Recently Junior Farmer Field and Life Schools have been implemented in the region for education and skill training among vulnerable children (Djeddah et al., 2006); it may be interesting to see to what extent an interactive approach to agricultural innovation can be adapted to address the needs and wishes of this group.

Interactive approaches and lessons learned may also be useful in relation to other problems and domains. As we have seen in this study, it is difficult to separate the impact of HIV/AIDS from other shocks and stresses, such as the impact of poverty, drought, failed market mechanisms, environmental degradation etc. This requires a better understanding of interactions between these factors and how people perceive their risk-environment and potential responses to address them (see Richards and Rugalema, 2004; Seeley and Allison, 2005). It will also be a challenge to better understand urban-rural linkages and the extent to which these may affect the impact of interactive approaches on HIV prevention and mitigation.

Furthermore, it is too early to say whether interactive approaches, like the ILA, present an effective way of main-streaming HIV/AIDS into farming systems research and development efforts. It does not only require more experience with lessons learned, the labour intensity and the ongoing requirement for external funding seem to make it difficult to scale up activities. Substantial gains can be made through self-financing mechanisms and the introduction of micro-credits and saving schemes (Kim et al.,
2002; Okoth et al., 2003). Other studies have shown that scaling up is feasible with adequate institutional support and political commitment (Hagmann et al., 2002; Zweekhorst, 2003). The pros and cons of an interactive approach have to be considered against other – more instrumental – strategies to improve food security and well-being among poor and HIV/AIDS-affected household and may depend on the specific context of application.

Finally, this study indicates that more people centred approaches are needed which take public health not as individual concern, but as communities responsibility. Differences in approach, ‘language’, and method can foster insights and innovations that help to unravel the pathways of HIV through people’s livelihoods and through their lives, but they also bring challenges (see Gillespie, 2006). It requires more attention to aspects as institutionalization, intersectoral collaboration, transdisciplinary interaction and long-term sustainability.


References


AIDS is an important social and development concern in sub-Saharan Africa. The HIV/AIDS epidemic is directly linked to food insecurity. HIV/AIDS precipitates and exacerbates food and nutrition insecurity as people are weakened and unable to engage in production activities, while poverty and food insecurity may lead people to engage in more risky strategies to ensure a livelihood.

Scientists and development practitioners have particularly stressed the importance of using integrated and interactive approaches to prevent and mitigate the impact of HIV/AIDS on agriculture and rural development. In contrast to top-down approaches – often based on positivistic thinking – interactive approaches ensure a complete integration of knowledge through participation of and mutual learning among a variety of stakeholders. Results are promising so far, but interactive approaches are relatively new, and particularly at the interface of agriculture and HIV/AIDS there is little systematic knowledge to build upon.

The objective of this study is to contribute to the (further) development of a conceptual and methodological framework for interactive approaches to agricultural innovation in the context of HIV/AIDS in order to realize better informed, more sophisticated and effective intervention programs dealing with improvement of food security and well-being among poor and HIV/AIDS-affected households. The main research question addressed in this thesis is:

*Which key issues and strategies can be identified to realize effective interactive approaches to agricultural innovation in the context of HIV/AIDS?*

The research design consisted of two elements: 1) the identification of key issues in the design and implementation of interactive approaches to agricultural innovation in the context of HIV/AIDS; and 2) practical testing of identified methodological elements in the context of HIV/AIDS and agriculture, in this case the sub-district of Msinga, a rural HIV high-prevalence area in the province of KwaZulu-Natal in South Africa.
In 2003, a community-managed health centre in Msinga initiated an action research project in collaboration with an agricultural NGO from the University of KwaZulu-Natal and the Athena Institute from the VU University Amsterdam. Role players in agriculture and health were brought together to mitigate the impact of HIV/AIDS among rural households. The aim was to stimulate discussion among three support groups of poor and HIV/AIDS affected people, mostly women, on how HIV/AIDS impacts on their lives, to discuss and negotiate ways of protecting themselves against HIV and the impact of AIDS, and to achieve food security and well-being at the household level through agricultural innovations in the context of HIV/AIDS.

Firstly, a conceptual study was conducted to gain insight into the mains lessons and challenges with respect to the design and implementation of interactive approaches to agricultural innovation in the context of HIV/AIDS. Literature review of interactive approaches in agriculture and natural resource management shows that several principles and process guidelines are considered key factors to successful implementation. They include: a central role of farmers; commitment to a shared vision; enhancement of trust relationships; facilitation of social and experiential learning; integration of knowledge; enhancement of coalition building; capacity building; and scaling out, scaling up and institutionalization; it requires the application of an action-spiral, in which planning, action, monitoring, and reflection keep recurring; a variety of methods and tools; participatory monitoring and evaluation; and process facilitation.

Although HIV/AIDS does not seem to change these conditions, personal experiences from researchers, development practitioners and extension workers do reveal new and unforeseen problems: 1) Poverty – A household affected by HIV/AIDS faces enlarged constraints on time and resources, while vulnerability to other shocks/stresses increases; 2) Diversity – Not all people are equally at risk for HIV infection or AIDS impact, while risk changes over time; 3) Stigma and gender – HIV/AIDS is a taboo and deeply ingrained in cultural norms and values and triggers stigma and discrimination; this particularly affects women as they are not only more susceptible to HIV infection than men or boys, but also more vulnerable to the impact of AIDS; 4) Mobilisation of stakeholders – As HIV/AIDS is a sensitive issue and a taboo, the initiative for interventions often relies with outsiders, while other stakeholders may not ‘see’ their potential contribution; 5) Integrating different perspectives – The wide variety of relevant stakeholders implies increased differences in knowledge, ideas, beliefs, meanings, discourses and practices; 6) Innovation(s) in response to HIV/AIDS – The increased number of orphans, middle-aged widows and elderly requires low risk strategies and a focus on food security and livelihoods; 7) Hope, optimism and self-
initiative – The uncertainty and fear of illness and death and impoverishment lead to despair, helplessness, and depression; 8) Additional competencies of facilitators – The variety of topics and new partnerships puts a high demand on the knowledge and skills of facilitators.

To test the outcomes and methodological implications of the conceptual study in the practical context of Msinga, it was needed to start from a broad practical framework. A specific participatory methodology – the Interactive Learning and Action (ILA) approach – was selected, which is appropriate for the purpose of agricultural innovation based on mutual learning between stakeholders. The ILA provides a set of principles and guidelines that need to be adapted to the context of application. Roughly four phases can be distinguished: 1) initiation and preparation; 2) data collection, exchange and integration; 3) planning; and 4) project formulation and implementation. These phases partly overlap and may be revisited in time. A few decisions were made for application of the ILA approach in the context of HIV/AIDS. Since the marginalized position of women and the silence surrounding HIV/AIDS were seen as a major concern, the project emphasized capacity building and organizational development among women through a process of group-based learning (using the Farmer Life School), while the concern for safety and confidentiality was given extra attention.

As part of the ILA approach (phase 2), a descriptive-analytical study was conducted. The study shows that HIV/AIDS exacerbated poverty and food insecurity. The epidemic touched not only upon ‘human capital’ (health), but also on financial, social, natural and physical resources; food insecurity featured as a main problem among the HIV/AIDS-affected households in this study. Moreover, many households seemed to live in fear, denial, and hopelessness, while misconceptions and myths around HIV and AIDS were rife. However, the study also shows that the psychosocial impact and associated coping strategies, as well as prevailing power relations and exclusion from social-exchange networks, affect people’s lives in different ways and depend on the specific situation of the individual or household concerned. Three key issues were identified as critical areas for concern: gender, access to social grants and access to ARVs. Access and control over resources seems even more problematic in a rural and resource-poor setting, due to limited infrastructure, lack of information, high illiteracy rates, and traditional norms and values.

What stood out was HIV/AIDS-related stigma. Stigma in Msinga was enacted through a variety of expressions at the family, community, and institutional level. The lack of in-depth knowledge, the association with immoral behaviour, stereotyping, active
and structural discrimination exacerbated people’s fear to test or disclose their positive status, and resulted in internalised stigma and self-policing behaviour. Although the form and content of stigma varied, various forms of stigma were interlocked and united to support systems of social inequality and control; this especially affects already vulnerable groups in society, i.e. women, youth and the rural poor. They are relatively far removed from service providers and additional support, while they lack the political power to counter existing inequalities.

Households in crisis are assumed to rely on friends and neighbours, but ‘social fabric’ is breaking down as result of the impact of HIV/AIDS, often exacerbated by violence and accusations of witchcraft. HBC workers played a crucial role in the communities of Msinga to cope with the impact of HIV/AIDS and the consequences of stigma and discrimination. They provide care and psychological (or even financial) support and functioned as a link between people who were ill or infected and other service providers and support groups for people living with HIV. In this way, they enabled HIV-positive persons to build up new support networks.

The ability of households and communities to meet their members’ increasing needs is limited; external support is required from government and NGOs to help communities to respond to other shocks and new demands created by HIV/AIDS impacts. The study confirms the need to restore a household’s resource base and to address psychosocial issues. An interactive program needs to be sensitive to differentiation of households and challenge the inequalities that drive HIV/AIDS susceptibility and vulnerability, while restoring social relations and community institutions. When considering HIV/AIDS mitigation in relation to agriculture-based livelihoods in rural South Africa, women and their dependents need to be central. They play a major role in ensuring food security, while taking care of the sick and of children. Given the importance of agriculture in the lives of the rural poor, agriculture seems to be a logical entry point to address other aspects of the HIV/AIDS impact spectrum; it can play a catalyzing role to reduce susceptibility and vulnerability to HIV/AIDS.

The action-oriented part of the study shows that the ILA approach provides a rational and constructive process to agricultural innovation, with actual influence from poor and AIDS-affected households and other role players in agriculture and health. Knowledge sharing between stakeholders resulted in changes of thinking that might facilitate future innovation processes. Building ‘trust’ at the personal and institutional level was a key factor to responsive facilitation. The FLS is a promising method for application within the ILA approach to introduce conservation agriculture in combination with health education and capacity building. Various strengths were identi-
fied regarding participation, learning and empowerment. The practical and informal nature enabled people to participate actively, while working together on agriculture and nutrition allowed them to explore HIV/AIDS at their own pace and terms. Especially song, dance, visualisation and imagination encouraged participants to open up and speak out among others, while experimentation boosted people's confidence and enthusiasm. The practice of conservation agriculture helped the support group members to grow crops with limited means.

The study also reveals various weaknesses. The intensity of the program made it difficult for some members to participate as a result of poverty and HIV/AIDS-related illness and death, often further constrained by stigma, gender relations and violence. Moreover, despite signs of more openness and willingness to share experiences on HIV/AIDS, it remained difficult for participants to reflect critically; especially where groups were newly formed, and could not build on pre-existing relations. Even if an open and respectful environment among members is created there still is stigmatization and discrimination emanating from the broader community. However, the reconstruction of community institutions and social capital is not the main focus of the FLS method. The period of implementation was also too short to have a profound impact on economic and institutional aspects of empowerment, while conservation agriculture has its initial costs. Furthermore, the study reveals that effective cooperation among participants and stakeholders at the interface of agriculture and HIV/AIDS takes time, is fragile and sensitive to erosion.

The diversified and gendered vulnerability among households and the deterioration of ‘social fabric’ requires an interactive approach that addresses the underlying factors that drive the epidemic and its impact. A process-oriented approach based on trust and learning, such as the ILA, provides opportunities to explore the livelihood system and develop appropriate solutions together with small-scale farmers. However, in order to facilitate processes that reverse, rather than reinforce, social inequalities, stigma and discrimination, it needs a thorough understanding and where possible adaptation to the (social) context. The ILA approach seems particularly relevant in such a complex context.

To make interactive approaches to agricultural innovation in the context of HIV/AIDS more effective, the following key issues and strategies should be considered:

- In the context of HIV/AIDS, motivation is a key factor for participation In an environment of social inequalities, poverty, diseases, deaths, and violence it becomes less likely that people are willing to take risks and engage themselves in a process
with uncertain outcomes. Under these circumstances motivation is a key factor for participation. Success, learning and social dynamics, and a future – but realistic – vision were identified as key factors to stimulate motivation.

- **Importance of group-based, discovery learning, but need for diversification** The combination of experiential learning, group dynamics, and discussion, seems very appropriate to engage (illiterate) people actively in a learning process. The practical focus on farming enabled them to explore more sensitive issues as HIV/AIDS at their own pace and terms. But, some people still felt uncomfortable and some exclusion occurred. Therefore, a flexible approach is needed that is better adapted to people’s personal situation. Sometimes it may be more appropriate to form more homogenous subgroups; this can either take the form of mitigation strategies for specific vulnerable groups (gender/pro-poor) or be targeted to people living with HIV in particular.

- **Gender focus** Women continue to bear the brunt of the epidemic and to be highly vulnerable to HIV infection. This demands gender-based responses that focus on how the different social expectations, roles, status and economic power of men and women affect and are affected by the epidemic. Eventually both men and women, young and old, need to be involved in an interactive process in order to come to a shared understanding and agreement on underlying factors and strategies to address these.

- **Integration of an ARV component** Antiretroviral medicines may give other strategies the chance to work. Apart from saving lives, ARV treatment enables people to remain economically and socially productive. This may indirectly affect prevention strategies and reduce stigma. The ARV component was not linked to the project in Msinga, but the potential synergy between a project focused on food and nutrition security and ARV treatment in a resource-poor setting is obvious: HIV-infected members who have access to treatment become stronger and healthier again, while healthy food is needed for effective treatment.

- **It requires a diversified and holistic program of development interventions** Although farming seems an appropriate focus for improving food security and well-being in the context of HIV/AIDS, a broader focus needs to be considered. This may include a shift in focus from farming to other income-generating activities, but also programs that include social and money aid, and short-term food assistance (e.g. for those with several orphans and few productive adults). The challenge lies in identifying the most appropriate interventions, targeting the right individuals and households, and providing it at the right time for the right duration.
Simultaneous and coherent activities and strategies are required at four levels: the individual, the household, the community, and the institutional. For a highly contextualized issue, such as HIV/AIDS, it is important that interactive approaches take into account the needs of individuals and households, and create a supportive environment at community level. It requires safe spaces for discussion, material and institutional support, and awareness/education campaigns in the communities on HIV and AIDS. As power dynamics come into play when existing relations are challenged, it does not only require specific interventions and strategies at each level, but also synergy between activities.

More attention for factors that constrain or enable institutional collaboration. Differences in organisational background, culture and tradition among stakeholders may raise uncertainty, anxiety and defensive behaviour. The ILA approach emphasizes the importance of responsive facilitation and shared activities to improve mutual understanding, but negotiation processes may initially be necessary. It also requires capacity building, possibly with more effective collaboration with other ('strong') stakeholders. To achieve impact and innovation over the longer term, changes may be required in larger sets of relationships or institutional arrangements. This involves coalition building and advocacy at the policy level.

Competent process facilitation and management requires attention for ethical guidelines, sensitive methods, and management of relations at the network level. Facilitators need to steer the process, not the outcomes. They have to operate as mediator. Facilitators have to be respectful, empathizing, responsive, and show interest, compassion and trustworthy behaviour. It requires technical skills on (sustainable) agriculture and experiential learning, and a basic understanding of HIV/AIDS; the involvement of (local) professionals for technical back-up and information is encouraged. The sensitivity and emotional impact of HIV/AIDS emphasised the importance of ethical guidelines, sensitive methods, and the need for psychological support.

Cost-effectiveness factors cannot be ignored during the development stage. The ILA seems most effective in complex situations in specific contexts, but for purposes of up-scaling, out-scaling and institutionalisation, more experimentation is needed with technical and social innovations (e.g. related to self-organisation and management), self-financing mechanisms and micro-credit/savings schemes, and a stronger embedding within existing programs and structures.

Summary
When we relate the lessons of this study to the three main concepts of an interactive approach – as described in the theoretical framework of this thesis, i.e. participation, interdisciplinarity, and a system perspective – some interesting issues emerge.

**Participation** Two elements are important. Firstly, specific attention needs to be paid on what activities will motivate various stakeholders to participate. Secondly, the outcomes of a particular activity can act as a motivation factor for subsequent activities. This results in an interesting and stimulating iterative process of action and reflection, with a stronger emphasis on feasible intermediary and ‘measurable’ (self-evaluative) outcomes, which can be followed up and taken further in a continuous cycle of refinement and improvement. In this way, the action-spiral becomes a motivation-spiral for change, whereby each activity has an effect on the next activity. ‘Visibility’ of results is one of the major stimulating and driving forces to stay on track, but it may not be enough. It may be useful to look at what it is that makes people ‘tick’, what drives people, and how can we link that to broader development goals. In a similar way, we need to look more closely at institutions and organisations, what makes them ‘tick’, and what more do we need to do to motivate and inspire them to become involved.

**Interdisciplinarity** In an interactive process it might be better to speak of co-creation of knowledge where by various stakeholders are actively involved as part of a ‘community of practice’. This requires interaction and shared experiences in order to build up trust, confidence, and a common understanding. This demands a safe and ‘liberating’ environment that allows more sensitive and conflicting issues to be addressed. The study suggests that it might not always be the best strategy to discuss and address HIV/AIDS primarily within the context of health. It may be better to take up the discussion within the context of other domains, in this case agriculture through the establishment of food gardens. Although the domain of agriculture as an entry point is related to motivation, the activity has a more fundamental ‘liberating’ character, as it helps people to escape from their daily problems and obstacles. Shared experiences of success and failure may facilitate the co-creation of knowledge. However, this may not always be easy given the diversity among participants and between stakeholders. Therefore a relevant issue in the context of interdisciplinarity is that of ‘conflict’. The ILA approach strives to a common understanding and overlap in perspectives through dialogue, but it may have to include straightforward negotiation. In this respect, the study shows the importance of a process facilitator, who could re-direct the overlap-conflict spiral in a positive turn.
System The study confirmed the complexity of HIV/AIDS. This requires not only the active involvement of community people, but also from a variety of actors from different domains and level. However, at the level of institutions and organizations, there is often a sense of rigidity and ineffectiveness. This makes it difficult to realize a successful interactive approach with these institutions and organizations. In such a situation, the search for collaboration has to take place on the basis of the degree of flexibility. In first instance it makes most sense to start small and work together with those who are prepared to operate in a flexible way in a process of mutual learning. Complex problems may be characterised by ‘uncertainties’ related to a lack of knowledge, differences in problem perception and its solutions, and the lack of rules for cooperation at the institutional level. There is a need to pay attention to these underlying systemic factors and mechanisms that may prevent or hinder effective stakeholder collaboration. Joint problem solving through a process of mutual learning, cooperation and interaction, is a way to reduce these uncertainties. When enough momentum has been created it may be easier to involve other organizations. At the system level the management of a positive momentum spiral is crucial for success.

AIDS is entwined with a range of other stressors in rural South Africa and it is difficult to separate out the issue of the disease from other negative factors. A holistic response includes thinking and approaching HIV/AIDS and food insecurity within an integrated rural development strategy – this is sorely lacking in South Africa and would mitigate many of the associated issues around HIV and AIDS. A more focussed and explicit attention to concepts as the motivation spiral, the overlap-conflict spiral, and the momentum spiral may help in the discussion to improve interactive approaches in the context of HIV/AIDS. In this way, the interactive process becomes a more dynamic and ‘breathing’ process. It creates good-will, motivation, shared ideas and values, enabling to tackle tensions and conflicts. Tensions and conflicts in turn, can help to clarify issues, in order to develop better informed and more sophisticated interventions and policies in the context of HIV/AIDS.
Samenvatting

Het overschrijden van grenzen
Interactief Leren en Actie op het snijvlak van HIV/AIDS en landbouw

AIDS is een van de belangrijkste ontwikkelingsproblemen in Afrika ten zuiden van de Sahara. De HIV/AIDS pandemie is direct gerelateerd aan voedselzekerheid. HIV/AIDS vergroot voedselonzekerheid wanneer mensen zwakker worden en niet meer in staat zijn om deel te nemen aan het productieproces. Daarnaast kunnen armoede en voedselonzekerheid er ook toe leiden dat mensen risicovolle strategieën gaan toepassen om in hun levensonderhoud te voorzien.

Wetenschappers en ontwikkelingswerkers benadrukken het gebruik van geïntegreerde en interactieve benaderingen om de gevolgen van HIV/AIDS op de landbouw en rurale ontwikkeling te verzachten. In tegenstelling tot topdown benaderingen – die vaak gebaseerd zijn op positivistisch denken – kan met behulp van interactieve benaderingen een brede kennisintegratie worden gerealiseerd door participatie van en wederzijds leren tussen verschillende partijen. Resultaten zijn tot nu toe veelbelovend, maar interactieve benaderingen zijn relatief nieuw en vooral op het grensgebied van HIV/AIDS en landbouw is er weinig systematische kennis om op verder te bouwen.

Dit proefschrift heeft als doel om bij te dragen aan de (verdere) ontwikkeling van een conceptueel en methodologisch raamwerk voor interactieve benaderingen voor landbouwwinnovaties in de context van HIV/AIDS; dit om beter geïnformeerde, meer geavanceerde, en effectieve ontwikkelingsprogramma’s te realiseren die zich richten op voedselzekerheid en welzijn van arme en HIV/AIDS getroffen huishoudens. De centrale onderzoeksvraag van dit proefschrift is:

_Welke hoofdzaken en strategieën kunnen worden geïdentificeerd om effectieve interactieve benaderingen te realiseren voor innovatie in de context van HIV/AIDS en landbouw?_

Het onderzoeksontwerp bestaat uit twee elementen: 1) de identificatie van hoofdzaken in het ontwerp en implementatie van interactieve benaderingen voor landbouwwinnovatie in de context van HIV/AIDS; en 2) het praktisch testen van
geïdentificeerde methodologische elementen in de context van HIV/AIDS en landbouw; in dit geval het subdistrict van Msinga, een landelijk gebied met hoge HIV prevalentie in de provincie van KwaZulu-Natal in Zuid-Afrika.

In 2003, initieerde een gezondheidscentrum in Msinga in samenwerking met een landbouw NGO van de Universiteit van KwaZulu-Natal en het Athena Instituut van de Vrije Universiteit Amsterdam (VUA) in Nederland een actieonderzoek. ‘Spelers’ in de landbouw- en gezondheidssector werden bij elkaar gebracht om de gevolgen van HIV/AIDS op rurale huishoudens te verzachten. Het idee was om discussie te stimuleren onder leden, voornamelijk vrouwen, van drie ‘support’ groepen voor arme en HIV/AIDS getroffen huishoudens in Msinga, over hoe HIV/AIDS hun leven beïnvloedt, het bediscussiëren en onderhandelen van manieren om zichzelf te beschermen tegen HIV en de gevolgen van AIDS. Tevens was het idee om via discussie en experimenten voedselzekerheid en welzijn te realiseren op het niveau van huishoudens met behulp van landbouwwinnovaties.

Allereerst werd een conceptuele studie uitgevoerd om inzicht te krijgen in de belangrijkste lessen en uitdagingen met betrekking tot het ontwerp en de implementatie van interactieve benaderingen voor landbouwwinnovatie in de context van HIV/AIDS. Literatuuronderzoek betreffende interactieve benaderingen in de landbouw en het beheer van natuurlijke hulpbronnen laat zien dat een aantal principes en richtlijnen als hoofdzaken worden beschouwd voor een succesvolle implementatie. Deze zijn: een centrale rol voor kleinschalige boeren; toewijding aan een gezamenlijke visie; versterking van vertrouwensrelaties; facilitatie van sociaal en ervaringsleren; integratie van kennis; het versterken van coalitievorming; capaciteitsopbouw; en opschaling en institutionalisering; het vereist de toepassing van een actie-spiraal, waarbij planning, monitoring, en reflectie elkaar continu afwisselen; een variatie aan methoden en technieken, participatieve monitoring en evaluatie; en procesfacilitatie.

Hoewel HIV/AIDS deze condities niet lijkt te veranderen, onthullen persoonlijke ervaringen van onderzoekers, ontwikkelingswerkers, en voorlichters nieuwe en onvoorziene problemen: 1) Armoede – Een huishouden getroffen door HIV/AIDS ervaart toenemende beperkingen in tijd en middelen, terwijl de kwetsbaarheid voor andere stressfactoren toeneemt; 2) Diversiteit – Niet iedereen loopt hetzelfde risico om geïnfecteerd te worden met HIV of is even kwetsbaar voor de gevolgen van AIDS; daarnaast veranderen risico’s over tijd; 3) Stigma en gender – HIV/AIDS is een taboe en is diep geworteld in culturele normen en waarden en lokt stigma en discriminatie uit; dit treft vooral vrouwen, omdat zij niet alleen gevoeliger zijn voor HIV infectie dan mannen of jongens, maar ook kwetsbaarder zijn voor de gevolgen; 4) Mobilisatie
van stakeholders – Aangezien HIV/AIDS een gevoelig onderwerp is, ligt het initiatief voor interventies vaak bij buitenstaanders, terwijl andere belanghebbenden misschien niet eens ‘zien’ wat hun potentiële bedrage kan zijn; 5) Integreren van verschillende perspectieven – De grote variatie in relevante partijen impliceert toenemende verschillen in kennis, ideeën, geloof, betekenis, taalgebruik, en handelingspraktijken; 6) Innovatie(s) in reactie tot HIV/AIDS – De toename van gezinnen met wezen, jonge weduwen, en ouderen, vraagt om risicovermijdende strategieën en een focus op voedselzekerheid en het voorzien in een levensonderhoud; 7) Hoop, optimisme en zelfinitiatief – De onzekerheid en angst voor ziekte, de dood, en verdere armoede, leidt tot wanhoop, hulpeloosheid en depressies; 8) Additionele competenties van facilitatoren – De variatie in onderwerpen en nieuwe samenwerkingverbanden legt een grote claim op de kennis en vaardigheden van facilitatoren.

Om de uitkomsten en methodologische lessen van de conceptuele studie in de praktijk te testen, is het wenselijk om uit te gaan van een breed praktisch raamwerk voor interactief onderzoek. Een specifieke participatieve methodologie – de Interactive Learning and Action (ILA) methodologie – werd geselecteerd. Deze methodologie is geschikt voor het doel van innovatieontwikkeling in de landbouw op basis van wederzijds leren tussen verschillende partijen. De ILA voorziet in een set van principes en richtlijnen die moeten worden aangepast en gespecificeerd in de context waar het wordt toegepast. De ILA onderscheid vier fasen: 1) initiatie en voorbereiding; 2) het verzamelen, uitwisselen en integreren van data; 3) planning; en 4) het formuleren van projecten en implementatie. Deze fasen overlappen gedeeltelijk, en komen terug in de tijd. Op basis van de resultaten van de conceptuele studie werden een aantal aanpassingen gemaakt. Omdat de gemarginaliseerde positie van vrouwen en het zwijgen rondom HIV/AIDS als belangrijke zorgen werden gezien, benadrukte het project capaciteitsopbouw en organisatieontwikkeling onder vrouwen door middel van leren in een groepsverband (door gebruik te maken van de Farmer Life School); bovendien werd extra aandacht geschonken aan veiligheid en vertrouwelijkheid. Als onderdeel van de ILA-methodologie (fase 2) werd een beschrijvend-analytische studie uitgevoerd. De beschrijving van de probleemsituatie laat zien dat HIV/AIDS onderdaad de armoede en voedselonzekerheid versterkt. De epidemie heeft niet alleen een negatieve invloed op de humane middelen (gezondheid), maar ook op financiële, sociale, natuurlijke en fysieke middelen van bestaan; voedselonzekerheid was een van de belangrijkste problemen onder huishoudens die getroffen zijn door HIV/AIDS. Bovendien, leefden veel huishoudens in angst, ontkennings en wanhoop, terwijl misverstanden en mythes over HIV en AIDS veel werden aangetroffen. De studie toont echter ook aan dat psychosociale gevolgen en ‘coping’ strategieën, evenals
de machtsrelaties en uitsluiting van sociale netwerken, het leven van mensen op verschillende manieren beïnvloeden. Het is sterk afhankelijk van de specifieke situatie van het individu of huishouden in kwestie. Drie onderwerpen werden geïdentificeerd als kritieke gebieden van zorg: ‘gender’, toegang tot sociale uitkeringen, en toegang tot anti-retrovirale medicijnen. De toegankelijkheid van en controle overmiddelen lijkt problematischer in arme landelijke gebieden als gevolg van de beperkte infrastructuur, het ontbreken van informatie, een grote mate van ongeletterdheid, en traditionele normen en waarden.

Wat er uitsprong was HIV/AIDS-gerelateerde stigma. Stigma is wijdverspreid in Msinga en wordt in de praktijk gebracht door een diversiteit aan uitingen in het gezin, de gemeenschap en op institutioneel niveau. Het gebrek aan specifieke kennis, de associatie met immoreel gedrag, stereotyperingen en discriminatie verergeren de angst van mensen om zich te laten testen en om een seropositieve status openbaar te maken. Het resulteert in geïnternaliseerd stigma en zelfcorrigerend gedrag. Hoewel de vorm en inhoud van stigma varieert van de ene context tot de andere, zijn verschillende vormen van stigma met elkaar verbonden en ondersteunen zij systemen van sociale ongelijkheid en sociale controle. Dit treft vooral groepen in de samenleving die al kwetsbaar zijn, zoals vrouwen, jongeren, en de armen op het platteland. Zij zijn relatief ver verwijderd van dienstverlenende instellingen, terwijl het hen ontbreekt aan de politieke macht om zich te verzetten tegen de bestaande ongelijkheid.

Het is gebruikelijk dat huishoudens die het moeilijk hebben, hulp zoeken bij vrienden en buren. De sociale relaties staan echter onder druk als gevolg van HIV/AIDS. Dit wordt versterkt door geweld en beschuldigingen van hekserij. ‘HBC workers’, zogenaamde thuisverzorgers, spelen een cruciale rol in de gemeenschap van Msinga met betrekking tot het verzachten van de impact van HIV/AIDS en de gevolgen van stigma and discriminatie. Zij ondersteunen mensen die geïnfecteerd zijn met HIV niet alleen sociaal (en zelfs financieel), maar zij vormen ook de schakel tussen de gemeenschap en dienstverlenende instellingen. Op deze wijze stellen zij mensen die geïnfecteerd zijn met HIV of getroffen zijn door AIDS in staat om nieuwe netwerken op te bouwen.

Het vermogen van huishoudens en gemeenschappen om in hun toenemende behoeften te voorzien is beperkt. Er is ondersteuning nodig van de overheid en NGO’s om op andere problemen en de nieuwe behoeften, die gecreëerd zijn door de impact van HIV/AIDS, te reageren. De studie bevestigt de noodzaak om de bestaansbasis van een huishouden te herstellen en psychosociale problemen te adresseren. Het is belangrijk dat een interactieve en participatieve benadering rekening houdt met
de verschillen in de gevolgen van HIV/AIDS voor huishoudens, en de factoren die daarvoor verantwoordelijk zijn. Wanneer we HIV/AIDS-interventies richten op gemeenschappen op het platteland, dan is het van belang dat vrouwen (en degenen die van hen afhankelijk zijn) centraal staan. Vrouwen zijn verantwoordelijk voor de voedselzekerheid en de zorg voor zieken en kinderen in het gezin. Gegeven het belang van landbouw in het leven van de armen op het platteland, lijkt landbouw een logische ingang; het kan een katalysierende rol vervullen om de kwetsbaarheid voor HIV/AIDS te reduceren.

Het actieoriënteerde deel van de studie laat zien dat de ILA methode voorziet in een rationeel proces voor landbouwinnovatie, resulterend in daadwerkelijke invloed van arme en AIDS getroffen gezinnen, en van spelers in de landbouw- en gezondheidssector. Er was sprake van kennisuitwisseling tussen stakeholders, die resulteerde in veranderingen in denken onder deelnemers en belanghebbende partijen. Dit zou toekomstige innovatieprocessen kunnen vergemakkelijken. De ‘Farmer Life School’ is een veelbelovende methode voor toepassing binnen de ILA benadering om duurzame landbouw (‘conservation agriculture’) te introduceren in combinatie met gezondheidsseducatie en capaciteitsopbouw. Verscheidene sterke punten werden geïdentificeerd met betrekking tot participatie, leren en ‘empowerment’. De praktische en informele aanpak stelde mensen in staat om actief deel te nemen, terwijl het samenwerken op het gebied van landbouw en voeding hen in staat stelde om het onderwerp van HIV/AIDS verder te ontdekken in hun eigen tempo en op hun eigen voorwaarden. Vooral zang, dans, visualisatie en verbeelding stimuleerde deelnemers om zich open te stellen en zich uit te spreken tussen anderen, terwijl het experimenteren het zelfvertrouwen en enthousiasme een impuls gaf. De praktijk van duurzame landbouw hielp hen om met beperkte middelen gewassen te telen. Het scheppen van vertrouwen was een belangrijke factor voor het faciliteren van veranderingprocessen.

De studie maakt ook verschillende zwakke punten zichtbaar. De intensiteit van het programma maakt het moeilijk voor sommige leden om deel te nemen. Daarbij zijn armoede en HIV/AIDS gerelateerde ziekten en sterfgevallen – vaak versterkt door beperkingen vanwege stigma, gender, en geweld – belangrijke belemmerende factoren. Daarnaast bleef het, ondanks tekenen van meer openheid en de wil om ervaringen met HIV en AIDS te delen, moeilijk voor deelnemers om kritisch te reflecteren, vooral als de groepen nieuw waren opgezet en niet voort konden bouwen op bestaande relaties tussen leden. Zelfs als een open en respectvolle omgeving tussen leden is gecreëerd, dan is er altijd de kans op stigma en discriminatie van de ‘bredere’ gemeenschap. Het reconstrueren van instituties en sociale relaties staat echter niet centraal in de FLS. Daarnaast was de periode van implementatie te kort om zichtbaar
invloed te hebben op economische en institutionele aspecten van ‘empowerment’, terwijl technologische veranderingen initiële kosten met zich meebrengen. Tenslotte laat de studie zien dat effectieve samenwerking tussen deelnemers en belanghebbende partijen op het snijvlak van landbouw en HIV/AIDS tijd nodig heeft en fragiel is.

De diversiteit in kwetsbaarheid onder huishoudens en de verslechtering van sociale relaties vraagt om een interactieve benadering die de onderliggende factoren van de epidemie en de gevolgen daarvan adresseert. Een procesgeoriënteerde benadering, gebaseerd op vertrouwen en leren, biedt mogelijkheden om problemen samen met de kleinschalige boeren te identificeren en te analyseren en gezamenlijk geschikte oplossingen te ontwikkelen. Om processen te faciliteren die sociale ongelijkheid, stigma en discriminatie terugdraaien, in plaats van versterken, is echter een grondig begrip van en waar mogelijk aanpassingen aan de (sociale) context nodig. De ILA benadering lijkt geschikt voor toepassing in een dergelijke complexe context..

Om interactieve benaderingen voor landbouwinnovatie in de context van HIV/AIDS effectiever te maken, moeten de volgende hoofdzaken en strategieën worden overwogen:

- **In de context van HIV/AIDS is motivatie een cruciale factor** In een omgeving van sociale ongelijkheid, armoede, ziekte, sterfte, en geweld, is het minder waarschijnlijk dat mensen bereid zijn om risico’s te nemen en mee te doen in een proces met onzekere uitkomsten. Onder deze omstandigheden is motivatie een essentiële factor voor participatie. Verschillende factoren zijn geïdentificeerd om motivatie te stimuleren: (vroeg) succes, leren en positieve groepsprocessen, en een toekomstvisie.

- **Belang van een groepsbenadering, ervaringsleren, maar aandacht voor diversificatie** De combinatie van ervaringsleren, groepsdynamiek en discussie lijkt zeer geschikt om ongeletterde deelnemers actief te betrekken in een leerproces. De praktische focus op landbouw stelde mensen in staat om gevoelige onderwerpen zoals HIV/AIDS in hun eigen tempo en op hun eigen voorwaarden te ontdekken. Sommige deelnemers voelden zich echter nog steeds ongemakkelijk; tot op zekere hoogte werden mensen buitengesloten. Daarom is een flexibele benadering gewenst die beter is aangepast aan de persoonlijke situatie van mensen. Soms is het beter om meer homogene groepen te vormen. Dit kan de vorm aannemen van strategieën voor specifieke kwetsbare groepen (gender/pro-poor) of gericht zijn op mensen die geïnfecteerd zijn met HIV.
• **Een focus op de relatie tussen mannen en vrouwen** Vrouwen ondervinden, meer dan mannen, de gevolgen van de AIDS epidemie en zijn kwetsbaarder voor HIV-infectie. Dit vraagt om een focus op ‘gender’ en hoe verschillende sociale verwachtingen, rollen, status, en economische macht van mannen en vrouwen invloed hebben op en beïnvloed worden door de epidemie. Uiteindelijk moeten zowel mannen als vrouwen, jongeren en ouderen, betrokken worden in een interactief proces om te komen tot een gedeeld begrip en overeenstemming over onderliggende factoren en strategieën om deze te adresseren.

• **Het integreren van een ARV component** Antiretrovirale medicijnen bieden andere strategieën een betere kans van slagen. Behalve het redden van levens, stelt ARV-behandeling mensen in staat om economisch en sociaal productief te blijven; men kan weer hopen op een toekomstig leven. Dit kan indirect van invloed zijn op preventiestrategieën en de reductie van stigma. Er was geen ARV-component verbonden aan het project in Msinga. De potentiële synergie is echter duidelijk. HIV-geïnfecteerde leden die toegang hebben tot behandeling worden sterker en gezonder, en gezonde voeding is belangrijk voor een effectieve behandeling.

• **Het vraagt om een gedifferentieerd en holistisch programma van ontwikkelings-interventies** Hoewel landbouw een geschikte focus lijkt om voedselzekerheid en welzijn in de context van HIV/AIDS te verbeteren, moet een bredere focus worden overwogen. Dit kan een verandering zijn naar andere inkomensgenererende activiteiten, maar ook programma’s met sociale en financiële ondersteuning, en voedselhulp op de korte-termijn (bijvoorbeeld voor gezinnen met meerdere wezen en weinig productieve volwassenen). De uitdaging ligt in het identificeren van de meest geschikte interventies, gericht op de juiste individuen en gezinnen, op het juiste moment, voor de gepaste duur.

• **Coherente activiteiten en strategieën zijn gelijktijdig nodig op vier niveaus: het individu, het huishouden, de gemeenschap, en instituties** Voor een onderwerp dat sterk contextgebonden is, zoals HIV/AIDS, is het belangrijk dat interactieve benaderingen rekening houden met de behoeften van individuen en huishoudens, en brede steun creëren op gemeenschapsniveau. Het vraagt om een veilige omgeving voor discussies, materiële en institutionele ondersteuning, en educatieve campagnes op het gebied van HIV en AIDS. De studie toont echter ook aan dat machtsdynamiek in het spel komt wanneer bestaande relaties in de familie, de gemeenschap of instituties op de proef worden gesteld. Dit vereist niet alleen specifieke interventies en strategieën op elk niveau, maar het benadrukt ook de noodzaak voor synergie tussen activiteiten.
• Meer aandacht voor factoren die institutionele samenwerking verhinderen of vergemakkelijken. Verschillen in achtergrond, cultuur en traditie tussen (belanghebbende) partijen kunnen leiden tot onzekerheid, ongerustheid, en defensief gedrag, terwijl verschillen in capaciteit, kennis en vaardigheden tussen organisaties in een samenwerkingverband spanningen kunnen veroorzaken over elkaars rol. De ILA benadering benadrukt het belang van ‘responsieve’ facilitatie en gedeelde activiteiten om wederzijds begrip te verbeteren, maar onderhandelingsprocessen kunnen noodzakelijk zijn om verschillen te reduceren. Het vraagt ook om capaciteitsopbouw onder deelnemende organisaties, mogelijk in combinatie met effectievere samenwerking met andere (‘sterke’) partijen. Om effect en innovatie op de langere termijn te waarborgen, kunnen veranderingen nodig zijn in grotere netwerken van relaties en institutionele verbanden. Dit vraagt om aandacht voor coalitievorming en lobby op beleids- en politiek niveau.


• Factoren van kosteneffectiviteit verdienen meer aandacht in het ontwikkelingsstadium. De ILA lijkt vooral geschikt voor complexe situaties, maar voor het opschalen en institutionaliseren van het proces, is meer ervaring nodig met: technologische en sociologische vernieuwingen, (bijvoorbeeld gerelateerd aan zelforganisatie en management), mechanismen voor zelffinanciering en microkredieten/spaarschema’s, en het integreren van het proces in bestaande programmas en structuren.

Wanneer we de lessen van deze studie relateren aan de drie hoofdconcepten van een interactieve benadering – zoals beschreven in het theoretisch kader van dit proefschrift, namelijk participatie, interdisciplinariteit, en een systeem benadering – dan komen een aantal interessante kwesties naar voren.
Participatie Twee elementen zijn belangrijk. Ten eerste, is het van belang dat specifieke aandacht wordt besteed aan welke activiteiten verschillende belanghebbende partijen zullen motiveren om deel te nemen. Ten tweede, kunnen de uitkomsten van een bepaalde activiteit fungeren als een motivatiefactor voor volgende activiteiten. Dit resulteert in een interessant en stimulerend interactief proces van actie en reflectie, met meer aandacht voor haalbare intermediaire en meetbare (zelfevaluatieve) uitkomsten, die opgevolgd en verder ontwikkeld kunnen worden in een continu cyclisch proces van verfijning en verbetering. Op deze manier wordt de actiespiraal een motivatie-spiraal van verandering, waarbij elke activiteit een effect heeft op de volgende activiteit. Het zichtbaar maken van resultaten is een van de belangrijkste factoren om mensen te motiveren, maar het is niet altijd genoeg. Het is belangrijk om na te gaan wat mensen beweegt, en hoe individuele drijfveren gekoppeld kunnen worden aan bredere ontwikkelingsdoelstellingen. Op een vergelijkbare manier moeten we nagaan wat er gedaan kan worden om organisaties and instituten te motiveren om deel te nemen.

Interdisciplinariteit In een interactief proces is het wellicht beter om te spreken van coproductie van kennis, waarbij verschillende partijen actief betrokken worden bij een ‘community of practice’. Dit vraagt om interactie en gedeelde ervaringen om vertrouwen en zelfbewustzijn te kweken, en een gedeeld begrip. Het vraagt om een veilige en een ‘bevrijdende’ omgeving die ruimte biedt om gevoelige en conflicterende onderwerpen te adresseren. De studie suggereert dat het niet altijd de beste strategie is om HIV/AIDS vanuit het gezondheidsdomein te bediscussiëren en te adresseren. Het is misschien beter om de discussie op te pakken op een ander terrein, in dit geval het domein van de landbouw. Hoewel landbouw als ingangspunt gerelateerd is aan motivatie, heeft de activiteit een meer bevrijdend karakter, omdat het mensen helpt om te ontsnappen aan hun dagelijkse problemen en obstakels. Gedeelde ervaringen van succes en falen kunnen bijdragen aan gedeelde kennisvorming. Dit is echter, niet altijd eenvoudig vanwege de diversiteit tussen deelnemers en tussen partijen. Daarom is ‘conflict’ een relevant begrip in de context van interdisciplinariteit. De ILA benadering streeft naar een gedeeld begrip en overlap in perspectieven door dialoog, maar het kan zijn dat directe onderhandeling technieken noodzakelijk zijn. Het toont het belang van een procesfacilitator, die de overlap-conflict spiraal een positieve wending kan geven.

System De studie bevestigt de complexiteit van HIV/AIDS. Dit vraagt niet alleen om actieve betrokkenheid van mensen uit de gemeenschap, maar ook van verschillende sectoren en niveaus. Met name op het niveau van instituten en organisaties is er vaak sprake van rigiditeit en ineffectiviteit. Dit vormt vaak een hindernis voor het
implementeren van een interactieve benadering. In dergelijke situaties, moet de zoektocht naar samenwerkingspartners plaatsvinden op basis van flexibiliteit. Het is beter om klein te beginnen met diegenen die bereid zijn op een flexibele manier samen te werken. Complexe problemen worden gekenmerkt door ‘onzekerheden’, zoals het gebrek aan kennis, verschillen in probleemperceptie en oplossingen, en het gemis aan procedures voor samenwerking op het institutionele niveau. Het gezamenlijk oplossen van problemen door een proces van wederzijds leren, samenwerking en interactie is een manier om deze onzekerheden te verminderen. Wanneer voldoende ‘momentum’ is gegenereerd, kan het gemakkelijker zijn om andere organisaties te betrekken. Op het systeem niveau is het faciliteren van een positieve *momentum-spiraal* cruciaal voor succes.

A long journey has come to an end. However, the road could not have been completed without the encouragement, support, and help from many others. Here, I thank those who directly or indirectly have contributed to my thesis. A few people I like to mention by name.

First and foremost, I thank my promotor Prof.dr. Joske Bunders and my copromotor Dr. Jacqueline Broerse. Joske gave me the opportunity to follow my dreams and to work in a development context while pursuing a PhD. Although it took some time before the actual study took off, she always believed in me and encouraged me to continue. I especially value her honesty and creative and stimulating ways of thinking. Jacqueline has been my direct supervisor since the start of the project. I feel fortunate in having a supervisor who understood me so well, she really helped me by strengthening my capacities to deal with the many obstacles inherent in such a complex process as a PhD.

I am very grateful to the members of my thesis committee: Prof.dr. Bart van den Borne, Prof.dr. Cees Leeuwis, Prof.dr. Anke Niehof, Dr. Tim Quinlan, Prof.dr. Paul Richards, and Prof.dr. Gert-Jan van der Wilt. Their critical reading and remarks on the original manuscript have made a positive contribution. I especially thank Paul Richards, who encouraged me to pursue a PhD from the start, and with whom I had so many stimulating discussions on HIV/AIDS, agriculture, diseases, and ecological theories. I thank Tim Quinlan, not only for reading my thesis, but also as a reviewer of the original proposal of the action research project in Msinga on behalf of the RENEWAL program of the International Food Policy Research Institute (IFPRI). Monique Salomon, Scott Drimie, and Pamela Wright, are appreciated for their feedback and exchange of thoughts on parts of the original manuscript.

This research would not have been possible without the financial contribution of the IFPRI-RENEWAL program. The call for proposals in 2003 for research on the linkages between HIV/AIDS, agriculture, and food security gave me the prospect to conduct an action research project in Africa. I especially welcome the program for its willingness
to move beyond understanding the relation between HIV/AIDS and agriculture, and that it actually stimulates new types of interdisciplinary and action-oriented research to gain more insight in how to respond to the HIV/AIDS pandemic.

I am most grateful to my friends and colleagues in South Africa. First, I like to thank Monique Salomon, the former director of the Farmer Support Group (FSG). Monique gave me the chance to liaise with her staff and provided me not only an office, but a ‘home’ in the pleasant surroundings of Pietermaritzburg, at the campus of the University of KwaZulu-Natal. Monique is an excellent researcher and above all someone who stimulates and motivates. She opened my eyes for the ethical aspects of the study. I have really enjoyed her support in South Africa as colleague and a true friend with common roots. My thanks are extended to my other colleagues at FSG, with whom I shared so many joyful, but unfortunately also some sad moments. In addition, I owe my gratitude to the people who have contributed in various ways to the research and the project in South Africa: Rauri Alcock, Scott Drimie, Diane Gibson, Claire Kerry, Makhosi Mweli, Corrie du Preez, Heidi van Rooyen, and the members of the Think-Tank on HIV/AIDS and food security. Words of appreciation are for Franz Fischer and his family for the many relaxing moments in South Africa.

In particular, I wish to thank the members of the Msinga team on ‘HIV/AIDS and food security’ for their contribution to this project: Michael Malinga, Vusi Sithole, Mpilo Khanyile, B.J., and Maxwell Mudhara – who is currently director of FSG. Linda Zalisa is appreciated for assisting me and especially the students in the project for translation and guidance throughout the study. Special words are devoted to Michael and Mpilo, who worked as community facilitators in the project. Michael started this adventure with me. I enjoyed his stories about the life in Msinga, the tribal-wars, his life in Jo’burg and the visits to his family (and especially seeing his late grandmother). I have always admired his devotion to the people in Msinga and the positive energy he managed to create. I am very pleased that he has accepted my request to be my first Paranymph during the public defense of this thesis. Mpilo is an example of the ‘strength’ of women in Msinga. She surprised me with her technical skills, her self-awareness, her poems and her stunning dancing performance. She invited us to stay with her family during various community visits, for which I especially thank her mother. Finally, I am grateful to Gail du Toit – not particularly your silence before the storm – who was always willing to answer my questions and to sort out some last minute requests on financial, logistical or personal matters.
Except for my colleagues at FSG, I need to mention a few others in Msinga. First I owe my thanks to the staff from Sinozwelo drop-in center, and in particular Mr. Philani Madi, who engaged in this challenging process. I admire Dr. Tony Moll of the Church of Scotland Hospital. Rarely have I seen a Medical Doctor with so much devotion, eloquence, and willingness to understand the daily problems of people’s lives, and be ready to share his thoughts and time with us. I am grateful to the HBC workers in Msinga, who, despite the stigma and discrimination affecting them, form an example of the compassion and solidarity which is needed to overcome the adversaries of HIV/AIDS. Mary Mahlangu is appreciated for her effort to support and supervise the HBC workers and her participation in interviews. Special thanks are extended to the members of the support groups who were always willing to share their often private stories and who treated us as one of their own.

Furthermore, I have to refer to my colleagues in the Netherlands. The Athena Institute has been a safe-heaven for me where I could find time to write and focus on the research without the distraction of the practical and logical aspects of the project in South Africa. Despite the changes in staff and even relocation of the institute during my regular stays abroad, it felt always very familiar – although new staff may have questioned ‘Who is this guy?’. Without mentioning everyone, I thank Barbara, Franciska, Marjolein, Ciska, Tjard, and Balram, who were there for me from the start, and Frank, Anneloes, Annahoes, Roy, Jackie, Frea, Eric, Martijn who were willing ‘ears’ during the later stages; and Saskia, who helped me out during the final phase. I like to thank Prof.dr. Joost Ruitenberg in particular for introducing me to Joske Bunders and her department. Various Master-students participated in the study in Msinga. I am grateful to Irma van Diepen, Roos Spanjers, Maylin Meincke (VU University) and Margriet Bredewold (Wageningen University) for their contribution to the research that has been the basis of this thesis. I hope they will enjoy reading my thesis and that it brings back some positive memories from South Africa and the people they worked with.

Finally, I thank my friends and family. First I am lucky to have some friends, who, without being intrusive, regularly reminded me about my PhD – and in particular the party to come. But they knew, that it would come, some day. My dad and family may have asked themselves what exactly it is what I am doing, but they also gave me the freedom and encouragement to do what I stand for. For this I am especially thankful to my mom, who may not be among us, but she will be in my heart for as long as I live.
I am happy that my brother Louis has accepted to be my second Paranymp during the public defence of this thesis on behalf of my family. Last, but not least, I am grateful to my Ha. I cannot wish for a better companion and friend. But she is especially my girlfriend, for the love we share. I thank her for supporting me throughout my PhD and especially during the last few months.

A journey has come to an end. But it also feels like the start of new beginning. As for those families who are coping with HIV/AIDS, I hope that the roll-out of ARV medicines will create new opportunities and that a future life worth living for can be anticipated again. As for me, I will cherish my experiences from South Africa and the members of the support groups in Msinga. That they may help me to make the right decisions on new journeys to come. I thank you all.
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From 2002 until 2007, he worked at the Athena Institute (for research on innovation and communication in health and life sciences), VU University Amsterdam (the Netherlands). He participated in an action research project to improve food security and well-being among poor and HIV/AIDS-affected households in South Africa. As researcher/facilitator he was responsible for the methodological aspects of the project, the supervision of Master-students and dissemination of research findings. He was also closely involved in the development and facilitation of training workshops and networking with relevant stakeholders. Six months per year, he was based at an agricultural NGO for small-scale farmers linked to the University of KwaZulu-Natal. The outcome of this project has resulted in this PhD-thesis on interactive approaches to innovation development at the interface of HIV/AIDS and agriculture.

Except for his work in South Africa, he has worked for short periods in Kenya, Vietnam and Thailand on various public health issues. He has a special interest in the interface between biological/technical sciences and society, and in the role of action research and ‘learning networks’ in order to come to more effective and efficient strategies to improve the lives of disadvantaged groups. He currently lives and works in Hanoi, Vietnam.