Similarities and differences in the community response to HIV and AIDS in Matabeleland South and Manicaland

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## 1. Introduction

Rural African communities provide an important space for supportive resources to circulate and play a hugely important role in our fight against HIV and AIDS (Frumence et al., 2010; Gregson et al., 2011; Pronyk, Harpman, Morrison, Hargreaves, & Kim, 2008) as well as in caring for those affected (Campbell et al., 2012; Skovdal, Campbell, Nhongo, Nyamukapa, & Gregson, 2011; Skovdal, Mwasiaji, Webale, & Tomkins, 2010). A number of policy documents acknowledge the necessity of involving communities in HIV prevention, care and mitigation. An example is the UNAIDS 'five-pillar treatment 2.0' report (2010), which outlines the way forward in HIV treatment and prevention. UNAIDS states that — 'Community-based approaches to build trust, protect human rights and provide opportunities for socialization directly improve the ability of people to use HIV services and to benefit from antiretroviral therapy and prevent new infections'. In the context of support for HIV-affected children, UNICEF (2010) emphasizes the need for community involvement when considering the needs of HIV-affected children, stating that — 'Strengthening families caring for HIV-affected children, will not be possible without significant investment in social welfare systems and communities'. Similarly, and reflecting the commission of this report, the World Bank has also pointed towards the importance of community involvement in the HIV response. They draw on the community asset framework (Moser, 1998), arguing that by motivating all members of a community provides the opportunity to utilize a variety of skills and abilities, which in turn improves ownership and increases sustainability (World Bank 2011).

Over the years, researchers from the Manicaland HIV/STD Prevention Project have sought to pinpoint the complex social relationships that govern health and well-being (e.g., Gregson, Terceira, Mushati, Nyamukapa, & Campbell, 2004; Nhamo, Campbell, & Gregson, 2010; Skovdal, et al., 2011). Against this background, and, in the interest of encouraging greater community involvement in international health and development, the Manicaland HIV/STD Prevention Project, at the request of the National AIDS Council and the World Bank, revisited its data bank to explore ways in which local community group membership facilitates (or hinders) the development of a context where community members can work collaboratively to achieve optimal prevention, care and treatment – including behaviour change, care of the sick,

acceptance, kindness (vs. stigma) and practical support and assistance for the affected. What emerged was that community contexts, characterised as 'HIV competent', can play a key role in optimising access to prevention, care and treatment services, adherence to treatment, as well as access to external sources of health and welfare support and assistance where these exist.

These are important findings, with significant implications for policy and practice that enable us to identify the processes and resources required to build supportive community contexts for HIV-affected community members. However, as human health and well-being is conditioned by the social, political and environmental circumstances that shape the choices and decisions of individuals and communities (Thomas-Slayter & Fisher, 2011), the pathways between community involvement and HIV prevention, mitigation and care, should be understood with an appreciation of the contextual factors that facilitate or impede the community response to HIV (Campbell & Cornish, 2010; Skovdal, et al., 2011).

It is against this background and in the interest of assessing the relevance and generalizability of the findings from Manicaland, Zimbabwe, that researchers from the Manicaland HIV/STD Prevention Project, in collaboration with the National AIDS Council (NAC), set out to explore the community response to HIV in another context of Zimbabwe, namely Matobo District of Matabeleland South. Matobo District was chosen for this study because it is culturally and geographically very different from the districts participating in the Manicaland study. Whilst both Matobo district and the districts of Manicaland Province are experiencing the devastating impact of the HIV epidemic and have a network of international and local organisations working in the areas of HIV prevention, mitigation and care, the geographical differences between Matabeleland South (dry and rugged) and Manicaland (fertile and temperate) mean that HIVaffected households have got different needs for the organisations to attend to in the response to HIV. Matobo District has also been the recipient of substantial support through the multidonor Expanded Support Programme (ESP). ESP has sought to strengthen and broaden Matobo's response to HIV and AIDS, primarily through the funding of basic health care and antiretroviral therapy and the capacity building of the administrative management of HIV and AIDS responses.

As this study seeks to inform the on-going strategic planning exercise by the National AIDS Council of Zimbabwe, the research question guiding this report is: What are the similarities and differences in the community response to HIV in Matabeleland and Manicaland?

# 2. Methodology

This qualitative study forms part of an on-going study which was granted ethical approval from the Medical Research Council of Zimbabwe (A/681) and Imperial College London (ICREC\_9\_3\_13). Informed and written consent was gathered from all research participants on the condition that their identity would not be revealed. Therefore, we have used pseudonyms throughout this report.

### 2.1 Study area and sampling

Matobo District has a population of 110 000 people and an HIV prevalence rate amongst women attending antenatal care at District clinics of 20%. The District has managed to enrol 3 623 people living with HIV or AIDS onto antiretroviral therapy and has identified a total of 9 600 orphaned children – the majority of whom have been orphaned by AIDS and AIDS-related illnesses. Typical to the Matabeleland South Province, much of Matobo is arid, making cattle and goat keeping the primary source of income for residents in northern parts of the District. The south of the District has greater opportunities for small-scale and subsistence farming. The District borders South Africa to the south and Botswana to the west, whose industry, cash crop farming and mining companies attract a significant number of Matobo District, the migration of spouses presents serious challenges to HIV prevention, mitigation, treatment and care services, with some men discontinuing their treatment, and with husbands and wives having different levels of exposure of HIV services available to them.

Matobo District currently has 19 international (e.g., Save the Children Norway, Mildmay, Red Cross and World Vision) and local (e.g., Maranatha, Sikhethimpilo and Jairos Jiri) organisations that are collaborating with community members and groups. In addition to HIV work, many of

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these organisations also attend to the water and food shortages experienced by the people of Matobo.

A total of 91 community group members participated in this study through 9 focus group discussions. The participants were recruited by researchers from the Biomedical Research and Training Institute in consultation with community guides and a representative from the District AIDS Action Committee. Each focus group discussion was made up of members from a social group, which was carefully selected to reflect the kind of community group members participating in our Manicaland study. The social groups participating in this study include a church group, AIDS support group, burial society, rotating credit society, a women's group, sports club, youth group, co-operative and a farmer's group. All participants were over the age of 18.

### 2.2 Data collection and analysis

To tease out similarities and differences between Manicaland and Matabeleland South, key findings from Manicaland (Technical Reports 1-9)<sup>1</sup> were grouped into five broad thematic areas (see Figure 1), which were subsequently used to frame the structure of the interviews and examination of Matabeleland South data.

An HIV competent community is a community context where:

- 1. **Group membership and dialogue** encourage members to engage with HIV prevention, mitigation and care efforts
- 2. Community strategies are in place to support people affected by HIV
- 3. **Networks and partnerships** mobilize and make available much needed resources for the community response to HIV prevention, mitigation and care
- 4. **Community strengths and resources** are recognized and drawn upon in the community response to HIV prevention, mitigation and care
- 5. **Obstacles and barriers** are acknowledged and considered in responses to HIV.

Figure 1: Thematic Framework guiding data collection and analysis

<sup>&</sup>lt;sup>1</sup> Imperial College London and London School of Economics and Political Science. Social Capital and AIDS Competent Communities: Evidence from eastern Zimbabwe. Technical Reports 1-9 submitted to the World Bank. August 2011.

From each of the 9 different social groups participating in this study, we interviewed group members through in-depth interviews (IDIs) and focus group discussions (FGDs) (see Table 1). The individual and group interviews lasted approximately 90 and 120 minutes respectively and were guided by a topic guide that explored issues and topics that fall within the framework listed in Figure 1. The interviews were conducted by trained and experienced researchers with Ndebele as their first language. To compensate for their valuable time, we provided each participant with two bars of soap, lunch and reimbursement of transport costs.

Type of informants	IDIs	FGDs	Total
AIDS support group members	2 females, 1 male	1 (8 females and 1 male)	12
Burial society group members	2 females	1 (4 females and 2 males)	8
Church group members	1 female, 1 male	1 (11 females)	13
Cooperative members	1 female	1 (7 females and 1 male)	9
Farmers group members	2 females, 1 male	1 (4 females and 5 males)	12
Savings and lending group members	3 females	1 (5 females and 1 male)	9
Soccer club members	3 males	1 (8 males)	11
Women's group members	2 female	1 (4 females)	6
Youth group members		1 (5 females and 5 males)	10
Total no. of participants	19	9 (71 participants)	90

#### **Table 1:** Participant characteristics

Transcripts were translated from Ndebele to English and imported into Atlas.Ti, a qualitative software package designed for qualitative data analysis. Informed by the thematic framework (see Figure 1), the coding was done in an iterative process allowing for both *a priori* reasoning and surprises. The coding framework emerging from this qualitative analysis, which will guide our discussion of findings, can be found in Appendix 1. The framework also includes exemplary text segments derived from the interviews to provide thick description of the findings. As our discussion of findings is structured according to our coding framework, we encourage readers to read the coding framework alongside our discussion of findings. Although 'grounded' and inductive qualitative research is preferred within the social sciences, the framework approach we adopted for the data analysis of this report is useful in applied and policy focused research where the objectives are set in advance (Pope, Ziebland, & Mays, 2000).

We will now proceed to discuss findings emerging both from the current Matabeleland study (see Appendix 1) and from the Manicaland technical reports 1 to 9. In our interest to highlight

similarities and differences, we juxtapose key findings from both provinces drawing on the aforementioned data sources.

# 3. Review and discussion of findings

Although Manicaland and Matableland South are both provinces of Zimbabwe, there are distinct differences between the two provinces. The most striking difference to an outsider relates the differences in vegetation and rainfall between the provinces. As Figures 2 and 3 illustrate, Manicaland is slightly cooler and experiences more steady rainfalls, leaving it lush and fertile. Matabeleland South on the other hand is hot and water is in short supply. As a result, opportunities for subsistence farming vary and people are likely to adopt different strategies for food and income generation.



Figure 2: Manicaland Province

Figure 3: Matabeleland South Province

Manicaland and Matabeleland South are also inhabited by different ethnic groups with distinct cultural practices and languages. Manicaland is predominantly inhabited by SaManyika (Shona) people. Matabeleland South is predominantly inhabited by the Ndebele people.

Although mining for gold and other resources is found in both provinces, the lack of rain in Matabeleland makes industry difficult. Manicaland on the other hand benefits from tea and coffee estates as well as a healthy tree logging industry. The two provinces therefore have different migration patterns. In Matabeleland, it is not uncommon for men to migrate for work, many of whom go to neighbouring South Africa or Botswana to look for work. Labour migration from Manicaland is also common but there is also substantial internal migration and the study communities receive large numbers of migrant labourers from Mozambique and elsewhere in Zimbabwe who come to work in the thriving estates. These differences in movement and opportunities for food and income generation are likely to have a significant impact on how communities experience HIV.

With this in mind, we now seek to identify similarities and differences between community responses to HIV, exploring the generalisability and variability in HIV competence.

# 3.1 Group membership and dialogue encourage members to engage with HIV prevention, mitigation and care efforts

Throughout Zimbabwe, hardship historically has been dealt with through tight social networks and lineages. HIV and AIDS has placed new pressures on many rural families and contributed to the breakdown of these social networks and lineages. Drawing on traditional values, there has been a surge in group formations, reviving collectivist responses to hardship. But in what ways do group membership and dialogue encourage community members to respond to the HIV epidemic?

#### 3.1.1. Manicaland Province

In Manicaland, community groups were observed to be spaces for dialogue where health damaging social norms can be challenged and where group members can openly share personal experiences and HIV information – reducing stigma and misconceptions of HIV. In Manicaland, groups were also found to foster a sense of agency and confidence amongst group members, enabling them to i) translate medical information and technical terms into locally appropriate terms, and ii) identify a sense of common purpose and plans of action. These factors can (although not always) result in less risky behaviours, health-enabling attitudes, feelings of solidarity and mutual support (for people within the group and other affected by HIV and AIDS) and better use of HIV services. The potential of social spaces in reducing the spread of HIV emerged from our Manicaland survey data (covering the period 1998-2003), which found

uninfected women with HIV and members of community groups to be less likely, compared to other women, to have become infected. The opposite however was true for men participating in community groups, who tended to have a higher risk of having become infected – possibly explained by men joining groups where the dialogue is not about HIV and where the activities they engage in are less conducive to positive outcomes. Some of the limitations of group membership observed in Manicaland include the dissemination of false HIV information, which can reinforce myths and a sense of helplessness.

#### 3.1.2. Matabeleland South Province

The community group response to HIV is not dissimilar in Matabeleland South. What emerged from the interviews is that the dialogue that takes place within community groups is i) often characterised by female qualities; ii) enables support and empowerment of group members, and iii) facilitates the active involvement of community group members in the management of HIV.

Most of the groups, with the exception of the farmers association and a soccer club, were predominantly made up of female members. It is perhaps therefore no surprise that most of the groups were characterised as female spaces, where values of care and fairness dominated. Although the community groups participating in this study had different group membership criteria, a number of participants expressed the importance of groups being inclusive and that groups should not discriminate against people who are willing to participate. Members of a rotating credit and savings association, for example, said it was important that members who are both infected and affected by HIV can join their group. The idea that both HIV negative and positive people should 'join hands' and work alongside each other was seen by a number of groups as a strategy to normalise HIV.

It was generally agreed that men fear HIV, which may help explain their lack of participation in groups that embrace and talk about HIV. Men who did join a group dominated by women expressed gratitude for what they had learnt in the groups.

All community groups participating in this study provided their members with a sense of support and empowerment. It was widely recognised that being a member of a group is hugely beneficial. The groups were formed for different purposes and some (e.g., the burial society and the farmers' association) did not particularly seek to mitigate the impact of HIV for its members. The burial society provided its members with the insurance of burial support following the bereavement of self or a close family member. The farmers' association provided members with the skills to farm as well as access to farming implements from NGOs. Whilst some of the members of these two groups may be affected by HIV, this was not talked about. In addition to providing their members with life-skills, income generation opportunities and knowledge, all the other groups, although to varying degrees, sought – both implicitly and explicitly – to prepare their members for the impact of HIV. Through dialogue and reflection on the impact of HIV, the groups provided members with the confidence to act on the knowledge they received. The community groups were also spaces where members were able to identify other community members who had 'done well' and whom they could look up to as an example.

All the community groups provide members with the opportunity to develop close bonds with people outside their lineages and with people who share similar circumstances. For many members, the groups were effectively safe social spaces where they could come out and share their HIV status with other group members. For the majority of the groups, it was also a space where community members could talk openly about HIV and share information that makes them better equipped to either prevent HIV or adhere to their treatment. The community groups were also an important source of psychosocial support, a place of laughter and sense of security from life stressors.

In addition to being beneficial for the group members themselves, all groups, except for the burial society and the farmers' association, were committed to responding to HIV. There seemed to be a link between the sense of solidarity that the groups fostered and their desire to help people outside the group. Members of an AIDS support group, in particular, spoke about their devotion to reduce HIV transmission and to get people tested for HIV through encouragement and being open about their positive status. But, also, other community group

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members spoke about their contribution to home-based care, both through more organised activities in collaboration with NGOs and through informal arrangements through the care and support of neighbours.

In summary, many community groups, in addition to their primary purpose of, for example, bringing community members together for life skills training, savings and lending, small scale farming or football, were, through dialogue, encouraged their members to engage with HIV, both to mitigate the impact of HIV on themselves and other members of their groups, but also to community members at large. Although their dedication to HIV work differed, this could partly be explained by their lack of resources (e.g., time and money). Whilst we have no quantitative data for Matabeleland South to verify that group membership and dialogue about HIV can result in HIV avoidance, the group processes that arguably led to successful HIV avoidance in Manicaland were observed, albeit qualitatively, in Matabeleland South.

#### 3.2. Community-level strategies are in place to support people affected by HIV

Rural and remote communities in Zimbabwe have had to respond to the impact of HIV often with very little support from external change agents. As such, a number of community-level strategies have emerged to mitigate the impact of HIV. But what community-level strategies are in place to support people living with and affected by HIV?

#### 3.2.1. Manicaland Province

Community groups and community members in Manicaland were found to provide vital practical support (e.g., nursing care and food) and emotional support (e.g., understanding and kindness) as well as being accepting of people living with HIV. Local women were found to set up or join community groups, in an effort to mobilise local resources and access NGO support. Through these groups, women offer unpaid health and welfare services to HIV and AIDS vulnerable households. Church groups were said to be an important source of support for HIV-affected people in so far as the Christian framework encourages care for the sick. Churches in Manicaland were also observed to play an important role in HIV prevention through religious

idioms and moral stories of 'good behaviour' (i.e., to abstain from having multiple sexual partners). Although many Church groups were responding to the HIV epidemic, some Church groups, in particular some Apostolic sects, struggle to reconcile their Christian morals with biomedicine and draw on stereotypes and incorrect HIV information to alienate people affected by HIV and AIDS.

#### 3.2.2. Matabeleland South Province

Just like in Manicaland, a number of community members in Matabeleland South find the time and energy to contribute with the care and support of those infected or affected by by HIV. To facilitate the coordination of such efforts, community members join home-based care groups, where they also have better access to receive training, gloves and medications from NGOs. Community health workers visit bedridden and other unwell community members, provide them with comfort, a meal, and medications and a wash. Community members who do not have the 'community health worker' accreditation, help unwell community members by clearing their compound, fetching water and cooking meals.

Churches were also seen as supportive, particularly to orphaned and vulnerable children. A number of participants spoke of how their local church had contributed to the payment of school fees for vulnerable children. Churches were also reported to be supportive of the elderly and disabled community members. During the interviews, there were only a few examples of churches helping PLHIV with practical support. But when such support was mentioned, it highlighted the Church as an effective source of support. When called upon, priests could get congregation members together to donate food, clothes and money to HIV-affected households. Whilst there were examples of church groups being supportive and including HIV education into their preaching, it was generally agreed that there was a lot more potential for church groups to support PLHIV more actively. As in Manicaland, Matabeleland South has got a number of different church denominations, each of which responds differently to the HIV epidemic. The Salvation Army, Seventh Day Adventists and the Roman Catholics were mentioned as running HIV awareness lessons for their followers. The Seventh Day Adventists, however, were accused of only helping members of the congregation and not anyone else.

Aside from practical support, there was a consensus that religion and spirituality is very important for PLHIV and, in that sense, is an important source of support.

# 3.3. Networks and partnerships mobilise and make available much needed resources for the community response to HIV prevention, mitigation and care

As the aforementioned observations allude to, collectivism, group formation and social action are key strategies in the HIV response in both Manicaland and Matabeleland South. But what is the nature of these networks and partnerships in enabling community responses to HIV prevention, mitigation and care?

#### 3.3.1. Manicaland Province

In Manicaland, networks and partnerships were identified as playing a key facilitating role in making support available for HIV-affected people. Three types of partnerships or networks were identified. The first one relates to the partnerships between externally-funded organisations such as NGOs or government agencies and local community groups. Through such partnerships, community groups are able to bridge the needs of local people with the resources available from external agencies. Community groups do not only access funding and other resources, but also play a mediating role of the knowledge they receive through training, enabling them to provide health and welfare services that consider local practices and culture systems. Some community groups were initiated as a response to the 'demand' for community groups from NGOs. The second network of people working together in the response to HIV, relates to community groups who have not attracted international donor funding, but merely seek to respond to local needs using local resources - based on the premise that that more can be achieved as a collective. A third, but more informal network of social relationships comprising of extended family members and neighbours – remains a hugely important source of support for HIV-affected community members in Manicaland, particularly for orphaned children.

The presence of NGOs in Manicaland, and their partnerships with community groups, was observed to play an important role in facilitating community responses to HIV. Men and women

living in villages with greater NGO activity were observed to have greater health outcomes. However, better outcomes can arguably be achieved, if external agencies consider the nature of networks and partnerships in the community, both the partnership they initiate themselves, but also latent support networks, which, if incorporated into the programme, can contribute to programme success and sustainability.

#### 3.3.2. Matabeleland South Province

As described earlier, many parts of Matabeleland South are desolate, making it difficult for HIVaffected households to engage in subsistence farming and make ends meet. The difficult environment affects everyone, making it difficult for well-wishers to share the little they have. Even though community members form groups and have the motivation to support HIVaffected households, there is a limit to what they can practically do for community members living in difficult circumstances. For that reason, there was an overwhelming consensus that Matabeleland South is in urgent need for externally resourced organisations to come to the area and collaborate with the many community groups that make up the social landscape. Community group members argued that they had the motivation to support HIV-affected households, but argued that they lacked the resources to provide meaningful support. In summary, they argued that 'real' support is urgently needed.

Matabeleland South has got a number of active NGOs. In Matobo District, where these interviews were conducted, there are 19 organisations involved in HIV prevention, mitigation, treatment and care. These organisations include World Vision, Mildmay, Red Cross, Save the Children, Christian Care and New Life. These and other externally-resourced organisations were reported to fund HIV education programmes, water irrigation and farming programmes, community capacity building programmes and orphan care and support. Despite their presence, a number of the groups spoke about their limited support and only a few groups reported any kind of partnership with an externally-resourced organisation. There was a general consensus that the demand for external resources exceeds the supply and a number of pleas for support were conveyed through the interviews.

As is clear from the above findings, the community group members believed that only by working together could they respond effectively to the epidemic. Working together in groups is therefore seen as a prerequisite for supporting HIV-affected households. However, on a couple of occasions, it was also mentioned that groups should collaborate and share lessons. Members of the Cooperative group, for example, spoke about how their donor for farming activities encouraged them to meet and learn from other community groups benefitting from the support received by the donor.

Aside from being a prerequisite for collective action, group formations and membership were seen as a pathway to attract donor attention and funding. There was agreement across all the groups that groups and active community members are more likely to collaborate with and benefit from externally-resourced organisations. Many of the respondents hoped that their active participation in a group and implementing activities for themselves and HIV-affected households would be recognised by externally-resourced organisations who would subsequently want to support their activities. The participants gave a number of examples of where this had happened in the past, illustrating the relevance of this hope. Furthermore, there was a widely-held belief that externally-resourced organisations had to operate through local structures in the delivery of aid and HIV services. So, for externally-resourced organisations to get the buy-in and be permitted to operate in a ward, approval from local chiefs, village elders and community group members was seen as necessary. This gave the community group members a tremendous sense of control and ownership when working in collaboration with an externally-resourced organisation in the delivery of services. The attractiveness of community groups to NGOs, as well as the level of control community groups have in administering aid if partnering with an externally resourced organisation, may have contributed to the motivation of some community members to either join or establish a community group.

Although many of the community group members were keen to collaborate with externallyresourced organisations, there was a caveat to their enthusiasm. A number of participants expressed concern over externally-resourced organisations bypassing them and not consulting community members about their needs. It was argued that that NGOs draw on simplistic understandings of who is deserving of aid - resulting in unfair distribution. NGOs were also said

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to have a simplistic understanding of local needs and to not approach development holistically. Whilst there was an appreciation of the support that externally-resourced organisations provide, it was seen as inadequate compared to need.

Findings from Matabeleland South concur with those from Manicaland in the sense that community groups are hugely important in the local response to HIV, but also that these groups have the motivation and capacity to do more if working together with externally-resourced organisations.

# 3.4. Community strengths and resources are recognised and drawn upon in the community response to HIV prevention, mitigation and care

It has long been recognised that rural communities in Zimbabwe have a 'portfolio of assets' that help them deal with hardship and transform livelihoods. But what are some of the examples of indigenous community strengths and resources that can be drawn upon in HIV prevention, mitigation and care efforts?

#### 3.4.1. Manicaland Province

Study participants in Manicaland spoke of a range of community strengths and resources that enable community members to protect themselves from becoming infected, to support people living with HIV, and to help those affected to cope with hardship. What emerged from the Manicaland studies were that many community contexts contained a sense of solidarity, making it easier for people affected by HIV to negotiate access to support. Accurate HIV knowledge and skills also led to improved care and support of those affected by HIV. In addition to the many women who volunteer their time to visit and provide nursing support for those affected by HIV and AIDS, children were observed to play a key role as primary carers and occasionally as income providers. A number of symbolic resources were also identified, including, for example, the recognition of children as actors, giving them the space to negotiate access to support and legitimately care for sick adults. Also the normalisation of HIV, sparked by the growing availability of ART, serves as an important resource for those affected by HIV to talk openly about their needs and the construction of new norms of solidarity.

#### 3.4.2. Matabeleland South Province

Improvements in access to ART in Matobo District – largely due to support from the Expanded Support Programme – have also contributed to a normalisation of HIV in Matabeleland South. It is fair to say that improved HIV services, referred to as close access to health facilities that offer ART, have changed the social landscape regarding HIV. The fact that most people have been affected by HIV one way or the other and now, thanks to the response of the local District AIDS Action Committee, have good knowledge about HIV transmission has demystified HIV and contributed to a normalisation of HIV. This, coupled with the understanding that contracting HIV is no longer a death sentence, has contributed to a gradual openness and acceptance of HIV. Many community members argued that HIV could now be compared to other common chronic diseases such as diabetes. This has not only contributed to less stigma, but also to diminishing the acceptability of stigmatising attitudes and discrimination. As such, all participants spoke about the unacceptability of stigmatising those affected by the disease.

This normalisation of HIV has undoubtedly made it easier for those infected and affected by HIV to negotiate access for support from their social networks. A key observation from the interviews is that the local context in which these interviews were conducted is characterised by an ethic of care and assistance – much in line with what has been observed in Manicaland. People had a sense of understanding of the hardship endured by some people and an acceptance that it could be them and that one day they might be in a similar situation. This understanding contributed to a sense of collective solidarity from which care and support hinges. It was evident throughout the interviews that there is a strong commitment to 'do good' and help those in need of support. This commitment was sometimes sparked by religion and 'God's wish', but, for most of the time, it was an act of anticipated reciprocity. It was believed that, in showing compassion for your fellow community members, favours and support would be reciprocated if you find yourself in a situation where you need help. All of this contributes to a social norm and expectation to provide care and support for vulnerable community members.

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Against this background, numerous examples emerged of how community members close to those sick took initiative to provide care and support. Children, for example, were repeatedly referred to as the primary carers of their HIV-infected parents. Children not only carried out nursing duties, such as feeding their parents and administering medicines, they also sustained their livelihoods through income generation and the fetching of firewood and water. Neighbours and close relatives were also reported to support those who were ill as well as their children. It was common for neighbours to help out with the fetching of water and firewood as well as sharing their cooked food with the HIV-affected family.

But also community members without any ties to those affected by HIV could be found assisting vulnerable households. This could happen through support from a local community group or from designated community health workers (as discussed earlier).

These findings are similar to those observed in Manicaland.

#### 3.5. Obstacles and barriers are acknowledged and considered in responses to HIV

To optimise the impact of interventions facilitating the community response to HIV, there is a need to recognise and address obstacles and barriers to programme success. But what are some of the more common obstacles and barriers to the community response to HIV?

#### 3.5.1. Manicaland Province

In addition to highlighting facilitators to the community response to HIV, the Manicaland studies also uncovered a number of obstacles and barriers. In some parts of Manicaland, for example, stigma and discrimination was said to still be prevalent, making it difficult for those infected by HIV to come out and live positively. Although many Churches in Manicaland do provide social spaces for people to talk about HIV and provide a pillar of support for people dealing with extremely sick loved ones in situations of great poverty, a sub-group of Churches (primarily Apostolic sects) were found to be strictly against use of medical services (modern or traditional) and to emphasise faith healing. Also the prevalence of poverty made it difficult for some people to provide sustained levels of support for those in extreme poverty. In the care of

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HIV-affected children, changes in household composition (e.g., if the father migrates and child lives alone with a non-caring stepmother) and illness or disability of guardians had limiting effects on the quality of support available to HIV-affected children. Also symbolic resources, such as notions of manhood, were found to serve as a barrier for men to access HIV services. These obstacles and barriers not only highlight the complexity of working with communities in responding to HIV, but exemplify the extraordinary efforts of those people who defy and overcome the obstacles to support people affected by HIV and AIDS.

#### 3.5.2. Matabeleland South Province

Unlike Manicaland, the lack of rain, the long walking distances to the nearest water sources combined with infertile and rocky soils make many parts of Matabeleland South inhospitable and unsuitable for subsistence farming. HIV-affected families, therefore, often experience food insecurity, undermining children's concentration in school and the efficacy of ART for those living with HIV. This, coupled with poverty, makes HIV-affected households very vulnerable and in need of food aid and nutritional garden projects. Although this has been recognised by NGOs like World Vision, their food distribution programme for PLHIV is limited and does not reach everyone in need of food. Poverty, as also observed in Manicaland, puts a strain on households who have agreed to foster orphaned children. Many guardians are therefore unable to provide adequate care and support for orphaned children. Again, whilst some NGOs and programmes like the Basic Education Assistance Module (BEAM) have provided support for orphaned and HIV-affected children, it is argued by the study participants that they only reach a fraction of those in need. In essence, poverty was said to undermine the well-being of, and responses to, HIV affected and infected community members.

On a few occasions, macro-level influences were said to inhibit a conducive environment for the HIV response. Although the majority of respondents spoke about the promising opportunities of churches, some respondents said there was still a long way to go for churches to be fully supportive. Examples were given of churches that allow polygamy and encourage men to multiple wives. Respondents also said that few HIV infected people dared to come out in the open and declare to their congregation that they are HIV positive. For some of the respondents,

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this is an indicator of the intrinsic values of the Church and illustrates that religion continues to be a barrier in the response to HIV. Also at a macro-level, a few respondents spoke about how political turmoil and the change in currency had a devastating impact on their livelihoods. Water became unaffordable and groups relying on water for irrigation of their collective farms, as well as savings and lending groups, were suddenly unable to work towards their objectives.

Concerns were also raised about the poor infrastructure of the province, particularly in relation to the lack of water pumps and irrigation systems. A few people expressed the opinion that health facilities were too far away.

At a symbolic and cultural level, fear of HIV and AIDS continues to prevent some people and men in particular, from seeking support and treatment. This echoes findings from Manicaland. When asked about gender differences in HIV service uptake, there was widespread agreement that men – because of their commitment to local understandings of what it means to be a real man – are much less likely to access HIV services. The fear of being associated with HIV prevented some people from asking for help. Relatedly, and reflecting the continued presence of stigma, some people would try very hard to hide their HIV status, making it difficult for community groups to identify those in need of help.

## 4. Concluding comments

The aim of this report was to explore the generalisability of findings from Manicaland, which have contributed to our understanding of an HIV competent community context. To do this, this report has highlighted and juxtaposed findings from a qualitative study in Matabeleland that examined the community response to HIV with findings from our longitudinal Manicaland studies – highlighting differences and similarities between the two provinces in Zimbabwe.

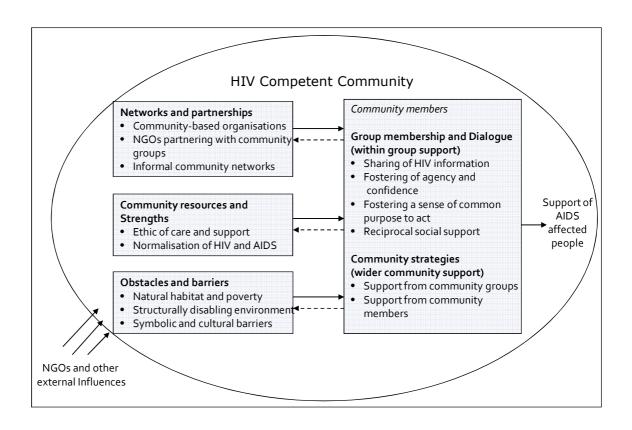
Although there are significant differences between the two provinces, primarily pertaining to their geographical locations resulting in different weather patterns and agricultural opportunities, what has emerged from the above discussion is that community members in

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both provinces – as a strategy to cope with hardship – cluster together into groups and social networks upon whom they can rely for care and support. The social networks span from close knit ties between neighbours and extended family to more organised community groups and right up to partnerships between community groups and externally-resourced organisations, such as NGOs and local government departments. A key difference between Manicaland and Matabeleland South is that because of the food shortages experience in the Matabeleland South, community groups and NGOs, in addition to their other activities; have to engage with nutritional gardening projects or the delivery of food in supporting HIV-affected community members. So, whilst there are differences in the content of their experiences of hardship and HIV and AIDS (e.g., people of Matabeleland experience more frequent droughts and food shortages), the underlying community response to hardship and HIV, characteristic of a HIV competent community, remain the same.

What this study has also highlighted is the importance of external factors in enabling the community response to HIV. This is well illustrated by the Expanded Support Programme, whose successful efforts to improve HIV services in Matobo District, have contributed to a normalisation of HIV – making it easier for HIV-affected people to navigate social support networks and negotiate access for support.

In Figure 3, we have tried to summarise some of the key social resources and processes that emerged from both Manicaland and Matabeleland that contribute to a HIV competent community context – a context where community members work together and interact in ways that facilitate optimal prevention, care and treatment (Campbell, Nair, & Maimane, 2007; Nhamo, et al., 2010).



What Figure 3 highlights is that communities in both Manicaland and Matabeleland are characterised by networks and partnerships and community resources and strengths as well as obstacles and barriers to the community response to HIV. Although these resources and barriers are available to different degrees, they materialise through the active involvement of community members through support and dialogue. Whilst the content of these resources and barriers to the community response to HIV might differ across Zimbabwe, this report highlights that there are generalizable community responses to HIV and hardship that can be tapped into in future programming and planning.

There is, however, a caveat to these findings. The different study designs drawn upon in Manicaland and Matabeleland South do not allow for a direct comparison. The Manicaland data, which comprise of both quantitative and qualitative data, was collected over an extended period, starting in 1998. It comprises of the perspective of many different respondents, including health staff, children and youth as well community members who may, or may not, participate in community groups. The study in Matabeleland South, on the other hand, was

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qualitative and only involved a small number of community members who were actively participating in a community group. The Matabeleland South study was also conducted very recently and over a very short period of time (September and October 2011). These differences in methodology, respondents and timing of data collection must be recognised and considered when reading the findings out of this report.

Nonetheless, we believe that the findings presented in this report highlight key processes in the community response to HIV and provide a key lesson that resonates with the commitment of the National AIDS Council of Zimbabwe to create enabling environments for vulnerable community members in high HIV prevalence areas. In the new Zimbabwe National HIV and AIDS strategic Plan 2011-2015 (Zimbabwe National AIDS Council, 2011), the 'enabling environment' is one of four thematic areas, which also include: 'HIV prevention'; 'HIV and AIDS treatment'; and 'management and coordination of the national response', that will guide Zimbabwe's future response to HIV.

Based on our large-scale and longitudinal findings of both qualitative and quantitative data sets in Manicaland and this small-scale and confirmatory investigative qualitative study from Matabeleland, we recommend that an 'enabling environment', aside from good policy, legislative and regulatory reforms, should also include a commitment to develop and enable HIV competent community contexts. In the interest of improving the effectiveness of HIV programmes and the uptake of services, future HIV programming needs to embrace and encourage community participation and involvement in the HIV response, drawing sensitively on local resources and strengths, social networks and support strategies, whilst also being cognisant of local challenges and obstacles to the community response.

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## References

## **Manicaland Technical Reports**

- 1. Technical report 1 (TR1): Gregson et al. (2011). Parallel Quantitative Report on community mobilization and HIV for the World Bank.
- 2. Technical report 2 (TR2): Nhamo et al. (2011a). Church responses to HIV in Zimbabwe: To what extent are the Anglican, Apostolic and Catholic churches supportive of HIV care, treatment and prevention?
- 3. Technical report 3 (TR3): Scott et al. (2011a). In what way do formal community groups impact HIV-related behaviors? The role of social capital in building HIV competence in rural Zimbabwe (Dialogue).
- 4. Technical report 4 (TR4): Scott et al. (2011b). In what ways do community groups support optimal access and adherence to antiretroviral treatment in Zimbabwe? (Access ART).
- 5. Technical report 5 (TR5): Scott et al. (2011c). Grassroots community perceptions of a peer education intervention in Zimbabwe (Peer Ed).
- 6. Technical report 6 (TR6): Nhamo et al. (2011b). The role of community conversations in facilitating local HIV competence: Case study from eastern Zimbabwe (CCs).
- 7. Technical report 7 (TR7): Skovdal et al. (2011). Community-level factors enhancing or restricting the impact of a cash transfer program in Manicaland, Zimbabwe (CCT).
- 8. Technical report 8 (TR8): Morley et al. (2011). How do children represent the sources of support available to those affected by AIDS in their communities, in drawings and stories?
- 9. Technical report 9 (TR9): Scott et al. (2011d). Social capital and public policy: A review.

### **Other References**

- Campbell, C., & Cornish, F. (2010). Towards a 'fourth generation' of approaches to HIV/AIDS management: Creating contexts for effective community mobilisation. *AIDS Care*, *22*(Supplement 2).
- Campbell, C., Nair, Y., & Maimane, S. (2007). Building contexts that support effective community responses to HIV/AIDS: a South African case study. *American Journal of Community Psychology*, 39(3-4), 347-363.
- Campbell, C., Skovdal, M., Mupambireyi, Z., Madanhire, C., Nyamukapa, C., & Gregson, S. (2012). Building adherence-competent communities: Factors promoting children's adherence to antiretroviral HIV/AIDS treatment in rural Zimbabwe. *Health and Place*(in press).
- Frumence, G., Killewo, J., Kwesigabo, G., Nystrom, L., Erikkson, M., & Emmelin, M. (2010). Social Capital and the decline in HIV transmission A case study in three villages in the Kagera region of Tanzania. *Journal of Social Aspects of HIV/AIDS*, 7(3), 9-20.

- Gregson, S., Mushati, P., Grusin, H., Nhamo, M., Schumacher, C., Skovdal, M., et al. (2011). Social Capital and Women's Reduced Vulnerability to HIV Infection in Rural Zimbabwe. *Population and Development Review*, *37*(2), 333-359.
- Gregson, S., Terceira, N., Mushati, P., Nyamukapa, C., & Campbell, C. (2004). Community group participation: Can it help young women to avoid HIV? An exploratory study of social capital and school education in rural Zimbabwe. *Social Science & Medicine*, *58*(11), 2119-2132.
- Moser, C. (1998). The asset vulnerability framework: reassessing urban poverty reduction strategies. *World Development*, *26*(1), 1-19.
- Nhamo, M., Campbell, C., & Gregson, S. (2010). Obstacles to local-level AIDS competence in rural Zimbabwe: putting HIV prevention in context. *AIDS Care*, *22*(Supplement 2), 1662-1669.
- Pope, C., Ziebland, S., & Mays, N. (2000). Analysing qualitative data. BMJ, 320(7227), 114-116.
- Pronyk, P., Harpman, T., Morrison, L., Hargreaves, J., & Kim, J. (2008). Is social capital associated with HIV risk in rural South Africa? *Social Science & Medicine*, 66(9), 1999-2010.
- Skovdal, M., Campbell, C., Nhongo, K., Nyamukapa, C., & Gregson, S. (2011). Contextual and psychosocial influences on antiretroviral therapy adherence in rural Zimbabwe: towards a systematic framework for programme planners. *International Journal of Health Planning and Management*, DOI: 10.1002/hpm.1082.
- Skovdal, M., Mwasiaji, W., Webale, A., & Tomkins, A. (2010). Building orphan competent communities: experiences from a community-based capital cash transfer initiative in Kenya *Health Policy and Planning, doi: 10.1093/heapol/czq039.*
- Thomas-Slayter, B., & Fisher, W. (2011). Social Capital and AIDS-resilient communities: Strengthening the AIDS response. *Global Public Health, iFirst article*.
- Zimbabwe National AIDS Council. (2011). *Zimbabwe National HIV and AIDS Strategic Plan 2011-2015*. Harare: National AIDS Council Zimbabwe.

Codes	Data examples	Basic Themes	Organising Themes	Global Themes
Joining a group	Anyone who wants to be part of the group is always welcome, we do not really chose who can join the group, whoever wants to join us and wants to do what we do is welcome. Support group member	Community groups are built on egalitarian principlesCommunity groups are often characterised by female qualitiesGroup membership and dialogue encourage members to engage with HIV prevention, mitigation and care efforts		
Group governance	We called a meeting at our place there at Mankala and we grouped ourselves. We then sat down and organized ourselves, voting who was going to be chairman, who was going to become vice, the secretary and their vice, treasurer and three committee members and others down wards. Cooperative group member			prevention, mitigation
Equality in group	This club has taken aboard a lot people, it did not discriminate whether one was ill or not ill, and by that I mean those who are infected with the virus. It has brought everyone together. Saving and lending group member			
More women than men	"If you look at the composition of the home-based caregivers, you will not find a male figure among them. It would be better if men were to step forward and spread the awareness message. It is well that the disease is on the decline because of the pills but the lack of participation by the men is impacting negatively on the situation." Women's group member	More women than men take an active role in community groups		
Men less likely to join	"When we look at the issue of HIV, women are the ones who participate. I do not know, maybe it's because most of the men work outside the country, but most of the time it is the women who are active. For men to be there no, unless you tell men that there will be a party with beer, they will not come. If you tell them about AIDS, it will be pushing them away. Usually, really it is the women who participate in groups" Youth group member.			
Groups particularly useful for men	By joining a group, men get courage to face the future because they are cowards when it comes to such issues. But still it is lacking because most men still do not want to come out. As women we also get to talk and support each other emotionally. AIDS support group member	Men can benefit from joining mixed gender groups		
Group dialogue and attitude change	As for me when before I became part of the group before going for training on HIV/AIDS, before getting blood tested, I was afraid of it, blood testing. If I go for a blood test and be told that I have AIDS I will not cope. But we became part of the group and we discussed, I was taught and I began to know that this thing is there and is real, and when you have tested your blood, and you are diagnosed, you take your tablets, you live and last with your family until it grows. I realized that being part of the group is good because if I was alone I was not going to have the knowledge that I am supposed to go and get tested, I am supposed to learn, to	Community groups provide members with opportunities for psychosocial development	Community groups are an important source of support and empowerment for group members	

Appendix 1: Coding framework - An HIV competent community context in Matabeleland is where... [see Global Themes]

	learn so that I can be taught so that I can teach others about
	how good it is to get tested, how good knowing your status
	is. Cooperative member
Confidence and	"Joining this club has made me stay happy all the time and I
empowerment	am free from stress. If I'm stressed when I leave home, when
empowerment	I get here and the others ask me why I am so sad and I tell
	them the cause of my unhappiness, they comfort me and tell
	me all sorts of things to cheer me up. They tell me not to
	worry and that I will live to be a hundred years old. I am
	more confident now, in the past I used to be too
	embarrassed to be seen carrying my card that I use to get
	pills from the clinic but now I am so liberated that I am all
	over the "ground"." Savings and lending club member
Identifying role models	We usually get the messages on how one should behave in
	order to avoid HIV. Sometimes you hear that, 'no it is
	difficult to control yourselves until you get married', but then
	in this group we get a testimony of someone saying, 'I have
	controlled myself now look the white veil is covering my
	face, right'. So we also have the desire that we want to be
	<i>like them</i> . Practical skills youth group member
Gaining life-skills and	"What I can say we have benefited a lot from is knowledge
	on practical skills – keeping us away from antisocial
knowledge	behaviors. We spend much of our time working. Some group
	members can now construct buildings, they spend their time building while others grow vegetables and others sewing.
	Members who before had no money and thus sometimes
	ending up looking for it using bad methods, e-he, now they
	can make their money by doing hand work they have been
	taught." Youth group member
Psychosocial support	"With the comfort that we provide to each other in the
	groups, I think it gives us hope to live because when you are
	alone and not in the groups, there is nothing that you can
	think of most of the time besides your illness, if you are
	among other people, you can forget, and feel like you are
	living a life that is being lived by those who do not have the
	disease." Cooperative group member
Sharing and gaining HIV	"When we meet as groups, we stage these plays or
information	"sketches" that are about two families: one with a child who
	is healthy and the other one about a family with a child who
	lacks discipline till they get to some point where they have to
	take the wayward child to traditional healers after the child
	becomes infected with the virus. The play culminates in the
	family going with the child to get tested and recovers their
	health after being put on ART. This helps people to realise
	the mistakes that people make when they start blaming
	each other when such a thing happens. It makes people
	understand the "blood bonds" that exist between people

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	who are born in the same family and why a child will choose		
	to go and stay with a certain uncle where they feel more		
	comfortable. And it makes people aware of the illnesses that		
	result from the disease." Savings and lending group		
	member		
Self-gain	"I started with this garden right from the beginning. I liked	Community groups provide	
een gant	the idea that I will be farming and provide school fees my	members with a source of	
	children, and also food, which I get when I sell food."		
	Cooperative member	support during times of	
	"I would say one of the main objectives of our group is to	hardship	
Within group support	support one another socially and economically. When people		
	are sick they feel dejected and they think that they are about		
	to die hence there is need to support one another for us to		
	pull through such hardships, and we want to let them know		
	that even if we are not well there is something we can still		
	do about our lives." Support group member		
Solidarity and action	"Being part of a group has changed me because now I am	Many community groups, but	Many community groups
,	able to go and fetch water for sick people and if I visit them	not all, are committed to HIV	are active in <b>HIV</b>
	and I see that they do not have soap and I have then I can	work.	management
	cut a piece for them too, so that they may be able to bath."	WOIK.	management
	Burial society member		
Group engages in HIV work	"Our main aim was that we thought that if we start a group		
Group engages in the work	as people living with HIV we can try and reduce the HIV		
	prevalence in our community and we seek to disseminate		
	information in light of HIV/AIDS to those who are not in		
	these groups, we try and tell them that if they have not yet		
	been tested for HIV then they should go and get tested and		
	should not hide their HIV status because having HIV does		
	not mean that it is the end of life but it is actually the		
	beginning of a new and better life." AIDS support group		
	member		
No HIV work done by group	"We have never really talked about HIV issues here although		
, 3 1	here in the fields we have lost a lot of our fellow farmers.		
	Maybe if some of those who have passed on were still alive,		
	they would help us in solving some of the problems that we		
	are currently facing with our farming activities It would		
	also help us as farmers to find the best ways of assisting		
	those among us who would have revealed their HIV status."		
	Farmers association group member		
Lack of HIV knowledge and	"The bad thing about meeting as a group to talk about HIV		
sharing	is that when you are talking about HIV as a group there		
	should be someone in the group who has a deep		
	understanding and full knowledge about it because if we		
	do not know anything and we talk we may overlook some		
	things that are dangerous." Soccer club member		4
Groups encourage VCT	Our main aim was that we thought that if we start a group	Many community groups	
Cioups encourage ver	as people living with HIV we can try and reduce the HIV	wany commonity groups	

	prevalence in our community and we seek to disseminate information in light of HIV/AIDS to those who are not in these groups, we try and tell them that if they have not yet been tested for HIV then they should go and get tested and should not hide their HIV status because having HIV does not mean that it is the end of life but it is actually the beginning of a new and better life. AIDS support group member	contribute with HIV services		
Groups engage in HBC	We have come to realise that there are some who are ill and not able to support themselves. As women we go to them and do "something" for them, we fetch water, help them by waxing the floors or just do something for them that will help them after we leave. Even though they might have children who are able to do that for them, it will seem like we are "abusing" the children if we leave them do all those chores when, as Phathisanani group we can assist with doing those chores. Savings and lending group member			
Churches support orphaned children	"Churches they do help a lot by collecting monies towards those affected by HIV, especially households with orphaned children and poor guardians" Support group member.	Church groups often mobilise resources for the support of orphaned and vulnerable children	Church groups are important avenues of support	Community-level strategies are in place to support people affected by HIV
Changing Church values	For now I think for these churches there is now some level of understanding about this disease because they now see that it is there with the way people are dying. For now I see that many churches are participating in going to hospitals. At first they had not understood it, before this teaching had spread, they were relying more on prayers, people like those of the Apostolic sect, Zion. You would find a person being given water whereas that person will be having the virus. Cooperative member	An increasing number of church group embrace HIV prevention messages and support of HIV-affected families		
Churches can be supportive	I understand that there are churches such as Salvation Army, Seventh Day, I think and Roman Catholic, they do have lessons on HIV/AIDS. I understand that this helps members so that they can get knowledge about HIV and AIDS. I also understand that in other churches there are no such lessons, so I think that they still have an obligation to try and implement it so that they can reach out to those that others have failed to reach out to. Youth group member			
Home based care and community health workers	"What I can say is the most important thing about living in this community is that there are home based caregivers who look after children and orphans and those who are ill. They take care of them." Burial society member	A number of community groups provide home based care services	Community groups support vulnerable HIV- affected community members	
Burial societies	"The aim of the Burial society is to ensure that you will not be alone about covering for funeral costs. The Burial society's use is that when trouble looms, maybe I have passed away or I have lost a child, the group pulls together	Community groups provide members with a safety net in times of hardship	Thembers	

Rotating Savings groups	the little money that they can contribute in order to assist." Burial society member "What I have benefited by being a member of this group is that sometimes when I do not have money to go to the hospital, the other members make contributions for me to be able to visit the hospital and see the doctors." Savings and leading aroup member			
Groups engage in social enterprises	lending group member "I joined the group in 2011, in the group I get to discuss with my friends and we assist one another in a number of ways, and they can tell me what to do when I am faced with some problems and we think that if we work together then we can have our garden and plant vegetables like carrots and other nutritious vegetables so that we can get money." AIDS Support group member			
'Real' support is needed	"What I have noted is that we are not able to provide financial assistance. We are able to fetch water and bring handfuls of mealie-meal but in some instances what is really required is money to buy food that will help the patient to maintain a healthy diet, or maybe the person has children and they may want money to go to school, she may not have that because as she will be bedridden, she has no energy to work and provide for the children." Farmers group member	There is a need for externally resourced organisations because of limits of local support structures	Externally resourced organisations are important actors in support of HIV-affected community members	Networks and partnerships mobilise and make available much needed resources for the community response to HIV prevention, mitigation and care
Lack of resources to provide meaningful support	"There is nothing really that we do, we are starving here so we have nothing to give, so there is nothing." Burial Society member			
Agency support	"The support orphaned children get is for school because fees are paid for orphans by BEAM and there is econet they also help, that is the support that is there." Soccer club member	NGOs and other externally resourced organisations and active in supporting programmes for HIV-affected		
NGOs build the capacity of groups	"Our group has benefitted us a lot because before these men from ORAP came we did not have support as a group, we would just join without the objectives of doing things. We were told how things are done and now we have our own constitution, objectives and the direction to follow. It is more manageable now." Savings and lending group member	community members		
NGOs provide HIV education	"We were once part of a programme where we discussed HIV and AIDS, it was a programme from World Vision, it was something they called behavior change, there was a woman who used to facilitate the lessons, teaching us about behavior change." Burial society member			
NGOs provide agricultural inputs	"It is very important for us to be supported by NGOs because it can take us out of poverty. One NGO has given us goats, has taught us the garden, and also taught that if your goats are sick, what you should do. That prevents our goats from dying and then that poverty persists. In the gardens, we can sell vegetables, send our children to school, eat, sell, buy			

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	mealie meal. I think this assistance has removed poverty out		
	of us. I give thanks for that." Cooperative member		
NGOs provide services for PLWHA	"The aid that that we get from NGOs like World Vision, especially when i look at the support that is given to people		
	living with HIV, I think that they are really supporting us. We		
	feel taken care of and loved and we know that we are not		
	alone in this battle that we are fighting." AIDS support		
	group member		
NGOs support vulnerable	"There are organisations like Christian Care, Beam,		
children	CAMFED, Sikhethimpilo and others that help orphans in a		
	number of ways like school fees and stationery." AIDS		
	support group member		
No/limited NGO support	"There is no support for PLHIV other than the free pills from	There is a call for greater NGO	]
	the hospitals" Farmers association group member	support and presence as the	
No collaboration with /	"We have not been able to team up with an NGO to get	demand exceeds supply	
support from orgs	assistance with our farming activities" Farmers association		
	group member		
Groups collaborate	"Our group sometimes meets with other groups. We have	Community members realise	Community initiated
	other groups from Nathisa that are under the the Perma	that only by working together	groups continue to play
	Culture programme." Cooperative member	can they respond to the HIV	a key role in responding to HIV – serving as the
Working together is a	"I joined the Burial because it helps, alone you cannot	epidemic	
prerequisite	manage, since we are here in rural areas we do not work, we	•	entry point for NGO
	will be managing the little money that we get to assist		support
	others so that when you face a problem they will be able to		sopport
	assist you so that you are able to do something, that is why I		
	joined, realizing that alone I cannot carry the problem in a		
	single day, the money is difficult to come by. "Burial society member		
Groups collaborate with	"I understood and came to terms with the fact that	Groups and active participants	1
NGOs	HIV/AIDS is here to stay. I also realised that being a member	are more likely to collaborate	
NGOS	of a group could make me play a role in the fight against	with NGOs and contribute with	
	HIV/AIDS. Since I had it too there was need for me to think	the delivery of HIV services	
	of ways that could help me live with it, so I had to think of	the delivery of HTV services	
	how and doing what. So they had told us before that if you		
	are a group it is easier to get assistance from outside, which		
	is when we decided to form am group." AIDS support group		
	member		
Groups and service delivery	"I am a home based care giver and what we do is that we get		
	a list of orphans that we keep and when there is an		
	Organisation that wants to assist the Orphans then we take		
	out the list and see who can get help at that time." AIDS		
	support group member		
Community entry/buy in	I have noticed that there is a policy that outlines how NGOs	The donor-beneficiary	How NGOs engage with
	are supposed to operate that was formulated by the	relationship is negotiated	communities and
	government "from national up to village". The policy is there	carefully for a good fit.	community groups
	and the law that guides them when they come from outside		matters
	the country. It spells out that they work with the local		

	leadership of the communities and the groups that they find in the area, they do not just create their own but follow the guidelines of the people that they find in that area. As it is			
	you first approach the councillor and they brief me and after consultations with the council and having agreed with them that they can work in the area, they are asked what their programmes are. When they come down to the area, they			
	also do the same thing, which is how things are done to ensure that things go well and the organisation is "controllable". Savings and lending group member			
Donor-beneficiary relationship	"It used to be difficult because back then we would just see the organisation come and just do what they want but now the community plays a role in determining what they get. We hold meetings as villages to determine what people need and who gets what first." Support group member			
NGOs not doing it right	"Sometimes the orphans that are under the care of the guardians who are part of the farmers group that is practising irrigation are denied assistance simply because the guardians are working at the irrigation. This does not go well with us because it is discriminatory and it hurts us to think that these children are also orphans but they are not getting any assistance." Farmers association group member	NGOs are thought to have a simplistic understanding of local needs		
Limitations of NGO support	"Sometimes when the NGO comes with the intention of providing support, it is meant for a small number of people but the village is big and their number is small, so the majority of the people will be left behind and we are left with the task of feeding the people, but we do not have the resources." Savings and lending group member			
Local health facilities	"What I have observed is the role that the hospital plays. We have a hospital nearby and it maintains records of the people in the community in the "OI" department. This makes it easy for whoever needs the information to measure the requirements of the community when providing support." Farmers association group member	Improved HIV services have changed the social landscape regarding HIV	There has been a normalisation of HIV and AIDS	Community strengths and resources are recognised and drawn upon in the community response to HIV
Availability of ART has brought change	"I admire these pills so much, I am a Home Based Care giver and when I look back during the past times these hands were working, bathing people who had no one to bath them because we are Home Based Caregivers but today we do not bath anyone, all the people are healthy. You find that in the past in this community maybe those who are bed-ridden are thirty - but these days if I tell you that they are only two who are bed ridden, but even if they are bed-ridden, these days they are up, so that is why I say I am proud of these pills." Women's group member			prevention, mitigation and care
Openness around HIV	"In 2009, people were still in the dark, now people talk openly about HIV, back then when you asked people how	A gradual openness around HIV		

Talk openly about HIV	they are they would not tell you that they are ill, they would get angry and say that you say they are ill. Nowadays things have changed because they now open up and tell you that they are suffering from this and that, so things have changed, back then you would visit some households and they would close the door on you." Burial society group member "Nowadays there is a big difference because back then, it was not easy at all to talk about the disease. It was scary to talk about the disease because we were very afraid of it. These days we talk freely about it and we share advice and information on how to deal with the disease. It is becoming easier to talk about it but back then it would be very difficult for me to talk about HIV to anyone that I suspected to be infected by the virus." Farmers association group member	has contributed to the slow breakdown of stigmatising attitudes and health damaging practices.		
Less stigma	"Life has changed e a lot for PLHIV because people used to discriminate against people living with HIV/AIDS but now they are accepted, very few people will laugh at you, people now feel pity." AIDS support group member			
Breakdown of 'bad' customs	"In our culture, there are no other practices that promote the spread of HIV other than the one of wife inheritance that we mentioned. Nowadays it is quite rare to find people who are still practising that because of this disease." Farmers association group member			
Love for fellow human beings	"Love is the main thing encouraging community support because with love if you hear that so and so is ill you can decide to help them with something, but if you do not have love you cannot assist them." Farmers association group member	It is a social norm to provide care and support for vulnerable community members	Community contexts are characterised by an <b>ethic</b> of care and assistance	
'Doing good work' - reciprocity	"Caring for a child who is not yours is good because when they grow up, and if you treated them well, you will end up living well. That child will acknowledge you so much, and say 'you raised me to become a certain person, you educated'. This child will eventually raise you and remove you from some of the difficult circumstances you were in." Women's group member			
Community solidarity	"My pride about this community is in that I think we are united in the way we operate. We love doing whatever we will be doing to support each other, helping each other all the time." Cooperative group member			
Peace and understanding within the community	"We are proud because there is peace and understanding between members of this community, they understand when there is need for help and when to chip in, like the traditional leaders are also there and when we have any problems we tell them and they will go and tell higher authorities, until we get the help we need." AIDS support group member			

Children are important in the provision of care and support of vulnerable community members People can rely on the	"Having children, children are your future, as it is if I do not have children I will not live. If it happens that I fall ill, a child will nurse me, if I stroke and I cannot stand up, or become blind, they will help me. So if you have children you are proud because they are your future they will take care of you when you are no longer able to do it on your own." Burial society group member "Like we said that there is hunger here, that is how they help	Those close to families affected by HIV play a key role in the provision of care and support.		
support from neighbours and close relatives in times of hardship	us like these relatives and friends they assist with food. In most case neighbours and relatives chip in to assist. " AIDS support group member			
Community support of HIV- affected community members	"The good thing about living here is that we help one another in our village." AIDS support group member	Some community members support HIV-affected households		
HBC/CHW workers	"In our community there is help through village health workers, they have pills and condoms and they teach people that they should use condoms it is going to help them, that is the support that is available they go to then hospitals and get pills which they give to people for free." Burial society member			
Dryness	"What is bad about this place is that we have rainfall problems, so food thus becomes scarce if we are not assisted by the NGOs you may end up hearing about dead corpses being found in "Mat South", so this place has drought." Youth group member	The lack of rain water and alternative water sources leave many people without enough food	The <b>natural habitat</b> is inhospitable, making subsistence farming difficult	Obstacles and barriers are acknowledged and considered in responses to HIV
Water problem	"The challenges that we are facing in this community is the challenge of scarcity of water. That is what seems to be giving us problems." Cooperative group member			
Food insecurity	"The major challenge that PLHIV is facing is the problem of food, yes, food is the most important thing. They will not get an orange at home, they can't get porridge since our area is dry, there is no water, and it is not easy to get food. Sometimes the money to buy the food, sometimes here at home we won't afford. Yes, it becomes so difficult that you will see the child with a swollen stomach and then you realize that, no, there is kwashiorkor, food is scarce." Burial Society member			
Lack of food undermines ART	"Our biggest challenge here is that of hunger, so we should really talk a lot about that because if you take that pill on an empty stomach by 9 you will be feeling dizzy and if you look at the granary there will be nothing for you to cook so that you can eat. We also have children and they have nothing and yet they need clothes and blankets." AIDS support group member		<b>Poverty</b> undermines the well-being of, and responses to, HIV- affected and infected community members	
Struggles of HIV-infected children	"At times the elderly guardians forget the dates for going to the hospital to get ARVs for children. This has negatively	Poverty makes it difficult for caregivers of vulnerable		

	affected the health of these children. So we have to remind those we know that so and so do you remember that on such	children to adequately care for them		
	a date you are supposed to go with your child to the hospital for pills, what if you are not there to remind them. So those are some of the problems that are faced by these children." AIDS support group member			
Struggles of children affected by HIV	"I was saying in families where parents are ill, the father is bed-ridden the mother is also bed-ridden, children face difficulties on how to take care of their parents, they are the ones that have to wash clothes for their parents but maybe they are still too young to do that, it becomes a burden for the children such that you find the children very vulnerable." Burial society group member			
Struggles with orphan care	"The challenge that I'm facing is that I'm taking care of my deceased brothers' two orphans. I am no longer able to pay the school fees for them. One of the orphans is in Form Two and she might drop out of school this year because we have run out of options, the other one is in grade five. As you can see I am very old and I'm no longer able to do much and I have nowhere to send these orphans for help." Farmers group members			
Struggles with school fees	"We are really going through a hard time as people living with HIV. We have children and need to pay school fees for our children but don't have the means." AIDS support group member			
Poor infrastructure	"Very few NGOs have operated in this area maybe because of its poor roads and networks, even the school where we met had dilapidated buildings and the community is crying out for help." Burial Society member	The quality and access to public services occasionally prevent HIV-affected community members from	Structurally disabling environment inhibit support for HIV-affected community members	
Unsupportive schools	"What I have noticed is that, while the schools are nearby and easily accessible, they are too expensive. Considering that some of us are orphans and were left in the care of the elderly, as someone has already pointed out, it is very difficult to manage to pay the fees. The schools do not consider the plight of the orphans and they turn them away for non-payment of the fees." Farmers group member	accessing support		
Political and financial instability	"The irrigation was viable before the multicurrency economy but everything has since changed and the water charges have gone up. The money that we are making is all going towards the electricity and water charges. We are labouring in vain and can no longer provide for the orphans in our care. Those are the challenges that we are facing." Farmers group member	Some macro-level influences inhibit a conducive environment for HIV-affected community members		
Churches/religion barrier to support	"I go to church at ZCC; at ZCC you will not find AIDS education. They cannot explain or tell you and be direct about HIV, they go around it and say it is obscene." Women's group member			

'bad' customs	"The other thing that makes this disease to spread is that you hear other people saying I do not go to the hospital but we play the drums, especially these people who play the traditional drums, you hear them saying it is the ancestral spirits. So that person will refuse to go and get treated." Cooperative group member	Damaging cultural practices and idle talk can still serve as a barrier to HIV management	There continues to be symbolic and cultural barriers to the support of HIV-affected community members	
Gossip and unconfidentiality	"Orphaned children may be insulted, 'hey your mother was killed by AIDS'. If they say uncle I want to go school can I have a pen, they are told there is your mother's grave don't trouble me. I think there all sort of heavy names children get, 'hey your father was killed by prostitution' and that will result in them being harmed "psychologically". And also the child being made to work like a slave, being told that you are paying for my food, so it will become difficult for the child, that sometimes they will be arriving late at school, some will be waking up early and they go but he/she will remain working before they go to school." Youth group member			
Stigma is a barrier to HIV responses	"Most people are afraid of 'stigmatisation'. It still exists. No one will ever sit next to you, I am sure people would run away to the bush (she laughs) that is the reason why people actually prefer to remain "bottled up"[not wanting to know HIV status], although it is not healthy." Farmers group member			
Masculinity as an obstacle to HIV responses	"Men do not want to open up and admit that they are living with HIV. They only do that when the wife gets pregnant and tells the husband that the hospital staff want them to visit the hospital together or when he gets seriously ill and we visit and advise him to go get tested that is the only time maybe when they can go get tested otherwise they do not want" AIDS support group member	Fear of HIV and AIDS prevent some people, particularly men, from seeking support and treatment		
PLHIV may not accept/want help	"The challenges are the same ones that someone you may try to enlighten them but they do not want. The other issue is that of stigmatizing the sick person who tries to draw closer to them but they distance themselves. And the fact that you may try to share ideas with someone but they refuse, you try to draw them closer to you and then they refuse and they say did you see me ill." Cooperative group member			
Lack of disclosure of HIV status prevent support	We have a wish to help the people, and to know that it is they suffer from but most of them do not tell us their status. And also if you try to help them, those at home where they are staying will think that you think they are poor, and they may not want you to behave as if you are interfering into their lives. Cooperative member			