In what ways do communities support optimal antiretroviral treatment in Zimbabwe?

Scott, K; Campbell, C; Madanhire, C; Skovdal, Morten; Nyamukapa, C; Gregson, S

Published in:
Health Promotion International

DOI:
10.1093/heapro/dat014

Publication date:
2014

Document version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Scott, K., Campbell, C., Madanhire, C., Skovdal, M., Nyamukapa, C., & Gregson, S. (2014). In what ways do communities support optimal antiretroviral treatment in Zimbabwe? Health Promotion International, 29(4), 645-654. https://doi.org/10.1093/heapro/dat014
In what ways do communities support optimal antiretroviral treatment in Zimbabwe?

K. SCOTT1*, C. CAMPBELL2, C. MADANHIRE3, M. SKOVDAL4, C. NYAMUKAPA3,5 and S. GREGSON3,5

1Social and Behavioral Interventions, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Room E5533, 615 North Wolfe Street, Baltimore, MD 21205, USA, 2Institute of Social Psychology, London School of Economics and Political Science, London, UK, 3Biomedical Research and Training Institute, Harare, Zimbabwe, 4The Department of Health Promotion and Development, University of Bergen, Bergen, Norway and 5School of Public Health, Imperial College, London, UK

*Corresponding author. E-mail: kerry.e.scott@gmail.com or keescott@jhsph.edu

SUMMARY

Little research has been conducted on how pre-existing indigenous community resources, especially social networks, affect the success of externally imposed HIV interventions. Antiretroviral treatment (ART), an externally initiated biomedical intervention, is being rolled out across sub-Saharan Africa. Understanding the ways in which community networks are working to facilitate optimal ART access and adherence will enable policymakers to better engage with and bolster these pre-existing resources. We conducted 67 interviews and eight focus group discussions with 127 people from three key population groups in Manicaland, eastern Zimbabwe: healthcare workers, adults on ART and carers of children on ART. We also observed over 100 h of HIV treatment sites at local clinics and hospitals. Our research sought to determine how indigenous resources were enabling people to achieve optimal ART access and adherence. We analysed data transcripts using thematic network technique, coding references to supportive community networks that enable local people to achieve ART access and adherence. People on ART or carers of children on ART in Zimbabwe report drawing support from a variety of social networks that enable them to overcome many obstacles to adherence. Key support networks include: HIV groups; food and income support networks; home-based care, church and women’s groups; family networks; and relationships with healthcare providers. More attention to the community context in which HIV initiatives occur will help ensure that interventions work with and benefit from pre-existing social capital.

Key words: antiretroviral treatment; social capital; community groups; Zimbabwe

INTRODUCTION: COMMUNITY MOBILIZATION AND THE RESPONSE TO HIV

HIV is a global health issue having the greatest impact on sub-Saharan Africa. With the growing accessibility of antiretroviral treatment (ART), attention is increasingly focused on how access and adherence to ART can be optimized, particularly in low-resource settings. Traditionally, donor-driven community programmes have taken the form of top down interventions imposed on communities by outside agencies. Little attention has been given to pre-existing indigenous community resources, especially social networks (such as social clubs, relationships between healthcare
worker and patients and family or neighbourhood connections). These community resources can be viewed both as positive social capital in their own right, and as having the potential to strengthen externally initiated programmes. More attention to the community context in which HIV prevention, treatment and impact mitigation efforts occur will help ensure that new forms of HIV support work with and benefit from pre-existing indigenous social capital.

The authors of this paper had the opportunity to examine this link between social participation and responses to HIV, particularly around access and adherence to ART, in 2009 in Manicaland, an eastern province of Zimbabwe. Our qualitative research explored indigenous responses to HIV and local facilitators of successful ART access and adherence.

This paper presents our findings from Manicaland, asking the following questions: (1) what indigenous resources in Manicaland promote community-level HIV competence? (2) What role do they play in facilitating the success of external interventions, specifically optimal access and adherence to ART? We focus on the role of indigenous community resources in terms of (a) groups facilitated by NGOs and funders (e.g. support groups), (b) indigenous community groups (e.g. women’s groups), and (c) informal networks (e.g. neighbours, friends) and relationships (e.g. nurse-patient relationships).

MANICALAND RESEARCH ON COMMUNITY GROUPS AND ART ADHERENCE

Our study took place over 2 months and involved over 100 h of ethnographic observation of treatment sites. We also conducted 67 interviews and eight focus group discussions (FGDs) with 127 people from three key population groups: healthcare workers, adults on ART and carers of children on ART (Table 1).

Ethical approval for the study was granted by the Medical Research Council of Zimbabwe (Ref: A/681) and the Imperial College Research Ethics Committee (Ref: IREC_9_3_13).

Context of research

In 1980, Zimbabwe gained independence from colonial rule. The country underwent a period of initial positive growth in GDP; free primary education and improved healthcare services were introduced in the 1980s (Richardson, 2005). However, from 1999 onwards, the country has undergone political and economic turmoil, leading to GDP decline and hyperinflation. This turmoil, coupled with the devastating effects of HIV/AIDS, has seen quality of life dramatically decline, echoed in a decline of life expectancy from 61 years in 1992 to 42 in 2010 (WHO, 2010; ZCSO, 2007).

Despite the highly challenging political and economic environment facing citizens, Zimbabwe is one of the first African countries to show a declining HIV rate with the adult prevalence rate falling from a peak of 26.5% in 1997 to 14.3% at most recent measure (ZMoHCW, 2009), attributed in part to reductions in high-risk behaviour (Gregson et al., 2010). While there have been antiretroviral (ARV) drugs in Zimbabwe since the early 2000s, they were in short supply and prohibitive expensive for most people. In the late 2000s, the government and partner aid organizations succeeded in a massive scale up of ART. By December 2009, 218,589 people, about half of those in need, were on free ART through the public health sector (UNAIDS, 2012).

The HIV rate in Manicaland is approximately 20% (Gregson et al., 2010). Residents of the region are primarily subsistence farmers or work on large commercial mining and forestry estates. Most live in rural homesteads (compounds with several mud and thatch houses, a pit-latrine and animal pens), often without electricity. Many families have members working in major cities, some of whom send money back to the rural areas. Poverty is a major challenge and many local people struggle to access adequate food and afford school fees for their children.

Table 1: Summary of study participants

| Participants   | Interviews | FGDs |
|----------------|------------|------|
| Total          | 127        | 67   |
| Male           | 44         | 83   |
| Female         | 83         | 82   |

| Healthcare workers | Male | Female | Interviews | FGDs |
|--------------------|------|--------|------------|------|
| 14                 | 11   | 18     | 1           |

| Adults on ART      | Male | Female | Interviews | FGDs |
|--------------------|------|--------|------------|------|
| 30                 | 32   | 28     | 4           |

| Carers of children | Male | Female | Interviews | FGDs |
|--------------------|------|--------|------------|------|
| 0                  | 40   | 21     | 3           |
Research methodology

Adults on ART and carers of children on ART were sampled using snowball, opportunistic and typical case sampling. Snowball sampling involved inviting openly HIV-positive community members already known to the researchers through previous work to ask their peers to participate. Opportunistic sampling involved self-selected informants who approached the researchers asking to be interviewed because they had heard about the project. Typical case sampling involved approaching adults on ART or carers of children on ART as they visited hospital or clinic sites and asking them if they would like to participate. We accessed healthcare workers (nurses, HIV counsellors, pharmacists and a clerk) by first attaining permission to interview staff and observe hospital sites from the doctor or nurse in charge. We then asked the staff working most closely with people on antiretroviral care if they would like to participate.

Researchers’ requests for interviews were only refused in one case, by an ART patient who cited time limitations. Topic guides explored changing perceptions of HIV, social support and ways of coping with HIV and ART, issues surrounding treatment adherence and experiences at the health care centre. All interviews and focus groups were guided by a loose framework of subject-based questions to elicit rich in-depth responses about the contextual factors that facilitate or hinder optimal access and adherence to ART. Questions varied depending on the interviewee (i.e. nurses, people on ART and carers of HIV-positive children were asked somewhat different questions) but generally included: ‘What are some things that prevent people from accessing care at the clinic?’ ‘What encourages people to be tested for HIV and to visit the clinic?’ ‘What helps people on ART take their pills when needed?’ ‘Can you tell me about a time when someone you know was unable to adhere to ART?’ and ‘Tell me about a positive/negative experience at the clinic.’ All audio files were translated into English and transcribed by trained researchers. To thank the informants, focus group participants were given soap, and interviewees were given a t-shirt.

Over 100 h of ethnographic observation were conducted at the health centres, observing interactions as HIV patients waited for the doctor, paid hospital fees, visited the pharmacy and waited for nurses to review their progress on ART and prescribe refills of their ARVs. Researchers did not observe private interactions between patients and staff. Observation focused on hospital activity, including interactions between patients and staff and the arrangement of people in hospital spaces. Extensive detailed notes were taken by the researchers throughout the hours of observation, recording what occurred, how people were organized within the clinic space and comments made about the experience. These notes were included in the body of text data (along with the focus group and interview transcripts) for analysis.

Data were collected by three Shona-speaking fieldworkers and a fourth researcher working with an interpreter. We analysed the data transcripts using the thematic network technique (Attride-Stirling, 2001). This technique involved carefully reading and then coding text sections according to our research interest in indigenous community networks that support ART access and adherence.

OBSTACLES TO ART ACCESS AND ADHERENCE

Before discussing the various forms of social participation helping people access and adhere to ART, we briefly describe the various obstacles facing those in need of ART in Manicaland (see also Skovdal, 2011a, c, d).

Poverty is a key constraint on adherence, hindering patients’ ability to access the clinic and take their drugs in many ways, particularly around a lack of food and money. Some patients discontinued their treatment because they struggled to find nutritious food to accompany their treatment, witnessed little progress and experienced the discomfort that comes with taking powerful drugs on an empty stomach. Patients also struggled to meet the transport costs and hospital fees associated with attending monthly clinic reviews and picking up their supply of antiretroviral drugs. Medicine other than antiretrovirals, such as drugs to treat opportunistic infections, must be purchased. Patients who had to take on extra work or travel in search of support from family members struggled to attend appointments and take their pills on time.
At an institutional level, some churches and aspects of the health services available presented barriers to optimal ART adherence. The Apostolic Church was often cited for ignoring the impact of AIDS and discouraging its followers from taking medicines. Health services were constrained by staff shortages, resource constraints, poor management, difficulties with repairing dysfunctional equipment, power cuts and limited access to water.

Beyond material and institutional constraints, social norms and stigma also created challenges. Men in particular saw HIV as a threat to their identity and exhibited a profound fear of the disease. Sickness and hospital visits were associated with weakness and the loss of capacity to provide for the family. Men also feared that testing positive would represent them as irresponsible and promiscuous. This fear led them to avoid visiting the clinic for testing and treatment. Notions of masculinity and associated male fear of HIV were also reported to cause some men to undermine women’s treatment (see Skovdal et al., 2011a). Women were often dependent on their husbands for financial resources and were unable to access treatment if their husbands did not support them. Many women felt unable to disclose their HIV status to their husbands, forcing them to take their pills in secret and act without a supportive treatment partner. There were some reports of men refusing to let their wives take ARVs or stealing the drugs for their own treatment. Women also reported feeling vulnerable to re-infection because of their husband’s extra-marital relationships and being stopped from attending clinic or support group meetings because husbands feared being associated with HIV.

People repeatedly spoke of stigma in the general community as a key obstacle to effective HIV/AIDS management. HIV’s sexually transmitted nature links a positive HIV status to deep shame and being labelled ‘promiscuous’. The fear of being considered promiscuous is a reason many people choose not to know or confirm their HIV status and are hesitant to access treatment openly.

**SPECIAL GROUPS THAT FACILITATE ACCESS AND ADHERENCE TO ART**

These dimensions of context can all present obstacles to ART access and adherence. However, our research found that various forms of community support helped people overcome these barriers and achieve high levels of ART adherence.

**Formal health-related groups and interventions**

Formal groups facilitated or supported by NGOs and outside funders include HIV support groups (often linked to clinics), NGO-linked community HIV education and NGO financial and food aid networks. These groups played a major role in facilitating ART access and adherence.

**HIV support groups**

HIV support groups were the most frequently and emphatically discussed form of social support in interviews and focus groups with people on ART. HIV support groups, usually organized by clinics or NGOs, were mentioned repeatedly as a major facilitator of optimal treatment. People spoke passionately of their HIV support group as central to their ability to cope with life as an HIV-positive person and ART adherent. Support groups provided people with an opportunity to speak openly with others in the same situation. They offered a vital connection to others and a place to share problems and gain confidence to cope with challenges: ‘Every time when I am feeling low, I rely on the support group. I talk about it with my colleagues in the support group’ (TE, female, ART patient).

Interviewees and focus group participants discussed how support groups encouraged them to keep attending clinic appointments: ‘...People still need a lot of encouragement and push. As members of support groups we keep encouraging each other not to miss our reviews’ (AL, female, ART patient). Rather than saying the support group *reminds* people to go to the clinic, FGD participants like TS (above) said that the support group *encourages* people to remember to go to the clinic. The issue is not presented as people actually forgetting to go to the clinic. Instead, it is discussed as an issue of people losing the encouragement and sense of hope necessary to ‘push’ them into continuing to attend appointments. This difference highlights the role of social supports to create a facilitating environment in which people can overcome the many barriers to ART adherence.
Practical information is also exchanged in support groups, such as recommendations on using condoms to avoid re-infection, when to visit the clinic and tips on how to adhere correctly (such as sending one another’s children to remind each other, getting an alarmed watch and carrying pills to work in case of unexpected overtime). Support groups can also provide people living with HIV/AIDS (PLWHA) access to income generating projects, as mentioned below:

We are also happy that HIV positive people here are organized and we have our support group. It is so encouraging to have an arrangement whereby we meet on a regular basis as people living with HIV/AIDS. There are prospects that we can do more income generating projects. (OT, female, ART patient)

While financial support was considered desirable, our FGD and interview participants were more emphatic about the emotional and social elements of support groups. The following quotation highlights the types of positive emotional and social exchanges that can occur in HIV support groups. When asked what she would say to someone newly diagnosed as HIV positive, MA replied:

I will tell the person that I have been through the same road and I have been able to get advice and counseling from others at the support group. I will advise the person to join the support group. I will discuss with the person all the fears I used to have and how I overcame them. I will also advise them to go to the clinic every time they don’t feel good. (MA, female, ART patient)

Support groups offer a range of essential supports, including: talking to others undergoing the same process, discussing fears, exchanging practical advice about going to the clinic, rebuilding a shattered sense of self, accepting one’s status and raising hope among newly diagnosed people for ongoing health through treatment. Members of support groups also reported a desire to reach out beyond their group to discuss HIV with the larger community: ‘I think as members of support groups, we should always educate others we meet in the community about the goodness of going for HIV tests’ (TH, female, ART patient). This interest in reaching out to the general community highlights that support groups have enabled members to resist stigma to an extent that they can talk publicly about HIV. Members of support groups expressed a positive sense of self, speaking of their groups as having a responsibility to help others in the community.

NGO-linked community education

HIV education programmes in the area had an indirect link to facilitating ART adherence. Peer education often focused on clearly outlining the ways in which HIV spreads, ensuring families living with an HIV-positive person that regular interaction would not lead to infection. Education programmes can build awareness of the treatment options available, encouraging more people to get tested for HIV earlier. In the following, a woman on ART expresses her approval of education campaigns, linking education to early engagement with healthcare services:

I think NGOs that deal with HIV/AIDS issues should continue the good work … Continue visiting and talking to people … People should be educated that it’s better to go to hospital before they are bed ridden. I think information campaigns should continue. (MA, female, ART patient)

Healthcare workers expressed faith that NGO education programmes could increase support available for PLWHA and their carers, especially elderly grandparents caring for children on ART. In the following quotation, a nurse illustrates how indigenous local volunteer groups accessed NGO support to run community education programs aimed at building supportive environments for children on ART and their carers:

We have talked to the home based care volunteers about the problem [of grandparents struggling to support their grandchildren on ART]. They then approached [an NGO] for assistance to facilitate a workshop. They educated the community that they should try to build trust with grannies who are caring for orphans. In the event that the granny volunteers to disclose the status of the child then the community can also become the child’s treatment partner.’ (RS, female, nurse)

The network of actors discussed by RS (nurses, local volunteer groups, an NGO, community, grandparents caring for children on ART) highlights the need to engage many groups to build supportive environments for people on ART.
NGO-linked financial and food support networks

Support networks involving NGO contributions of financial support and food were frequently cited during interviews and focus groups as a vital facilitator of optimal treatment. Food aid, distributed by local NGOs to families with HIV positive members, served to help overcome material, symbolic and relational barriers to treatment. On a material level, increasing the amount of food available in the home helped ensure families could access adequate nutrition. Having enough food to go around for all members of the family ensured that PLWHA could eat the necessary meals to accompany each dose of antiretroviral pills. Access to food for families headed by grandparents was a vital step in enabling children on ART to receive optimal treatment and nutritional support.

Informants reported that people became more open to being tested as a way to access food aid, as discussed below:

[Before,] it was never like that. Nobody would really want to be associated with such a disease. A lot of people now want to get tested so that they can also get some food which is sometimes given to people living with HIV/AIDS. (GI, male, ART patient)

In addition, food aid strengthened symbolic and relational support for PLWHA in their households by reducing the burden of caring for sick family members. Having an HIV-positive person in one’s home enabled families to access much needed food aid.

I would say that what encouraged most people is that… [An NGO] initiated food handouts… People started flocking here to come and get tested. They wanted to know whether they are HIV positive or not. Almost everyone came for testing. (BE, female, nurse)

MU, a nurse, points out that the food packs both encourage testing and adherence to clinic appointments.

People want to get tested so that they can also access the food aid. Those already on ART also make sure they come every month because that’s when they will be getting their food packs. (MU, male, nurse)

Men have been found to be more resistant to HIV testing and treatment than women (Skovdal, 2011a). Food aid has played a particularly important role in encouraging men to get tested. Allowing HIV-positive people to access food aid appears to have enabled some to reassert their masculine identity as providers for the household.

Indigenous, community-initiated groups

Communities have extensive indigenous networks of support which exist without external funding or organizations. A recent study found that 34% of men and 58% of women in Zimbabwe were members of at least one functional community group (Nhamo et al., 2010). These groups include church groups, burial societies, rotating credit societies, farmer’s groups, sport and dance clubs, youth clubs and women’s groups. While many of these social groups likely have indirect effects on access and adherence to ART, two groups in particular (home-based care groups and church groups) emerged during our research as playing a central support role.

Home Based Care groups

One of the most remarkable indigenous community initiated groups in Manicaland are Home Based Care (HBC) groups. Closely associated with support groups and often linked to churches and women’s groups, HBC groups are voluntary organizations with primarily female membership that visit the homes of sick people in their communities. They offer to help with cooking and cleaning and will provide encouragement, spiritual support (praying for the sick) and advice (encouraging a healthy diet and to visit the clinic). At times, they even helped transport people to clinics for HIV testing and treatment. HBC networks were said to play a particularly important role as treatment partners for children on ART living with elderly guardians:

… On the challenges of old carers, the workshop came up with resolutions that it was the responsibility of the HBC volunteer to assist them so that the child correctly take his medication. If she [the HBC worker] is visiting someone she should have another person monitor the child. (RS, female, nurse)

Often, home-based care workers were the first response point to HIV in the community, by
suggesting chronically ill people visit the clinic and by offering guidance to local people seeking advice. For example, widowed women often sought help from HBC workers after their husbands passed away from suspected HIV. Members of HBC groups reported encouraging them to get tested. These volunteer groups, most of which operate without office space or financing, were referenced many times during interviews and focus groups as a source of practical and emotional support.

Church groups

Churches play a somewhat conflicted role in the narrative of HIV in Manicaland. While they perpetuate some views that lead to fear and stigma surrounding HIV, they also provide a pillar of support and encouragement for those caring for PLWHA in very difficult circumstances. The support provided to PLWHA can help them adhere to ART.

Many people drew social, spiritual and occasionally material support from their faith and from their fellow church members. Church members worked individually or organized in groups to provide a range of supports. They supplied money for PLWHA to buy food or other goods and get transportation to the hospital and pay medical fees. There were many reports of church members being motivated by their faith to physically care for PLWHA (washing them, cooking for them, carrying them inside or outside, applying lotion to skin infections) and donate labour in the form of ploughing fields or fetching things (such as medicines). In many cases, churches organized members in groups to provide care for families of PLWHA (especially bathing and feeding the children of PLWHA) and to have ongoing prayer circles for PLWHA.

Informal networks and relationships

Family/home networks

The network of support available to PLWHA in the home has a strong effect on ART access and adherence. Respondents reported that their family members encourage them to take their drugs and remind them about upcoming appointments. Treatment partners and, in the case of children on ART, adult carers and guardians can provide practical, material and emotional support. Other people in the home, including older children, can also help create a supportive context for people on ART. In the following quotation, a nurse highlights the link between adherence and family support:

I have realized that generally [those who adhere to ART are] those people who have others who support them in the family... Those who don't have any support from family members are the ones who would say, 'Some days I forgot to take the pills'. (EV, female, nurse)

Carers of children on ART repeatedly stated the strength of their commitment to support optimal ART adherence. They emphasized their commitment to the child’s well being and recounted their efforts to ensure that children attended their monthly hospital review and accessed the food and drugs necessary to stay healthy. Strong family links also served to encourage PLWHA to adhere to their treatment. The desire to see one’s children grow up and to support the family was often cited as a central consideration and source of hope for those on ART:

I love my family so much that I don’t want to die and leave them so I religiously do what I am supposed to do to keep myself fit. I try to be there on all appointments... My main motive is to keep all that I am advised to do so that I can at least look after my children and at least see them through their young ages. (AG, female, ART patient)

Older children were frequently reported by interviewees to help facilitate ART adherence of adults or younger children in the home. As MA, a nurse, explains that children sometimes had higher literacy skills than their parents and, along with other adults in the home, could help those on ART remember when to take their pills:

Let’s say at times it is a mother or father who can’t read, he can tell his children to tell him when the time is 6 o’clock so that he can take his medication. Explaining to family members the instructions of taking the medication helps a patient take the medication properly as they would remind him when the time for taking his pills is due. So you would find children saying to their mother have you taken your pills it is now 6 o’clock am or pm. So it helps that if children or relatives know about your status they can help in taking their medication. (MA, female, nurse)
Elderly guardians (usually grandparents) frequently referenced the contributions made by children, both financially through bringing money into the home, and practically, through doing chores and reminding them about a younger child’s pill time and appointments.

The other children are the ones who are reminding me, they remind him [the child on ART] to take the tablets and they also tell me that he has taken the tablets and is now leaving for school. (NK, female, elderly guardian of child on ART)

ART patients and nurses stressed that even one key supportive family member can make a huge difference to adherence and overall patient well being. OT, an ART patient, describes the importance of her strong relationship with her daughter-in-law:

My daughter-in-law is my source of strength and support. She does not have living parents herself but she cares for me as if I was her own mother. If she gets a message that I am not feeling well the next morning she will be here to see me. I want to thank God for my family because they support me so much. (OT, female, ART patient)

Extended family also played a support role, often by sending food and money to PLWHA. This was particularly the case when PLWHA had relatives working in the cities.

Community/neighbourhood networks
In conditions of poverty, a key contributing factor to ART adherence is community support. One patient highlighted how people in his village have organized themselves so that they all support each other.

The best thing about my village is the way we are living. When it comes to ploughing, people share knowledge so that they can plant for themselves and sell to each other. People are encouraging each other to take their children to school. If there is anyone who is sick, and the relatives have died, people will come and help. (KA, male, ART patient)

Relationships with healthcare providers
The development of positive long-term relationships between healthcare workers and patients was cited by participants as central to achieving optimal adherence. Patients and care givers attended several sessions with both HIV nurses and HIV counsellors before being initiated on ART and after initiation, at regular periods throughout treatment. In the following quotation, a nurse emphasizes the importance of developing strong nurse–patient relationships:

That relationship or that openness between the nurse and the patient can encourage a patient to adhere to drugs. Then health education between the patient or the family member or the caregiver and the nurse can encourage adherence of the patient. (MS, female, nurse)

Developing trust and mutual respect between healthcare workers and patients encouraged patients to continue coming to the clinic and to openly discuss confusion, adherence problems and concerns. Patients spoke frequently of the importance of networks of support available through the clinic. In the following, TC, an ART patient, drew on her relationship with the counsellor at the clinic for emotional support and a referral to a home based care group:

In fact for me it was really hard, very hard indeed, especially when I first discovered that I was HIV positive. I got so stressed...So I decided to go back to the hospital and discussed my issues with the counselor who was there. She talked to me at length and also referred me to the home-based care team who talked to me and try to make me understand that it was not the end of my life. (TC, female, ART patient)

Patients valued the dedication of healthcare staff and often described them as a key source of support.

DISCUSSION
Social participation offers people on ART and their carers access to vital forms of support to overcome obstacles to adherence. Externally implemented programmes, such as the roll out of ART across sub-Saharan Africa, can benefit from understanding and working with pre-existing community support networks.

HIV support groups were the most emphatically praised form of social participation by ART patients, with many suggesting that these groups offered them emotional support needed to gain hope, remain committed to treatment and challenge stigmatizing attitudes (Campbell et al., 2011). NGO food and income generation support helped PLWHA overcome material
barriers to optimal treatment as well as relational and symbolic barriers through restoring their capacity to contribute food or money to their households.

Home-based care groups emerged during our research as remarkably dedicated and valued volunteer organizations. ART patients and healthcare staff frequently referred to HBC groups as acting as emotional and practical support. Church groups also supported people on ART, primarily through tending to the sick. The extensive work done by these two groups to encourage HIV testing and ongoing ART was deeply valued by PLWHA and their carers.

Family networks were another resource available to people on ART with great potential to help them access and adhere to ART. Treatment partners, such as a spouse or (in the care of children) guardian, provided emotional support and encouragement as well as practical help. Family members reminded ART patients about appointments and when to take their pills, although we did also find that elderly guardians struggled in their role as treatment partner to HIV-positive children in their care (Skovdal, 2011b). Families also helped ART patients access enough money for food, travel and hospital fees. Strong relationships between healthcare providers and patients enabled people on ART to access optimal ART. Counselling before and throughout treatment was cited as a very valuable form of support whereby PLWHA gained both information and a sense of camaraderie and hope.

CONCLUSION

This paper illustrates that even in highly resource-constrained environments, a wide range of indigenous community resources are available to promote positive responses to HIV. These community resources facilitate the success of ART, an external intervention, through providing social, emotional, spiritual and material support for those on treatment and their families. Through these extensive indigenous networks of support PLWHA are able to overcome many of the barriers in order to access and adhere to ART. Supporting optimal ART adherence necessitates that the clinical system works with these pre-existing support networks.

ACKNOWLEDGEMENTS

The authors are grateful to all the research participants. We also thank Cynthia Chirwa, Samuel Mahunze, Edith Mupandaguta, Reggie Mutsindiri, Kundai Nhongo, Zivai Mupambireyi and Simon Zidanha for translation, transcription, research and logistic assistance.

FUNDING

This research was supported by the Wellcome Trust.

REFERENCES

Attride-Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. Qualitative Research, 1, 385–405.
Campbell, C., Skovdal, M., Madanhire, C., Mugurungi, O., Gregson, S. and Nyamukapa, C. (2011) ‘We, the AIDS people...’: through what mechanisms have antiretroviral therapy created a context for ARV users to resist stigma and construct positive identities? American Journal of Public Health, 101, 1004–1010.
Gregson, S., Gonese, E., Hallett, T., Taruberekera, N., Hargrove, J. and Lopman, B. et al. (2010) HIV decline in Zimbabwe due to reductions in risky sex? Evidence from a comprehensive epidemiological review. International Journal of Epidemiology, 39, 1311–1323.
Nhamo, M., Campbell, C. and Gregson, S. (2010) Obstacles to local-level AIDS competence in rural Zimbabwe: putting HIV prevention in context. AIDS Care, 22(S2), 1662–1669.
Richardson, C. (2005) The loss of property rights and the collapse of Zimbabwe. Cato Journal, 25, 541–565.
Skovdal, M., Campbell, C., Madanhire, C., Mupambireyi, Z., Nyamukapa, C. and Gregson, S. (2011a) Masculinity as a barrier to men’s use of HIV services in Zimbabwe. Globalization and Health, 7, 1–14. http://www.globalizationandhealth.com/content/pdf/1744-8603-7-13.pdf (last accessed 5 March 2013).
Skovdal, M., Campbell, C., Madanhire, C., Nyamukapa, C. and Gregson, S. (2011b) Challenges faced by elderly guardians in sustaining the adherence to antiretroviral therapy in HIV-infected children in Zimbabwe. AIDS Care, 23, 957–964.
Skovdal, M., Campbell, C., Nhongo, K., Nyamukapa, C. and Gregson, S. (2011c) 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, 26, 296–318.
Skovdal, M., Campbell, C., Nyamukapa, C. and Gregson, S. (2011d) When masculinity interferes with women’s treatment of HIV infection: A qualitative study about adherence to antiretroviral therapy in Zimbabwe. Journal of the International AIDS Society, 14, 1–7. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3127801/pdf/1758-2652-14-29.pdf (last accessed 5 March 2013).
UNAIDS. (2010) Global AIDS Response Progress Report 2012. Zimbabwe Country Report. http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_ZW_Narrative_Report.pdf (last accessed 5 March 2013).

WHO. (2010) World Health Statistics 2010. WHO Press, Geneva. http://www.who.int/whosis/whostat/EN_srWHS10_Full.pdf (last accessed 5 March 2013).

ZCSO. (2007) Zimbabwe Demographic Health Survey 2005/6. Central Statistics Office, Harare, Zimbabwe. http://www.measuredhs.com/pubs/pdf/FR186/FR186.pdf (last accessed 5 March 2013).

Zimbabwe Ministry of Health and Child Welfare. (2009) Zimbabwe National HIV and AIDS Estimates. Zimbabwe Ministry of Health and Child Welfare, Harare.