

KNOWING YOUR RIGHTS IS SOMETHING, BUT NOT ENOUGH: EXPLORING COLLECTIVE ADVOCACY AND RIGHTS TO TREATMENT AND SERVICES FOR PEOPLE LIVING WITH HIV IN TANZANIA

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ABSTRACT

Citizen and collective advocacy is often regarded as a critical way to hold governments to account for the services they are expected to deliver and combat the marginalisation of certain groups. This article presents a qualitative analysis of the application of a “rights-based” and advocacy approach as a means for People Living with HIV (PLWHIV) to claim their legislative rights to basic services such as education, and combat behaviour that is stigmatising. Data was obtained from a project in Northern Tanzania that works with more than 40 self-help groups to empower them to claim their rights as stipulated in the 2008 HIV/AIDS Act. The findings suggest that knowing one’s rights does seem to enable groups to start asking questions about their entitlements to services. However, it is not enough for one to simply know their rights when their actions and responses are fundamentally limited by lack of resource and power, vague legislative commitments and weak local institutional capacity to respond. These findings have implications for the many social policy initiatives, which seek to use citizen or group-based advocacy to address discrimination or poor public service delivery.

Keywords: advocacy; accountability; PLWHIV; right-based approach; Tanzania



INTRODUCTION

Advocating for the rights of marginalised groups is seen by some as a way of addressing discrimination (e.g. poverty and lack of access to basic services). This is the basis of the rights-based and advocacy approach, which seek institutional and legal reform to address the structural disadvantage of marginalised groups. Such approaches are commendable as they promote the participation and inclusion of the marginalised groups into existing institutions. Advocating for the interests and rights of these groups through building their capacity and ability to assert themselves and articulate their needs forms a critical aspect of bringing about change. This process is regarded as “empowering”, and is often seen to encourage increased accountability on the part of governments to provide services (Green 2013).

However, in reviewing the outcomes of such approaches, one must also acknowledge their limitations. Relationships of power and control over resources cannot be easily overcome through small-scale advocacy and the promotion of a rights agenda (Tadros 2015). Samuel (2007) reminds us that changing discriminatory positions and relationships is an inherently political process. Significant structural inequalities in power and resources may severely constrain the agency of individuals to assert themselves, even if such rights formally exist.

This article begins by contextualising the response of the Tanzanian state to the HIV/AIDS pandemic. The article further shows how community-based organisations and NGOs came to dominate social policy and practice in this area. The article also presents evidence drawn from the experiences of People living with HIV (PLWHIV) in Tanzania by analysing an attempt made by a local Tanzanian NGO to utilise a rights-based approach (RBA) as well as the advocacy approach to build the capacity of groups of PLWHIV to negotiate and claim their rights as contained in the 2008 Tanzanian HIV/AIDS Act.¹ Forty-one qualitative, semi-structured interviews with PLWHIV group members and key informant were used to examine emerging narratives of rights, group identity, claims and access to services.² We then conclude by establishing what roles rights-based and advocacy approaches play in addressing discrimination and ensuring that marginalised groups get access to services.

HIV/AIDS, Its Impacts, Responses and Consequences

HIV/AIDS acts as a shock on people’s livelihoods both in the loss of economically and socially productive individuals, but also in the increased burden of care for the sick and

1 Village-to-Village (Tanzania) implemented the project between 2008 and 2011, funded by the UK DFID Civil Society Challenge Fund. Anna Mdee assisted Lisa Thorley and Tanzania staff to formulate the original project proposal but was not involved in the implementation of the project.

2 The data was collected by Lisa Thorley (then Chair of Village-to-Village (UK) with the assistance of the Project Manager, Paul Otieno). This exercise served as a Learning and Evaluation process of the two NGOs and aimed to reflect on the successes and failures of the project.

their dependents. (Baylies 2002; Morton 2005; Samuels and Rutenburg 2008; Slater 2004; White 2005). In the context of sub-Saharan Africa (SSA), HIV/AIDS magnifies gender inequalities, in that women are less able to avoid risky sexual contact, but also disproportionately bear caring responsibilities. In addition, women tend to be stigmatised more often than men (Anderson 2012; Beckmann and Bujra 2010; Burchardt 2010; Copeland 2011; Feldacker, Ennet and Speizer 2011; Kathewera-Banda et al. 2005; Oglethorpe and Gelman 2008; Poku and Mdee 2011; Seckinelgin, Bigirumwami and Morris 2011). Therefore, HIV/AIDS, poverty and inequality are intrinsically linked – hence, when analysing the local response to HIV/AIDS, it is impossible to do so without thinking through issues of poverty, power, inequality and access to basic services.

In the neo-liberal period debates on poverty reduction and the responsibilities of the state to deliver basic services to all have led to increased engagement with those advocating for community-driven development, and the assumed rise of civil society actors that will cover the inadequacies of state provision (Lange 2008; Mansuri and Rao 2004). The global response to HIV/AIDS is underpinned by this discourse (Poku and Mdee 2011). It is sometimes assumed that non-state actors can deliver services more efficiently and equitably than the state. However, critics suggest that this approach actually leads to increased institutional fragmentation, localised conflicts for resources and even entrenchment of inequalities. Governments have negated their responsibility to deliver service; often hiding this behind promises of “decentralisation” that supposedly “empowers” those at local level, but does not provide a supporting financial and strategic institutional framework in which alternative actors can operate (Boesten, Mdee and Cleaver 2011; Cleaver and Toner 2006; Lange 2008; Wild et al 2015). This is what appears to have played out in the response to HIV/AIDS in most of sub-Saharan Africa, perhaps with the exception of South Africa (Poku and Mdee 2011).

While it can be argued that neo-liberal approaches to poverty reduction³ makes the state lax to take the responsibility for eradicating poverty and inequality, they do not preclude the possibility for social mobilisation, solidarity and collective action by community-based groups. This article explores the nature and function of groups of PLWHIV in Tanzania, with regards to this role. Earlier studies have analysed the role of these groups in self-help initiatives and home-based care (Boesten 2007; Boesten 2011, Marsland 2012); and also in relation to the idea of biological citizenship (Beckmann et al. 2010). PLWHIV groups in Tanzania emerge from such research as clientelist, and engaged in a struggle for resources that *might* be accessible to them, owing to their status. Green’s (2013) idea of “anticipatory development”, where local NGOs create a bureaucratic visibility (committees, documents, visions etc) in anticipation of receiving funds for development is particularly pertinent with respect to these groups.

3 A neo-liberal approach refers to economic growth that is regarded as a critical driver of poverty reduction, and is in favour of a state that facilitates rather than deliver public services. See Chang (2012)

HIV: The Social Policy Response in Tanzania

It was estimated in 2014 that 1.5 million people in Tanzania were living with HIV 800 000 of these were women over the age of 15 (UNAIDS 2014a). The cumulative number of PLWHIV enrolled in HIV care programmes in 2014 was 1 366 401, with 831 663 of these being women over the age of 15. A major concern; especially with regards to undetectability and universal treatment access for all is that only 512 555 of PLWHIV were on ARTs (UNAIDS 2014a, b).

In 2010 97 per cent of funding for HIV/AIDS in Tanzania came from foreign donors, while 86 per cent was off-budget; and therefore, beyond the control of the government. TACAIDS (2010: x) notes that “national ownership is weak and accountability is poor.” Many donors pool resources for local organisations through donor-created umbrella bodies such as the Foundation for Civil Society or the “Rapid Funding Envelope”, which led to considerable resources being spent on an array of competing NGO-led projects, rather than on a systematic structural response by the Tanzanian state. TACAIDS (2010) has expressed its frustration in advocating for increased national funding to enable more meaningful action and coordination at local government. In this environment, PLWHIV must negotiate their needs and entitlements with a multitude of organisations (Boesten 2011; Marsland 2012). The Tanzanian 2008 HIV/AIDS Prevention and Control Act provides one potential route into this terrain. This article therefore, explores an attempt by one local NGO to use the Act to try an enable PLWHIV to assert their rights to access support, treatment and be widely represented.

A Rights-Based Approach for PLWHIV

The point of departure for a rights-based and advocacy approach is the assumption that citizens have rights that can be claimed from the state, often with reference to specific national legislation, a national constitution informed or linked to international instruments such as the United Nations Universal Declarations of Human Rights or the International Covenant on Economic, Social and Cultural Rights (ICESR).⁴ The existence of “rights” in international treaties does not mean that such rights are either written into law in signatory countries, or that there are resources to effectively enforce those rights that can be claimed by individual citizens. Rights-based approaches begin from the normative aim that citizens can claim and realise such rights. However, for such claims to be made, citizens must understand and know the nature of the rights, as well as the mechanisms and institutions they can use to claim those rights. Where citizens do not know their rights, it is often assumed that they need to be “sensitised” of their existence in order to be able to claim them (Green 2013).

4 <http://www.un.org/en/universal-declaration-human-rights/> ; <http://www.ohchr.org/EN/ProfessionalInterest/Pages/ICESCR.aspx>

There is some evidence of the value of a rights-based approach to the awareness and mobilisation of people in attempting to formulate claims; based on the knowledge of legislative rights – see for example a study by Cousins (2009) on land rights in South Africa, or the increased numbers of women in legislative bodies through legislation on quotas (Tadros 2015).⁵ The Treatment Action Campaign (TAC) in South Africa serves as a good example of success stories, after it has applied the constitutional and legislative rights to claim the rights to treatment for People Living with HIV (Heywood 2009). However, a notable feature of the South African context is that the state has sufficiently robust legal institutions and sufficient resources to enable a national programme to be implemented.

Gready (2008) argues that a rights-based approach is more than a direct application of the law. He further argues that the approach applies the law indirectly and forges links between the direct and indirect use of the law, through the centrality of normative principles such as participation, equality and non-discrimination, transparency, empowerment and accountability. Such principles then feed into the political and social applications of esoteric legal frameworks and become real and accessible in the everyday and local interactions of citizens and their representatives. Gready (2008) refers to this as a “legal boomerang” and entails the renegotiation and re-imagining of a variety of contesting legal and rights regimes (customary, religious, national and international) at local level.

It is hoped that this research would make it possible for us to draw some tentative conclusions on the four suggested strengths of this approach, as stated by Gready (2008) as (i) an RBA forces us to re-focus on the responsibility of the state to promote rights and ultimately human development, (ii) it enables a focussed and specific engagement on the accountability of rights-holders and duty-bearers (not only in relation to the state, but to any actors working in the public sphere), (iii) it re-politicises poverty and processes such as participation and representation, and (iv) necessitates a structural and relational understanding of poverty, and is therefore, underpinned by narratives of power.⁶

Our analysis of the activities of an NGO in Tanzania enables us to explore whether an overt rights-based framework for supporting PLWHIV groups can provide a strategic and institutionally grounded route for action. If this is the case, then it should follow that when PLWHIV have defined their right and entitlements to services, and are moreover aware of, and understand those entitlements; they are able to organise themselves to present claims to those rights. If such an assumption is proved to be right, then there is a case to support the mobilisation of such groups so that they can claim their rights.

5 An RBA also underpins a number of large NGO civil society projects in Tanzania – for example, Oxfam and Twaweza work on Gender-Based Violence; and similarly work by Caucus for Children’s Rights (CCR) and Save the Children on the rights of children.

6 Such conclusions are supported by work on rights and chronic poverty (Cornwall and Nyamu-Musembi 2004; Green and Hulme 2005)

Rights-Based Work with PLWHIV in Tanzania – A Case Study

This article, which is also an exploratory case study draws on data from Moshi Rural and Same Districts in Northern Tanzania. Moshi Rural and Same Districts are rural agricultural areas with some small townships. Few people are employed in the formal sector, with the majority making a living from agricultural production and small scale, informal business activities. The 45 groups of PLWHIV surveyed in this study were based in a mixture of small towns (with greater access to transport and health infrastructure), and in remote mountainous areas with limited infrastructure and transportation links.

Village-to-Village (Tanzania), a local NGO based in Uchira in Moshi Rural District, which had links with the UK, was awarded a grant of £33,000 under the UK Department for International Development (DFID) Civil Society Challenge Fund (CSCF) in 2008. The project sought to apply a rights-based approach in working with groups of PLWHIV in 40 villages. The aim was to use the grant to support existing and new support groups formed by PLWHIV to access pre-existing representational structures such as the “ward multi-sectoral AIDS committee” (WMAC). It was argued that the activities of these groups could be strengthened if members can increase their knowledge of the contents of the Tanzanian 2008 HIV/AIDS Act. The aim of the project was to encourage PLWHIV to use entitlements under this Act to negotiate better access to services and wider representation through active engagement and activism.

Tanzania has chosen to enshrine the rights of PLWHIV into law. Provisions of the 2008 HIV/AIDS Prevention & Control Act are wide-ranging and relate to fighting the stigma, protecting the rights of citizens to have free access to education and Anti-Retroviral (ARV) treatment, amongst others. However, it is worth noting that most of the provisions of the Act are aspirational rather than concrete guarantees of services.⁷ Furthermore, they are contingent on the availability of sufficient resources.

This study also aimed to understand how the groups of PLWHIV navigated this terrain of vague entitlements, using the 2008 legislation. The primary aim was to establish whether the increased awareness of these entitlements, combined with collective agency through group membership, resulted in greater access to resources and support amongst themselves, or from the local agencies and gatekeepers.

Data was collected by interviewing PLWHIV between November 2010 and January 2011; through semi-structured interviews with 41 groups of PLWHIV; in addition to key informant interviews with Project Staff and Local Government Officers. Those interviewed were members of the support groups for PLWHIV who volunteered to take part. Some interviewees were group leaders while some were nominated by group leaders. To this extent, those interviewed were active and engaged group members. Therefore, the data should be considered with this caveat. The Project Manager, Paul Otieno worked with Lisa Thorley in collecting the data. It is important to understand

7 See: http://www.saflii.org/tz/legis/num_act/haapaca2008336.pdf for the full provisions of the 2008 HIV/AIDS Prevention and Control Act.

that the purpose of collecting the data was not to produce an uncritical and donor-focused evaluation report; but to undertake a critical and reflective learning exercise of the two organisations. Therefore, a wide range of views and experiences of the project were sought.

The majority of the people who participated in the research were female (31 out of 41); many of which came from female-headed households, who had either lost their husbands through AIDS, or had been abandoned after they were diagnosed. With the exception of one of the interviewees, who was in formal employment, all the other participants were either subsistence farmers, casual labourers, or had informal businesses.

KNOWING YOUR RIGHTS; BUT WHAT RIGHTS?

The 41 interviewees discussed a range of issues that included an assessment of livelihoods status, HIV/AIDS biography, PLWHIV group membership and level of participation, knowledge of HIV/AIDS legislation in Tanzania, as well as how they had or had not used this information to access services and fight the stigma.

Only one person out of 41 people who was interviewed said they were aware of the existence of the HIV/AIDS Act, 2008 prior to their membership, and that they were involved in the Village-to-Village project. Many of the PLWHIV were diagnosed before the HIV/AIDS Prevention and Control Act, 2008 came into effect. Data from the interviews indicate that the majority of them discovered that they were HIV-positive in either 2006 or 2007 – at the time when the Tanzanian government started a campaign to encourage voluntary counselling and testing (VCT). However, none of the participants who were diagnosed between 2008 and 2010 were apparently informed of their rights. This may lead to the conclusion that health officials at testing centres were either not aware of the Act, or that they did not have the capacities to disseminate the necessary information. One recurring theme throughout the interviews was that interviewees were informed that they should join or form a support group for PLWHIV at the point of diagnosis. Fifteen of the interviewees, who were diagnosed after 2005, remembered that they were also informed of the places where they *could* access ARVs for free, while others reported that they were not aware of their right to access free ARVs.

GROUP SOLIDARITY AND SUPPORT– NO ALTERNATIVE

Given that all the interviewees reported that they were advised to join a support group of PLWHIV, it is perhaps surprising that at the time when this research was conducted there was no national support programme for the creation and maintenance of such groups. In many places no support groups were formed, and in numerous instances other groups were constrained by their limited capacity, lack of knowledge and resources, as well as inept leadership. It was thus, this limitation that the Village-to-Village project sought

to address. All members of the 45 groups were made aware of the provisions of the HIV/AIDS Prevention & Control Act, 2008, and were given advice on how to organise themselves and seek representation within existing local institutional structures such as the District, Ward and Village HIV/AIDS committees.

The interviews that we conducted with active group members confirm that group members value the existence of the groups. In response to the question, *why are you a member of a PLWHIV group?* participants gave a range of reasons, which fall into three categories:

- i. *Psychological reasons*: solidarity, comfort and mutual support, reducing isolation and having a purpose in life:

“In the group I can share my fears with other people who are facing the same disease as me”.

Myamba group member

- ii. *Economic reasons*: starting group business projects, attracting funding and other support from external agencies:

“The best groups have an economic project, such as vegetable gardening or chicken keeping, whereby members can work together to improve their incomes.”

Uchira group member

- iii. *Knowledge and voice*: sharing ideas, experiences and coping strategies, counter-acting stigma and advocating for change, as Copeland (2011) has argued before.

“The group is where we can share ideas with each, for example on what will be the fate of our children if we are gone. We also get knowledge on things affecting us like how to get the medication and if we are entitled to help from some other organisations.”

Myamba group member

Responses given by interviewees suggest that PLWHIV join groups to form social networks. This finding is supported by the findings of the study by Boesten (2007; 2011). It becomes easy for people who are organised to gain recognition from government and donor institutions, as they are able to mobilise to access some of the HIV/AIDS targeted services. This again supports Green’s (2013) idea of anticipatory development. The support given to the support groups for PLWHIV under the V2V-Tz project has increased their visibility and recognition by newly diagnosed PLWHIV and local government institutions. As one respondent who was diagnosed in March 2010 said,

“I did not hesitate to become a member of the group. I knew this was my best option if I was to know something about HIV/AIDS. I wanted also to find people who were suffering from the same thing so that I could confront the illness. This group is my source of strength. I have seen a noticeable difference in the village since the formation and growth of these groups, especially in the way that stigma and discrimination are addressed.”

It should be noted that not all groups of PLWHIV are equally effective; and this is a significant barrier to the broader transformational potential of a rights-based and advocacy approach. The interviewees articulated that an effective group of PLWHIV has strong leadership which is committed, fair and interested in benefiting the collective. They also indicated that members should be active and honour regular attendance, participation, cooperation, unity, trust, and respect, as well as operate through a set of agreed rules. In addition, successful groups were particularly identified as those who have initiated projects to ensure their livelihoods; where all members of the group could participate; for example, in a farming project. It was also reiterated by a number of interviewees that members needed to enjoy a nutritious diet as it is difficult for people to be effective in meetings when their stomachs are empty. Several of the characteristics of effective groups mentioned earlier are directly related to the physical capacities of group members. It is interesting to note that successful groups are perceived to be those that have a collective enterprise or project, rather than just being successful in representing the right of PLWHIV. Moreover, the groups that are identified as the most successful in running projects were those that were led and inspired by charismatic individual leaders.

Groups that were made up of members who were not active and leaders who could not mobilise their members were regarded as unsuccessful. Chronic poverty, social exclusion and illness could easily exclude the poorest and those that are very sick from accessing the benefits of group membership (see also Marsland 2012)

Given that the activities of the project cover some remote rural areas, where poverty is high and many of the interviewees are partially dependent on food aid, for the group of PLWHIV to have a “project”, and specifically an income-generating livelihoods project is seen as an important uniting factor for a group that gives it substance and purpose beyond mutual support. Most groups in the V2V-Tz project have been involved in projects that have the overall objective of generating some form of cash income; however their successes have been limited. In one village in the district of Same, one of the groups was “given” a fishpond with fish by Mildmay International (an NGO) – however none of the members knew how to cultivate and tend fish.

“We do have a fish project but we did not ask for this project, we were just given it and it is not practical for us.”

In Uchira, several interviewees spoke positively about the group’s chicken project. However, the success of many of these planned livelihoods projects were severely constrained by resources. A reoccurring theme in relation to such projects was that even if they do have some form of physical capital for example land, they lack the resources to invest in cultivating the land. In Myamba the husband of a female member of PLWHIV that was interviewed was ready to donate a piece of land to her group – however, owing to lack of financial capital the women in the group were unable to buy seeds and other inputs; and as a result, they were unable to use the land.

In this respect, the benefits that the group appears to be enjoying include mutual support and solidarity in relation to being HIV positive – but they also aspired for collective enterprise – hence only few of the interviewees raised the issue of rights, when asked about the benefits of group membership. This is perhaps an indication that the most pressing challenge that group members are facing daily is the struggle to earn a livelihood, rather than contending with the more abstract notion of being aware of their rights, and fighting to have access to basic services.

WHAT ARE THE BENEFITS OF KNOWING YOUR RIGHTS?

The data indicates quite a number of specific areas where being increasingly aware of the provision of the Tanzanian HIV/AIDS Prevention & Control Act, 2008 has made a difference to the daily experiences of PLHWIVs. Data from the interviews identified some advantages of using RBA as an organisational focus. Interviewees valued the knowledge they had gained through the project, and argued that they could now advocate for their rights and challenge corrupt and stigmatising practises through official legal channels and local institutions. As one interviewee puts it “stigmatise me and you land yourself in jail.” Similarly, corrupt health workers could no longer demand payment for ARVs as group members knew that the law granted them free access to these drugs. Other interviewees spoke of having something to focus on beyond being HIV positive.

“knowing about our rights makes it better for us to plan how we can work together, rather than us just being together because of this disease.”

However, data from the interviews has shown that the relationship between rights, knowledge and action is also context-specific; and in many cases contingent on other capacities, as it will be explored further in relation to i) access to ARVs, ii) challenging the stigma and iii) access to basic services and other support.

i. Free access to ARVs

ARV medication has become increasingly available in Tanzania and active use of the medication has increased substantially in both districts since 2005 (Boesten 2011). Thirty-one interviewees were on ARVs; and some of them indicated that they did not know that they were legally entitled to a free supply of the drugs prior to joining the support group of PLWHIV.

“Prior to knowing my rights, I did not know that ARV’s were free. I had refused to go to hospital for treatment. Having this knowledge has saved my life.”

However, this knowledge alone did not solve all the problems that PLWHIV encountered with accessing the medication; in particular those who lived in rural areas – for instance, one female interviewee reported that she had not collected her medication for several weeks as she did not have the 500Tsh (£0.20 equivalent) return bus fare to the District

Hospital. This interviewee was not the only individual interviewed who had experienced these difficulties. For those who lived in the mountainous villages of Same District, where there is limited access to transport, the walking time to the nearest dispensary could be a journey of five hours or more. Therefore, access to ARV medication was constrained by access to the physical, financial and social capital required to reach the dispensing point.

From this research, many PLWHIV do recognise this as a point of struggle and are advocating for improved access that tries to address the limited capacity of some to travel. The specifics of the HIV/AIDS Prevention & Control Act, 2008 stipulate that PLWHIV should be able to access ARV medication within a 5km radius; but with access points limited to District hospitals only, this is far from being achieved.

ii. Challenging the stigma

HIV is one of, if not the most stigmatised health condition globally – however data obtained from the interviews suggest that there are some positive impacts brought about by the specific HIV/AIDS Prevention & Control Act, 2008 provisions on stigma; which state that anyone who shows discriminatory behaviour towards a person because of their status should be prosecuted. A female interviewee gives an example of how stigmatisation can destroy the lives of those living with HIV:

“My friend experienced such high levels of stigma and abuse because of her status that she chose to kill herself. I believe that if she had known her rights then she would still be alive today as she would have had the confidence to challenge those people.”

Several interviewees related to how their livelihoods had been affected after disclosing their positive status. However, data obtained from the interviews have revealed that the stigmatisation of PLWHIV has since decreased, following the vigorous dissemination of information on the illegality of discrimination. This appears to be one area where PLWHIV have been able to act through local institutions. One woman in Myamba took her neighbour to the local customary court: *“I knew my rights so I took him to court and was awarded 10,000Tsh. But I decided not to take it as I believe he had learnt his lesson.”* This case was cited by another interviewee as having changed the perception and behaviour of local people towards PLWHIV. The impact of the Act in counter-acting stigmatisation appears to be widespread. One interviewee cited a case of a member of the community in Arusha *chini*, who repeatedly discriminated against people with HIV, but was brought before the relevant Ward Executive Officer and educated about the rights of PLWHIV before being ordered to give one month of volunteer service as a form of a fine (oral report interviewee). While these stories are encouraging, it is unclear from this research as to how many cases of this nature are being brought to the courts, as well as the extent to which they bring about behavioural changes.

Self-stigmatisation is also an issue that was expressed by interviewees: *“if you were stigmatised it was because you were doing this to yourself. With the support of your*

fellow group members and knowing the law, then people can also stop stigmatising themselves.”

Another male interviewee concurs: *“stigma has reduced tremendously. I said no to stigma and am now very open about my status. I feel that I am like a role model.”*

The above cases can be interpreted as evidence that applying a rights-based approach at local level has had some success. These cases suggest that knowledge of the legislation, mutual support and the willingness of local institutions to enact the law empowered some individuals to act differently; to their benefit. It is however, difficult to draw conclusions, based on the findings of this research alone, the degree to which stigmatisation has been reduced – as it is highly possible that one or two examples of successful cases are being repeatedly cited by interviewees.

A caveat to this potentially-positive finding is that several of the interviewees who became female-headed households talked of the loss of family land, and in some cases their children, following the death of their husbands. One woman did take her case to the customary court when her in-laws tried to evict her and successfully retained her land access and ownership, but others had not managed to retain rights to property. This is one area where a lot still needs to be done – as women already had formal legal rights to own or access land in Tanzania; but often cannot exercise this right under customary practice and therefore, outcomes for women in this situation are highly variable (see also Dancer 2015).

iii. Access to support and other basic services

There was also variation between groups in their success in accessing support and other basic services. The HIV/AIDS Prevention & Control Act, 2008 compels local authorities to provide support in the form of access to health services, ensuring improved livelihoods and better education, but only “where resources allow.” Funding for a local government co-ordinated response to HIV/AIDS response is very limited (TACAIDS 2010). This research reveals variations in the responsiveness of local government mechanisms. Some interviewees spoke positively about the local district government, and the fact it involved them in planning projects. In one case in Same district, a number of groups mobilised under the banner of *Ujasiri* (a district umbrella group bringing together small PLWHIV groups); with the Village-to-Village successfully applying for funding from the Tanzanian Social Action Fund.

Conversely, in another case the Chair of the TPC group suggested that relations with the Moshi District Council were not so effective: *“They are only active when money is involved. We were told to build chicken coops and we would be given chickens. So we built the coops but the chickens have never arrived.”*

The law also entitles children for free education; but paying school fees is only one aspect of free access to education. As one woman noted, *“yes my child can go to school for free, but the meals still need to be paid, as too does his school report, uniform and books.”* Another interviewee said her children could no longer attend school as she

was in debt, and no longer able to cater for her children's other school-related needs, other than the school fees. This perhaps indicates a lack of clarity and variation in the interpretation of the HIV/AIDS Prevention & Control Act, 2008; in relation to access to education; but this is a problem not confined to those living with HIV, but is more a function of a weak economy and ineffective policies regarding free access to education.

On the whole, interviewees expressed their frustrations at the slowness of a rights-based and advocacy approach; particularly with regards to accessing support and basic services. Interviewees speak of the frustration of knowing your rights but not being able to access them; and the fact that this is the main source of their stress.

As one interviewee puts it, *"It is painful not being able to access your rights when you know them and when they are a legal entitlement."*

CONCLUSION

Our research suggests some tentative findings that would bear further exploration. A rights-based and advocacy approach as an entry point for working with PLWHIV groups in order to link them into wider institutional and legal frameworks appear to have some limited success in one or two areas; for instance in challenging stigmatisation and (with a receptive District Council), in securing financial allocations for group enterprise projects.

Where legal rights are clearly defined and specific, for example, as in accessing ARVs and fighting stigma, these rights potentially provide a focus for action. Enforcing these rights appears to have been more successful in challenging cases of stigmatisation, where we witnessed instances where the police and customary courts acted accordingly to resolve a complaint by a member of PLWHIV. On the other hand, the fact that ARVs should be accessed from within a 5 km radius, and this requirement is not met, is a bone of contention for PLWHIVs.

The support groups formed by PLWHIV seem to provide the much needed mutual support to their members. The value that these support groups add to the quality of life of the members was acknowledged by those who were able to participate in them. In conclusion, we need to caution that this research only engaged those who were actively participating in these support groups. Some interviewees pointed out that some PLWHIV could not join the support groups; owing to ill-health, the long travelling distances to meetings; as well as shyness amongst other factors. It is therefore, important to take into account the limitations of using groups of PLWHIV as the primary vehicle for the identification of rights-bearers. This approach potentially excludes the most vulnerable and sick.

Relying on the HIV/AIDS Prevention & Control Act, 2008 as a starting point for action is fundamentally limited in two ways: i) it does not sufficiently engage with gender, reproductive rights, and the rights of women to property, following the death of a spouse – for instance, our small dataset contains several examples of women who

have lost property and often their children, on the death of their spouses. This does not only involve women living with HIV, though the latter tends to be the most vulnerable. However, one example has been noted of a customary court upholding women's rights to land and other property. Legislation governing ownership of land has already been amended in Tanzania, but is not being applied. It is also difficult for groups of PLWHIV to become experts in all areas of the law.

The state as a duty-bearer is fundamentally challenged, as a result of the lack of resources and capacity. For the HIV/AIDS Prevention & Control Act, 2008 to be successful in relation to free access to schooling, basic health services and economic development or social protection, the state needs to have coordinated mechanisms to supply these services (even if these are directly supplied by other state actors). Local government remains weak in the co-ordination of intervention.

This chronic lack of state capacity to organise and resource action at local level is not a result of over centralisation, but highly ineffective decentralisation, which led to many state functions being devolved to resource-poor ward and village councils (see Cleaver and Toner 2006 (for examples on water policy), Grindle 2004; Lange 2008; Wild et al 2015). As suggested in the beginning of this article, one of the most promising functions of a rights-based and advocacy approach is to stimulate action at local level, so that people will re-focus on what government should be doing, and demanding that it bears the duties ascribed to it. This does not only apply to PLWHIV, but for all that are poverty-stricken. This research seem to suggest that a rights-based and advocacy approach, which involves a combination of legal rights; which are enforceable by local institutions in conjunction with organised citizens might begin to make small shifts in behaviour, discourse; and perhaps ultimately; in the structural inequalities that shape poverty and the burden of HIV/AIDS. However, this is the beginning of a political struggle and not the end of a journey. Such approaches are likely to be more effective, especially when implemented in contexts with effective social protection mechanisms in place. A cash transfer in conjunction with a rights-based and advocacy approach will go a long way in overcoming some of the resource-based limitations faced by PLWHIV in engaging in livelihoods activities and accessing treatment.

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