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COMMUNITY MOBILISATION SUPPLEMENTARY ISSUE

Global expectations and local practices: HIV support groups in the Gambia

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This paper looks at the ways that people living with HIV in the Gambia, as members of HIV support groups, engaged with the programmes available to them in this context. People living with HIV engage with the global in a variety of ways. Following Ong and Collier this paper analyses the way in which people in this context experience and negotiate with the “global assemblage” around international HIV work. This can be observed in everyday practice in the formation of networks and partnerships linking people and their activities into international structures. Using qualitative methods and a grounded theoretical approach, the research followed events around HIV treatment in the Gambia 2006–2007. Looking at the support societies and their members’ struggles to gain some material support, findings show how support group members negotiated and expressed agency within the available structures. They make use of accepted frames of international action which bypass the state, presenting an internationally linked “biological citizenship” which brings associated opportunities to access resources. Through the intervention of the president and his “cure” programme, this case also illustrates that people’s commitment to the value structures implicit in these funding streams may not be as strong as might be assumed. In these circumstances two alternate treatment programmes, linked to very different values, were on offer, both backed up by the powerful machinery of either the state or international funding. The negotiation by people living with HIV of these avenues through which to acquire benefits and so support and health, calls into question assumptions of a “buy in” to global ideas and values without further scrutiny of the ways in which such assemblages function in different contexts.

Keywords: people living with HIV; support groups; networking; global funding and programming

Introduction

Internationally global health initiatives (GHIs), and disease-focused health programmes, are changing the ways in which major health issues are defined and managed (Bernstein & Sessions, 2007; Birdsall & Kelly, 2007; Dry, 2008). This restructuring forms part of the formation of global assemblages (Ong & Collier, 2005); chains of policy and practice which carry certain expectations and practices, and put into practice webs of power and knowledge which impact upon the ways in which people interpret their own condition. In the case of HIV the “Global AIDS Industry” funnels vast funds into otherwise resource poor contexts (Pisani, 2008). This has many impacts, and also reinforces the power-knowledge claims implicit in these networks of organisations.

This paper focuses on the experiences of members of support societies for people living with HIV in the Gambia, setting out some of the tensions which play out through their engagements with development partners – and through them the world of international AIDS funding. This can be observed in everyday

practice in the formation of networks and partnerships linking people and their activities into international structures. The primary focus here is on the negotiation of the “global assemblage” within this context, however, as events around the presidential “cure” unfolded it is also clear that such discourses are not all-powerful, despite their seeming domination.

Literature review

Communities of people living with HIV are linked into a global architecture of policy and funding. Ong and Collier describe “global assemblages”; global “domains in which the forms and values of individual and collective existence are problematised or at stake, in the sense that they are subject to technological, political, and ethical reflection and intervention” rather than “broad structural transformations of society or culture” (2005, p. 4). In the support groups in Burkina Faso Nguyen identifies the ways in which:

These individuals, although few in number, have become the vanguard of a much broader phenomena

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emerging in the wake of successful transnational campaigns to increase the access to lifesaving treatments in developing countries. This vanguard, I argue here, is much more than a new social movement articulated around explicit objectives. Rather, it is a complex biopolitical assemblage, cobbled together from global flows of organisms, drugs, discourses and technologies of all kinds. (2005, p. 125)

Following this, I conceive of the “global assemblage” of HIV as being constituted around both clinical and non-clinical ideas and activities. Firstly an HIV+ diagnosis involves people in a world of clinics, tests and treatments. This is primarily dictated by medical practice. However, such practices are also socialised; for instance, the practices of VCT and specifically of counselling are implemented as universals, and yet are often negotiated by both practitioners and patients when transplanted to different contexts (Angotti, 2010; MacGregor, 2010). Standardisation in both care and support activities can be seen in the ways in which country applications have sought to secure international funding streams, looking to what will be funded rather than the specifics of the epidemic (Brugha et al., 2005). This diagnosis also links people into a web of meanings and international networks of funding associated with HIV.

Birdsall and Kelly’s focus on the dynamics of international HIV funding in relation to civil society organisations further illustrates the spread of AIDS responses, with a focus on Africa, outlining “a dramatic increase in the number of civil society organisations involved in AIDS responses... The scale of this growth is such that it must be regarded as a socio-political phenomenon” (2007, p. 187). As these authors also note, organisations, such as the support groups which I focus on here, struggle to make sense of funding arrangements, and “as systems for dispersing funding are further developed and refined, it is critically important not to lose sight of the effects of those mechanisms upon the communities they reach and the types of impacts they introduce into community settings” (Birdsall & Kelly, 2007, p. 200). This paper focuses on the ways in which networking functions as a “good”, a practice to be replicated in this context, as well as how it is negotiated and practiced on the ground.

As part of such assemblages people living with HIV, and particularly those within support groups are linked into travelling ways of framing the problem and sets of solutions, which encompass ARV clinics and their workings, condom demonstrations and education campaigns, and – as here – networks and partnerships. They are linked into accepted discourses around the “right” way to behave or to

mobilise, and what has “worked”, or not, in different contexts. They are also linked into networks of resource allocation, which can become a large part of people’s livelihood. These are established and reinforced through international funding and policy networks. It is important here to consider the ways in which global structures and ideas have shifted through the last 30 years of international engagement with HIV. Studies illustrate the importance of opportunity – of context – in coordination with waves of thinking, funding, and political involvement, which bring out committed individuals and activities taken up by funders, communities, or both (Allen & Heald, 2004; Grebe, 2009; Heald, 2002; Macgregor, 2009; Robins, 2006). With reference to support societies, where the conditions for mobilisation, and for allowing committed individuals to come forward with new ideas do not exist people can become recipients of patterns from elsewhere negotiating “invited spaces”, established patterns of engagement into which people living with HIV are drawn rather than actively create or take part in defining (Cornwall, 2002).

Support groups for people living with HIV fall within “civil society”, a category of actors positioned as the most legitimate to act according to community needs. Although this conception is problematic its power is demonstrated in, for example, the Global Fund (GF)’s¹ grant giving structures and their insistence on civil society inclusion. Seckinelgin (2006) describes a “looping” in the donor creation of civil society in relation to international HIV work, which can then respond to donor demands:

International actors consider actors who are able to participate in their frameworks as representatives of civil society, independent of any concrete evidence to the link between civil society and the way people live through other social forums. In addition it ignores that they define this civil society to which the people are responding. (2006, p. 21)

This is not to say that support group members are without agency or that they do not engage with the funders and programmes in the Gambia. Moving between different economic, social, cultural and bodily fields, people act to maximise benefits and reduce harms by exchanging resources with those in their networks, according to accepted norms (Bourdieu, 1985). Health is also a field in which different individuals have access to different kinds of capital, both through their own position and their position in relation to others. For people living with HIV, and particularly those taking ARVs, maintaining their health is a constant struggle. Health can be negotiated in a web which includes, for example,

access to food, or money to buy food, which then reinforces the body and health.

While people cannot control the “rules” of exchange, they can strive to amass and deploy their resources effectively (Meinert, 2004, p. 12). Positive relations in networks of prestige, links to NGO partners and funding streams, allow greater access to resources or facilities. They can also be risky; time spent voluntarily, or in education or training, may not convert as readily across fields as time spent working for money. Swidler (2009) argues that African realities of poverty spread into NGO practice, with patron-client relations forming through these interactions. Partner organisations and their staff are at once part of local networks and global ones, functioning simultaneously within these different frames, with both the pull of project aims and reporting structures as well as links of patronage, kinship and reciprocity. Thus people living with HIV express their agency within these fields, acting to maximise benefits from associations and roles which are ascribed to them in different relationships.

This paper follows on from Ong and Collier (2005) and Nguyen (2005) in analysis of the ways in which people in this context negotiate a global assemblage of HIV practices, put into play through GF and NGO partners. Looking at the support societies and their struggles to gain within different fields can illustrate people’s ability to negotiate and express agency within the available structures, where accepted frames of international action bypass the state presenting an internationally linked “biological citizenship”, and opportunities to access resources based on this (Rose & Novas, 2005; Nguyen, 2005).

Context

As across West Africa, the Gambia has a low-prevalence HIV epidemic, below 5%. Data from 2006 show an HIV-1 prevalence of 2.8% and HIV-2 0.9% (National AIDS Secretariat [NAS], Republic of the Gambia, 2008, p. 7). The Gambia’s HIV programmes began in the Ministry of Health, where a National AIDS Control Programme was set-up in 1995. In 2000 a World Bank Multi-Country AIDS (MAP) Programme grant of \$15million funded the HIV/AIDS Rapid Response Project (HARRP), which provided money for NGOs and CBOs working on HIV. A GF grant in 2004, allowed further development of the Gambia’s HIV response, and the starting of the ARV (antiretroviral) treatment programme provided through three clinics in the

coastal peri-urban area, which was the focus of this research (see also Cassidy & Leach, 2009a).

The first Support Society was set-up in the mid-nineties, by 2006 there were three groups attached to the main ARV clinics. Through 2006–2007 new groups were formed around the country, as roll-out of the treatment programme spread to clinics in new areas. This was a mediated process with strong involvement from clinic staff, the doctors and counsellors. Particularly in the early stages the clinics and support groups were strongly linked, and they remained the point of referral for new members. Each of the groups has a core of between five and 25 who attend the centre on a regular basis, and get involved in programmes. Other people come for monthly meetings or occasionally for events. Some members have registered but rarely attend the centre. Many people who test positive do not join a group at all. By the end of 2007 there were 10 groups, four within the scope of this research, linked by a national network – GAMNASS – and a network of women living with HIV – Mutapola.

The support groups are funded through a variety of programmes, projects and donations from different sources. Within the groups those who act as president, vice president and other official positions usually do not receive salaries. The major activities of the groups are as a drop in centre for members, providing nutritional support through meals cooked everyday, when funding allows. The groups compile lists of orphans and vulnerable children, and those needing further nutritional support, which is channelled through the clinics. They are also the target beneficiaries for a number of other activities; these are predominantly trainings and workshops. Skills training, particularly soap and tie-and-dye material making are common. However, follow up funding for people to reinvest is rare.

The Gambia’s political context is dominated by the president, Yahya Jammeh, and his often shocking statements and actions. He has a treatment programme for a variety of illnesses, originally AIDS and asthma in 2007 he now also treats diabetes, infertility and high blood pressure, among other conditions (Amon, 2008; Cassidy & Leach, 2009b). In 2008 the president threatened to behead homosexuals, and several people have been arrested. He also sent his personal militia – the “green boys” – with traditional healers to seek out witches in his home region; hundreds of people were rounded up.² Journalists, opposition politicians and others are imprisoned for criticising the government. In this context social or political activism and even political opposition is severely constrained.

Methodology

This paper is based on ethnographic research carried out in the Gambia through 2006–2007, focused on the treatment choices available to people living with HIV in the Gambia. Data collection included participant observation with four support groups and three clinics, attending meetings, trainings and activities as well as everyday tasks and discussions. Individual semi-structured interviews were carried out with 80 people living with HIV through the support societies and clinics in 2006. Focus group discussions using participatory methods were carried out at the end of 2007 with eight groups of 10 women and three groups of 10 men from the Support Societies. The difference in numbers illustrates the gender disparity in group membership. As well as interviews and interactions with clinic, NGO and other organisation's staff throughout the research.

Through analysis of the data, using a grounded theoretical approach, a major theme emerged around the development of organisations for people living with HIV, and particularly the relation between the global and the local in these spaces – the question addressed in this paper. The support groups sit at the intersection between opportunities created by global streams of funding and discourses on one hand, and needs and priorities felt by Gambian HIV-positive people on the other. During the research these groups developed and formed relationships with partner organisations, and sought to form national networks. However, these processes ruptured to some extent when confronted with the president's competing "AIDS cure".

In what follows, I begin with the local level actors' understandings and practices of participation in the support groups, presenting their views on their reasons for membership, which reveal both the influence of the global discourses, and of creative pursuit of their own interests. I then turn to examining the trajectory of an initiative to forge a network of support groups. The formation of the network again reveals the influence both of the global discourses, and of local priorities, particularly struggles over scarce material resources. This tension between global forms of organising and national/local demands and priorities came to a head when the president announced his "AIDS cure", which resulted in some people shifting their allegiance to the president's cure rather than international organisations and clinic-based medicine. In the following section, I illustrate and seek to account for this particular trajectory of the global assemblage in support groups in the case of the Gambia.

Findings and discussion

Support group membership

The meanings and practices of group membership reveal an uneasy balance and set of tensions between needs and priorities felt by group members themselves, and the expectations of donor, NGO and government partners as to what a support group operating in a world of globalised HIV funding ought to be like.

Individuals expressed their involvement in reference to donor programmes, for example income generating activities and trainings, and "good" practice in "speaking out", but also with a sense of personal agency and commitment. As this interviewee states, there are layers of benefits to be gained through involvement, both practical support and psychological gains;

I expect to be able to help in the fight against HIV. Although I still need to expect things like income generating activities to sustain the group...

They are helping me to speak more and talk to new people who are coming in. (HIV+ man, support group member August 2006)

Also evident here is a sense of the international – an awareness of and involvement in the "fight against HIV", which is often expressed as a national or international fight and linking individuals into a broader network of people living with the virus.

The groups provide an alternate supportive network for those who either have not disclosed, or for whom disclosure lead to problems within their existing family-based networks. The groups, attending meetings and taking part in activities provides a sense of common problems, which "eases the mind":

I joined the support group so that I would have company. I just joined the group three months back. I am very much impressed about the group activities...I am just a member and I am not involved in any activities, I just go for meetings, after meetings I go home. This has helped me because it eases my mind whenever I go to the centre. (HIV+ woman, support group member August 2006)

There are also altruistic motives for group membership; and a circular relationship between the support that is offered and which the members themselves provide for each other.

I join the [...] group last year to do home based care so that I would help the positive people. I am just a volunteer in the group; I do not have any responsibilities. They have helped me and I enjoy doing voluntary work. Socially I did disclose it [my status]

to the group. (HIV+ man, support group Member September 2006)

However, all group members stressed that their main concern is with the welfare role of support societies. This anticipated support is tied into institutional expectations which have been raised through engagements with other organisations:

The types of support people need is nutritional support, medical support, salary for the members of the support groups, especially for those who are not married. (HIV+ woman, support group Member August 2006)

Discussions and interviews throughout the research returned to the provision of nutritional support, school fees for children and funding for small business enterprises. While these programmes did exist the coverage was patchy and sporadic, contributing to a feeling of insecurity and dissatisfaction with partners; NAS (as PR of the GF Grant) and other NGOs and organisations active in HIV work. While such programmes were appreciated, many group members spoke about the insecurity of short term provision, and the difficulties experienced when not everyone eligible could be included.

By the end of 2006, support group members were actively engaged in partnerships with different organisations linked into the GF grant and other international funding streams. These active members had learnt the necessary procedural expertise and language to participate in the “global assemblage”. They were also well practiced at strategically accessing the resources offered by these partners, to address their more general concerns, such as income-generation and access to food.

Networking-struggles over resources

The concept of networks for people living with HIV, as well as support societies, is facilitated and funded by donor and intermediary organisations, fitting with concepts of civil society envisioned through policy networks around HIV (Seckinelgin, 2006). Such an approach is, for example, built into the structures of GF grant giving, and the many international organisations which fund and promote networking in development and for people living with HIV in particular.

As the national networks of people living with HIV in the Gambia came together in 2006 there was much discussion as to how this would relate to the existing groups. People’s perception was that the main national network – GAMNASS³ – would supersede the existing groups this would change the

power dynamics, and the routes through which partnerships were formed and benefits distributed. The process was supported by different partners, a national network being something which “should” exist, and could streamline the negotiation of such relationships. A few key individuals within the groups took the lead in organising, and pushing for a network, in tandem with those partners who wished to fund its inception.

For many in the Gambia this process was flawed; controlled by certain actors and marginalising others. For those who were in leadership positions within the groups, already managing relationships with partners directly, however imperfectly, this seemed to be a challenge to their ability to steer funding initiatives, as ongoing discussions in individual groups and planning the network illustrated. The women’s national network set-up a tension between the groups and a new organisation, but also a tension within the groups, where only female members were to be represented. The women’s network in particular faced allegations (from both men and women who felt sidelined) that it was not a national network, but represented women from only one group. The vocal leaders of both national networks were also at loggerheads – arguing over whether the national network superseded the women’s network, of which it should therefore be a member, or could stand side-by-side, and so in competition for scarce resources. A perception among the leaders of both networks of a funder prioritisation of women for activities fed this conflict. The language, programmes and practices of international funders – the “global assemblage” as experienced in this context, were secondary to the funding and welfare support offered.

Tensions arose where group members were unaware of what they were expected to do, or if their (predominantly welfare based, rather than advocacy or education based) expectations differed from those set out within project outlines. Although it is necessary to stress that partner organisations include funding for nutrition programmes and IGA, and group members want to take part in education programmes and advocacy campaigns (such as the candlelight walk and World AIDS Day celebrations). The tension lies in the prioritising of programmes and the attitudes of trust and suspicion which circle around often thwarted expectations.

Through 2006 there was discussion within the groups about the volume of money which came into the country “for us”, but which they did not receive, that those within intermediary organisations “just ate the money”. On the other side some within government and other organisations expressed disappointment that group members were not more

active, with a stronger spirit of voluntary action. One NGO worker in conversation compared them to TASO in Uganda, who, he said, carried on without payment or resources. Others said that group members “just sit and eat”. So towards the end of 2006, as the funding situation became more insecure (with the end of HARRP funding and refusal of GF grant) a tension arose where expectations of support had been raised, between group members who saw themselves taking on more and more professional roles without financial recognition, and those acting as conduits for these resources.

Networking – doing the “right” thing

As the networks developed, these struggles for resources continued, within a context of programmes and procedures with values attached as to the “right” way of working. One aim of networking – linking into international networks – highlights these tensions between the aims and expectations of different groups. The financial gains for Gambians travelling to international meetings can equal years of wages in dollars for a few days. While the opportunities to meet with and learn from people living with HIV in other contexts were valued, the financial security such an opportunity brings is just as important. Group management structures and relationships between members strained under the weight of choosing who should benefit.

At the end of 2006 after months of negotiations, GAMNASS had an elected national committee. A constitution was drawn up and agreed upon, through a painstaking process of translation into various local languages and discussion over several days. This process – of democratic elections, transparency and negotiation, is partner led according to international ideals of good governance and participation.

The network was rife with competition and rivalries. Accusations of self-interest were common, and although the elections were satisfactory to most there were whisperings in some quarters about what the network would really do for them. One woman who was elected to hold a position in GAMNASS was questioned by other members of her group; “do you go from home to that place, or do you go there from here?” Asking her to make plain her allegiance – whether she sat as an individual in that position, or as the representative of the existing group. Arguments such as this were common as people became accustomed to this emerging institutional landscape, and the values which accompanied it, and worked out how it could function for them.

In conversation with the then president of GAMNASS in September 2006 the discussion spanned

many different topics; achieving “parity” between the groups, the difficulty of obtaining funding from partners (he had the idea that bringing all partners together to hear what GAMNASS proposed to do might spur them into dividing the proposed activities between them); “bringing people out” to join the groups and so receive the benefits of membership; and the new policy of including people living with HIV as counsellors. This had been agreed in principle and taken up in two of the clinics.⁴

However, although there were many hopes the existence and funding for the network was insecure; for specific activities and meetings rather than running costs or salaries. This was frustrating for those people taking the lead as they worked full-time on a voluntary basis to set-up the network in a participatory and transparent way, these very values seemed to undermine their transition to future payment or benefit. Even as people struggled to do the “right” thing, their immediate needs were left largely unmet.

The presidential “cure” – changing allegiance?

When the president announced his “cure” for AIDS in January 2007 the first group of people to enter his programme were the most prominent members from the groups, including some from the national network. The messages and ideas which were linked into this assemblage were abandoned in favour of more customary allegiances; patronage and tradition rather than gender equity, participation and transparency. Here I introduce these issues to illustrate that although the dominant and powerful discourses around HIV programming in the Gambia were strong, there are alternative, and potentially equally powerful discourses available. However, it is beyond the scope of this paper to discuss these developments in detail (see Cassidy & Leach, 2009b for a full discussion).

The dynamics around people entering the president’s treatment imply that the “assemblage” working in the Gambia, as elsewhere – of clinic based ARV treatment, prevention programmes and information campaigns – were not as deep rooted as might have been expected. Some of those taking the lead in networking and linking with international partners moved to the presidential treatment and talked publicly about the benefits of the president’s “break-through” (Cassidy & Leach, 2009b). Through early 2007 the situation in the Gambia, for all those engaged in HIV work, was one of uncertainty and fear. The support groups and the networks did not dissolve, but many activities stopped. As some of the most prominent people had left the groups others came through to take leadership roles and by late

2007 activities went on as before, albeit within a difficult and dangerous political climate.

As people navigate the available “fields” to maintain their health the dominant “assemblage” and its practices of association and networking were taken on enthusiastically. However, that the president derailed this process so easily with his “cure” illustrates that alternative – and more familiar – patterns of accruing benefits, fitting within more usual practices of patronage and support, without the associated baggage of development language, could be just as appealing and appear potentially as beneficial (Cassidy & Leach, 2009b).

Conclusions

This paper seeks to understand the relationship between the “assemblage” of “Global AIDS” (Nguyen, 2005; Ong & Collier, 2005), and local understandings and practices within a community of people living with HIV in the Gambia. The power of the “assemblage” can be seen in the negotiations between these different actors and practices by people living with HIV. However, the fact that this dominant ideology was disrupted by the president’s “cure” and so an alternate route – or field – through which to acquire benefits and so support and health, calls into question assumptions of a “buy in” to global ideas and values without further scrutiny of the ways in which such assemblages function in different contexts.

The process of networking can be understood with reference to the ways in which “invited spaces” within dominant patterns of development make claims to community participation and involvement, but in practice fail to engage fully with people’s experiences or needs (Cornwall, 2002), similarly the ways in which “civil society” is imagined and brought into being through international donor practices and expectations (Seckinelgin, 2006). Theorising the ways in which “Global AIDS” is experienced, it appears for some this can be a site of creative engagement (for example the TAC in South Africa and TASO in Uganda; Grebe, 2009; Robins, 2006). Where these communities were able to engage in activism in a local-global context the urgency of the issues, the specific timing within the national and international responses to HIV, and certain individuals’ commitment to these aims, created situations where the priorities and patterns of engagement of these organisations “burst through” and became part of the assemblage of accepted practices. For other communities, such as the case study presented here, without these attendant factors a no less important set of

negotiations shows how these people struggle to express their priorities within existing patterns.

This case illustrates the experiences of people living with HIV engaging with what have become recognisable programmes and practices around the world, part of the “global assemblage” around HIV and AIDS, comparable with other programmes and experiences (see for example Hardon et al., 2007; Nguyen, 2005; Schumaker & Bond, 2008). On the other hand, the intervention of the president, and the ways in which this derailed accepted processes of networking indicate that this lack of fit between local priorities and programmes can open a discussion about how such global priority setting makes the acceptance of alternatives more likely. This raises questions related to how international campaigns and policy networks function, such as those focusing on HIV, and how, and how far, different constituencies are able to participate, or are seen to participate.

Notes

1. The Global Fund for AIDS, TB and Malaria.
2. “Hundreds accused of witchcraft persecuted in The Gambia”, Amnesty International, 18 March 2009. Retrieved from <http://www.amnesty.org/en/news-and-updates/news/hundreds-accused-witchcraft-persecuted-gambia-20090318>
3. GAMBian Network of AIDS Support Societies.
4. One clinic had previously had a policy of having “peer counsellors” and reintroduced it around this time; another took on two counsellors, one male one female who worked with the existing counselling team. This was a new development for them, but one which they took on enthusiastically. The third never introduced any kind of peer counselling in their clinic. A major advantage was seen in counsellors being able to say “I have this thing”, and particularly for the women in PPTCT that they could talk to someone who had been through the process themselves.

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