

More Hands in Complex ART Delivery? Experiences from the Expert Clients Initiative in Rural Uganda

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Abstract

This paper aims to analytically describe the experiences and outcomes of involving people living with HIV/AIDS in clinical care of HIV/AIDS within the healthcare clinic in a poorly resourced setting. With HIV/AIDS treatment finally available in poorly resourced settings, there was huge number of people in need of clinical care. As a result, professional health workers became overwhelmed by the demand for treatment and care. Consequently, this called for a new way to handle the rising numbers and needs of clients at the health clinic level so as to minimise the burden of care on the health professionals. An 18 months ethnographic study was conducted between 2005 to 2007 with professional medical workers (including Doctors, nurses and counsellors, clinicians), ART clients and with family care givers of ART clients, at a Health center IV-HIV clinic in a rural district in Uganda. The result shows that the scaling up of ART and subsequent introduction of Expert Clients as a new care arrangement within the health clinic has opened up the clinical space as some pseudo space where at least in principle, the patient has a voice in care with various outcomes.

Keywords: *HIV/AIDS, ethnography, poorly resourced setting, Expert Clients, ART*

Introduction

Many HIV treatment approaches remain highly dependent on scarce and expensive medical professionals and highly sophisticated laboratory equipment, which are in short supply in low-resource settings. Implementation of alternative, lower-cost human resource models for delivery of HIV prevention, treatment, care and support—including the deployment of auxiliary and community workers and engaging people living with HIV in service delivery – is urgently required (UNAIDS 2006).

Unlike any other disease so far, the ‘exceptional’ nature of HIV/AIDS has prompted debate about the nature of its treatment, but also the challenges of

treatment (Farmer, et. al. 2001). Antiretroviral therapy has been dubbed a complex therapy and therefore special for a number of reasons (Oyugi et. al. 2004, Amolo-Okeru et.al. 2006). Its complexity lies not only in the pharmaco-kinetics of the drug, it is a combination therapy which once 'initiated' into, remains on it for life (Barnett T, & Whitehead A, 2002). 'Initiation' into the therapy also requires thorough preparation of the patient including a prior HIV test and continued follow-up care. According to the Ugandan guidelines for implementation of ART (MoH 2003, 2005), one is required to bring along a treatment-supporter to whom they have disclosed their HIV status and who will help with treatment adherence. The professional health worker in consultation with the patient must draw up a treatment plan for each patient. Patients must be initiated to therapy by a medical doctor after thorough assessment (WHO 2005).

ART has changed AIDS from a deadly disease to a chronic one where the chronic care model is more favoured to the acute model (WHO 2001). The model requires the professional health worker to dialogue together with the patient about one's medical treatment and care. It also requires on-going counseling and treatment of opportunistic infections and at least a monthly face-to-face interaction between the client and the professional health workers. However, total adherence is also required (and sometimes a pre-requisite to initiation) and defaulting the drug is medically unacceptable. In ART, adherence is of utmost importance (Weidle P J, et. al. 2006). Poor adherence, indeed, may lead to medication failure, viral mutations and development of drug resistance (Bangsberg et.al. 2006) and future treatment options become limited because of cross-resistance. The risk of transmission of resistant viruses makes adherence a public health concern (Wainberg & Friedland 1998, Boden et.al. 1999). Research and daily practice have shown that strict adherence is difficult to achieve for many of the HIV-infected patients treated with antiretroviral therapy (Nieuwkerk et.al 2001, Hugen et.al. 2002). Adherence to HAART requires patients to behave in a way that cannot easily be incorporated into daily life (Vervoort et. al. 2007).

The Most extensive research in chronic care has been done in high income countries in disease specific programmes, such as diabetes (Tang et. al.. 2005, Stone et.al. 2005, Rosal et.al.2005), asthma (Bodenheimer et.al. 2002) and arthritis (Barlow et.al. 2000). However, these have focused on health status and health service utilisation (Kennedy et al. 2004 & 2005, Kober & Van Damme 2006). Fewer evaluations have focussed on generic self-management programmes for various chronic conditions (Lorig et al. 1999, 2001, Dongbo et al. 2003, Kober & Van Damme 2006). Most evaluations of self-management programmes focus on improvements in the core self-management elements from the patient's perspective, such as for example increased knowledge, skills

and sense of self-efficacy (Kober & Van Damme 2006). The current paper goes beyond patient perspectives to give in-depth analytical insights into provider perspectives of chronic care initiatives in a resource poor setting. Using data from a longitudinal ethnographic study I go beyond patient self-management to analytically explore the nature of emergent relationships between providers and patients engaged in chronic care.

Here I argue that to understand Expert Clients as a useful concept in chronic care in poorly resourced settings, it is important to go beyond a conceptualisation that emphasises their support functions (Kober & Van Damme 2006) to explore the emerging relationships which allows for a conceptualisation of their possible professional involvement as expert patients.

Background

The scaling up of a complex therapy for the treatment of HIV/AIDS in poorly resourced settings globally and in Uganda specifically was difficult because of overburdened health systems (Amolo-Okero et al. 2006). In the literature on creation of resources, it has been argued that although most health systems contain successful examples of service delivery for TB, chronic diseases and in recent times ARVs, expanding service provision beyond these islands of success faces significant obstacles (Crane et al. 2006).

The inadequate supply of skilled and motivated health care workers is now regarded as the key systems constraint to scaling up HIV treatment (Kober et al. 2004, Chen 2005). For example, in 2006 the Presidential Emergency Plan for AIDS Relief (PEPFAR) Report on workforce Capacity and HIV/AIDS treatment and care recommended task shifting from health professionals to lay health workers or volunteers.

The problem of human resource is multi-faceted – it includes supply, migration, distribution, skills mix, remuneration and productivity dimensions (Chen et al. 2005, Adetoyeje. 2007, WHO 2008). High levels of infection amongst health personnel may be one contributor to attrition of personnel in some countries (Tawfik & Kinoti 2004, Kober et al, 2005). For instance by the late 1990s, deaths constituted more than 40% of all nurses lost to the public sector in Malawi and Zambia (Kober et al. 2004), while in South Africa in 2002, 16.3% of health workers were infected with HIV (Shisana et al. 2002).

Furthermore, with HIV/AIDS treatment finally available in poorly resourced settings, there were overwhelming numbers of people in need of clinical care. Consequently, professional health workers became overwhelmed by the demand for treatment and care (UAC, 2006). This called for a new way to handle the

rising needs of clients so as to minimise the burden of care on the health professionals.

Scaling Up HIV/ AIDS Treatment in Uganda

In 2003, the Uganda government committed itself to provide more equitable access to AIDS treatment by scaling up HAART under a public sector care arrangement (MoH 2003, Wendo C. 2005). In June 2004, the government began dispatching ARVs to district hospitals and later to health centre IV clinics to be administered under routine healthcare conditions (MoH 2005) with emphasis on broadening coverage (MoH 2003, MoH 2005, Uganda Cares report 2004, UAC 2004, UNADS, 2007). By October 2007, there were 212 ART centres across the country and the number of people accessing ART reached 106 000 that is far less than half of the estimated 234 500 who need treatment now (MoH 2006, UNADS, 2007). The health sector in Uganda faces staff shortages. With a total of 30 000 health workers who were employed in 2004, 5000 qualified staff were required by then and certainly the demand is greater today. A shortage of health workers could negatively influence access to and quality of care (Chen & Hangvaravongchai 2005, Marchal et al. 2005). Moreover, in the wake of scaling up AIDS treatment and care, organisational responses in Uganda were implemented haphazardly and were limited to providing protective materials and the AIDS related services offered to patients while the health workforce was left without due attention (Dieleman et.al. 2007). Therefore, when the Uganda government scaled-up ART from regional hospital settings to lower levels (health centre IV and III) of care in support of the 3 by 5 initiative, the need to create resources necessitated initiative. But whereas there is a policy requirement for People Living With AIDS (PLWA) to be involved in every area that concerns their health (MoH 2005) in fulfilment of the “greater involvement of people living with HIV/AIDS (GIPA)” principle, currently, there is no policy document institutionalising and operationalising their involvement, regulating participation or even their recruitment into the clinical set-up.

With ART becoming more available, the high volume of patients and increasing demand for treatment at lower levels of care (health centre IV) necessitated significant re-organisation of health service delivery. So, to minimise the burden of care related to ART, medical care workers at a local clinic in rural Luweero district charted the delivery of HAART treatment by introducing lay providers called ‘Expert Clients’ within the traditional hierarchy of public clinic practice in the clinical space (health centre annual report 2005). Through this new care arrangement, people living with HIV/AIDS and using

HAART were given a chance to participate in delivery of chronic HIV/AIDS clinical care. The main aim of this initiative was to reduce the workload burden of medical health care providers in the clinical care of patients specially those on HAART. The question addressed here is: what has been the outcome of this new type of clinical care arrangement on those involved in the clinic space and on overall chronic HIV/AIDS care and treatment in a resource poor setting? The aim is to give in-depth insights and learn from the outcomes of emerging care dynamics within the health system at clinic level following the scaling up of chronic HIV/AIDS treatment. Results show that the scaling up of ART and subsequent introduction of Expert Clients as a new care arrangement within the health clinic has opened up the clinical space as some pseudo space where at least in principle, the patient has a voice in care with varying outcomes. The Expert Clients initiative also points to an emerging process of popularisation and domestication of ART within a constrained resource-limited healthcare setting.

Study Design

I conducted 18 months of ethnographic study between December 2005 to December 2007. A qualitative descriptive design (Sandelowski 2000) was deemed appropriate for this study as the aim was to provide a comprehensive summary of events in everyday lives and terms of those events as well as what actors, especially in the clinical space, thought and how they experienced the new expert-client clinical care arrangement. In October 2007, after almost two years of expert-clients' service, a one-day evaluation workshop was held by Uganda Cares group for 15 of the 20 Expert Clients who had been trained in December 2005. I attended the workshop. Five of the original 20 Expert Clients had died. Methodologically, I conducted Clinical participant observations, informal conversations, open-ended in-depth interviews and topical focused group discussions.

For such a sensitive topic, participant observation became key because it allowed for an understanding of the symbolic representations e.g. through metaphorical expressions as well as other life concerns like relations of caring e.g. bodily gestures and facial expressions, general expression of feelings and emotions. Such are not quantifiable aspects but are qualitative experiences of everyday life which people have learned to attend to. Statistical sampling or applying a structured questionnaire for that matter may not give in-depth insights. In-depth interviews and FGD data was collected using a topic guide to augment and validate the findings. This paper presents data from informal conversations

and clinical observations of 10 professional medical workers, open-ended key informant interviews with 6 professional medical workers (including 1 doctor and 3 clinical officers and 2 senior nursing officers), 2 FGDs with nurses, informal conversations and open-ended in-depth interviews with 4 Expert Clients, 2 FGDs with ART clients exclusive of Expert Clients, 2 FGDs with family care givers of ART clients. Participation was voluntary and confidentiality assured. The findings here have been augmented by the proceedings from the evaluation workshop mentioned above.

Study Site

The study was conducted at a public, static HIV clinic, of a Health Centre IV in Luweero district. This site was purposively selected following the criteria that it provided a static ART programme, was rural and with limited infrastructures, one of the very first sub-district level public health centre IV after the district level regional hospitals, where the government ARV roll out program started in 2004 and had the highest number (4) of the Expert Clients trained by Uganda Cares; therefore there is a wealth of experience to draw from. The HIV clinic is housed in a separate building in the backyard of the health centre. It is government funded and cared for 510 ART clients as of July 2007. The clinic provides voluntary counselling and testing (VCT), antiretroviral (ARV) distribution, treatment of sexually transmitted infections (STIs), opportunistic infections (OI) treatment and health education services. The ART programme runs every Monday, while Wednesday and Friday are voluntary counselling and testing (VCT) days. During these days as well as the rest of the week, all the staff at the clinic attend to care of other patients across different departments at the health centre e.g. maternity and labour section where prevention of mother to child transmission (PMTCT) is run as a separate program from the HIV clinic, theatre, general ward rounds, OPD, child nutrition ward.

Ethical Considerations

Approval of the study was gained from the Uganda National Council of Science and Technology and from the ethics committee at the clinic. The participants were given detailed information about the study during the exploratory fieldwork visit of three months to which they gave verbal consent. To ensure the confidentiality of the study participants, I use pseudo names in the script. All the study participants verbally consented to the take part in the study and their views being written in the study report.

Data Analysis

I used the guide analysis proposed by Attride-Stirling (2001) for qualitative descriptive studies. I designed a coding framework and dissected texts line by line. Basic themes that were explicit enough to encapsulate an idea as well as expansive enough to include varying text segments from the transcripts were identified. From the basic themes are generated clusters of organising themes that summarise the principle assumptions of a group of basic themes so they are more abstract and revealing of what is going in the text (Attride-Stirling 2001 p.389). The organising themes were explored for commonalities and relationship with each other. I further clustered the organising themes into a macro-theme 'more hands' which encompassed the principle metaphors in the data as a whole. I returned the transcribed material to the participants who confirmed that they were an accurate reflection of the discussions held. Data analysis run concurrently with data collection and coding was on-going until such a moment when data saturated.

As I was interested in the specific experiences of specific actors in the clinical space, a small sample size was deemed appropriate to produce the kind of in-depth knowledge necessary to understand the structures and all the processes within which individuals or situations are located. Because the study was conducted with a specific group of chronic ART care providers within a specific rural context, I took the approach of 'maximising information and not facilitating generalisations'. In other words, the aim was to produce findings that could potentially be transferable rather than be generalised to every setting. The validity of data was assured by triangulation using different methods of data collection and asking the same questions during focus group discussions and in-depth interviews, exploring the same topics among all study participants at different times and places and comparing and contrasting information from interviews with information from informal conversations and observations.

The Expert Clients Initiative: Structure of the Program

Uganda Cares is a donor funded non-profit organisation that pioneered the introduction of the Expert Clients program within the government funded public health care settings in Uganda in 2005. The main aim of the initiative was to help lessen the workload of professional health workers (resulting from scaling up of ART) within the clinical care setting. Expert Clients were HIV positive patients and using HAART themselves.

Those trained as Expert Clients were selected by fellow clients based on a

set criteria by WHO's principles of Greater Involvement of People with HIV/AIDS –GIPA. One had to be approachable, helpful, kind, willing to share, able to communicate with fellow clients & the medical care providers, in an improved state of health attributable to HAART and open about his/her HIV status. Selected clients were trained in a one-week skills building workshop. Professional health workers from Uganda CARES AIDS programme found in Masaka Hospital conducted this workshop. This training, which I attended as a participant took place in December 2005.

Participants were drawn from 2 static ART health care centres and 5 satellite ART outreach centres in four rural districts i.e. Masaka, Kalangala, Sembabule, Luweero in Uganda. 20 participants were trained in basic counselling skills; communication skills with patients, what & why counselling is needed, how HAART works, referral care support, positive living, disclosure and basic nutrition.

Accordingly, during training Expert Clients roles were stipulated as: initial clinical preparations of ART patients, help in monitoring, and supporting patients in comprehensive care and positive living. After training, Expert Clients were given T-shirts & caps for recognition as well as a letter of introduction of their new status of being Expert Clients. What follows is a description of the Expert Clients work in Kasana Health centre IV, a static ART care centre in Luweero district, which had the highest representation (4 participants) at the training.

After training, the Expert Clients became stationed at the HIV clinics (more or less as receptionists). They report and are answerable to the senior clinical officer in charge of the HIV clinic and the senior nursing sister who are in turn answerable to the Doctor who is the director of health services at the health centre.

On the side of patients, Expert Clients are answerable to their fellow clients who elected them under the leadership of the post-test club chairman.

At the clinic expert patients' specific roles included: registering patients, selecting out very ill patients for immediate attention, filling visitation cards/ registers, weighing patients and taking their height, encouraging patients to come for care and treatment of opportunistic infections, educating clients about the benefits of treatment by sharing their personal experiences and sharing basic nutrition facts. Expert Clients also solicited reports of those clients who are very ill and are unable to make it to the clinic – a rather informal way of following up on their friends.

They familiarised new patients with the clinic care procedures and also helped attend to those who need admission. Expert Clients also reported on the condition of those who are admitted in the wards especially soliciting for

psychosocial, emotional and moral support. The results and their implications in terms of lessons learned from this initiative both to Expert Clients and to providers and the health facility as an institution, are provided below.

Results

The results show greater in-depth insights but do not reflect striking changes in perceptions over time. From the clinical observations though, there was generally less inhibition and a greater degree of fluidity in social interactions between providers and Expert Clients. This could be interpreted as greater acceptance of the Expert Clients' presence or greater appreciation of their work in the clinical space. But the limited inhibition in interaction on the part of the Expert Clients could also be interpreted as a time factor. The longer they stayed at the clinic, the more their presence was normalised and thus they, more or less, naturally fitted in with time. Although relations sometimes tended to be rather conflictual and/or contradictory, Expert Clients played a significant role in mobilising PLWHA as critical support providers to their peers and health care personnel.

New Roles Acquired at Clinic Level

Expert Clients as intermediaries

Group counselling sessions acted as opportunities where Expert Clients took on an intermediary role of reporting to fellow patients and soliciting feedback on the overall situation of care at the clinic, general patient situation (in terms of attendance, dropout, deaths, constraints, etc), update patients on upcoming health related events in and around the district, and any upcoming plans by the management and reporting back to the clinician in-charge. Proposals are sometimes written and presented to the clinic in-charge who endorses them to management for action e.g. the porridge project, the window project that involved breaking and reconstructing the records room.

“we proposed what is now called the porridge project for the clients while at the clinic, we also proposed the breaking and opening up of a window in the records room to ease pressure and noise from the corridor of people collecting their files but also so that clients don't have to stand for long hours while waiting in a queue for their files. These are small changes but they have made a difference and improved overall care for us patients and the working environment for the health care providers” (in-depth interview with Expert Clients, July 2006).

Expert Clients as advocates

At another level, the Expert Clients act as advocates for fellow clients to improve overall care at the clinic. For instance, after listening to the woes of fellow clients about marital and family problems, they wrote and suggested to management that the Alliance of female lawyers (FIDA) be lobbied to come and assist clients with legal advice. There is a sincere desire to holistically improve the situation of the clients as well as the general care environment at the clinic.

“More recently through our bosses we invited FIDA to help educate us about our rights as HIV positive patients and they now come here once every month to give legal assistance to those who need it at no cost and also teach us how to write a will” (indepth interview with Expert Clients, October 2007).

New Roles at a Community Level

The findings show that Expert Clients roles have grown to extend beyond the clinic. They act as extension health workers linking the community and the health facility in a sense that they help deliver the drugs to those who live near their home areas and are too sick to come for the clinic days. They also act as ‘ambassadors of hope’ for the ART therapy through sharing their experiences not just with fellow clients at the clinic but also in the communities where they live, for instance they are usually called to address community health gatherings on HIV/AIDS, care and treatment.

Results from the interviews and the evaluation workshop clearly show that with time, Expert Clients acquired new roles beyond the clinic care context. They act as a bridge between the clinical set up and the community. They go out of their way and make home visits and sometimes offer material support as well as referral of patients to other care organisations and consequently, many people have been encouraged to test for HIV. Expert Clients were able to give peer support, counseling and encouraging adherence to other clients. Through training and practice, they gained more confidence and better skills of knowledge sharing, hence they act as role models giving hope to clients and caregivers. This is exemplified in the following quotes from an FGD with ART clients family caregivers;

“Our Expert Clients visits every home with an AIDS patient in this village at least once a month to encourage us not to loose hope in caring for our sick person”

“she is really an expert...she is a good example to us, she visits us often and encourages us and even helps us with house chores for the patient.”

“He has also encouraged many people here to get tested especially through sharing stories of his past experience with the disease”

“Her kind of comfort and encouragement is crucial not just for the patient to regain hope but also for us who are not yet sick to be nice while caring for others because tomorrow it might be me” (July 25, 2006).

Knowledge and Skills

From clinical observations, Expert Clients frequently search for opportunities to better their knowledge through asking questions and a keen watch of how medical health care providers carry out different tasks of their daily work, and even how they carry themselves around. Expert Clients also attempted to portray themselves with a similar demeanour and ways of expression with confidence, as the medical health care workers do. By doing so, they, somehow, continue to command and keep the newly acquired respect from fellow clients and the community. The findings show that Expert Clients attempt to display total command of what they say and do in the way they speak and attend to the patients which wins them further respect from fellow clients.

“we have to learn the rules of the game otherwise our patients sometimes suffer a lot. We even go and seek knowledge outside this clinic e.g. we go and visit other clinics to see how they do things and we come here and sometimes propose to our bosses. We also ask our friends who get medicines from elsewhere about questions on patient care at other HIV clinics – we simply want to help ourselves – we want to see things get better and better for us patients and for our providers who we recognize have a lot of work on their shoulders.” (in-depth interview with Expert Client, July 2006)”

The above quote also recognises that the level of care at the facility is still wanting in some ways and can be bettered. Expert Clients indeed took extra steps to find out how to improve themselves, other patients and the general care situation within and beyond the clinical setup.

“After our initial training by Uganda Cares, I attended a three months certificate course in counselling for ART and now I know a lot about the drugs and care. I am

often invited to give talks on HAART care. I also have started writing a booklet on what an AIDS patient using HAART should know because many of our people are just ignorant and they have stigma...there is a lot I can share with them”(In-depth interview with Expert Client, October 2007)

Trust and Disclosure

Ironically, Expert Clients became more trusted than the medical health care providers also because they identify, share and are open to fellow clients about their experience of the disease and the HAART therapy. As a result Expert Clients knew a lot of client information that is key to treatment but which was not necessarily yet known to health professionals. The attitudes of the health providers towards the patients strongly came out as key in facilitating disclosure and building relations of trust between clients and providers. Female FGD participants had this to say;

“This is the second time I am pregnant when on HAART but I prefer to tell our leaders (referring to the Expert Clients) who are more understanding and will guide me where to go without blaming me why I got pregnant. I cannot tell the doctor or nurses that I am pregnant simply because they may at times abuse the hell out of you” (here almost all FGD participants were nodding their heads in agreement).

Another participant interjects;

“for me when it happened the first time and they accused me of neglecting my own life when they are trying their best to help me ...they forget that I love my life more than they do care anyway. Am now five months pregnant but I have not told the other nurses yet so they do not know except nurse Harriet who treats us like a mother. However I told all our Expert Clients because they are very supportive of us all, they understand these things, they are jocular and will handle you with compassion...they really are good even if at times may complain about us...they are only human and suffering as we are and they are not even paid.

Another participant goes on to say;

Ehh...!!! some nurses here often don't know or even understand the great difficulty we women go through to survive and to convince men to have protected sex. This is even more so a challenge for us young women (FGD with female ART clients—Kasana Lurweero Health Centre IV, March 8, 2007)

The trust here may also be seen in terms of the degree of clinical information Expert Clients have about the patients which is seldom known to health professionals. Such information relates especially to signs and symptoms, state of mind, issues relating to counselling and state of wellness. The reason for this concealment of information may also relate to medical health care workers over emphasis on the drugs and adherence other than the totality of the body, soul and mind. The statement above also underscores the need for ongoing counselling that is lacking and undermining the confidence of HAART clients in medical health workers. Patients felt Expert Clients were more available to them, are open about their HIV status and openly use themselves as models for the patients to learn from which the medical care workers did not openly do. In the men's FGD, when asked to give their opinion about their nurses, one man said;

“they really don't give us time, they are selective of who goes to see the counsellor but most times you find that majority of us have problems beyond just taking pills yet which affect our adherence to the rules of the drugs – These Expert Clients are always here to listen to us and they actually understand us better than most nurses here so we share with them a lot about us than we even tell to the nurses and counsellors...(another patient goes on to add)... they are our heroes” (others nodded in agreement). (FGD with male Clients- Kasana Luweero Health Centre IV, March 8, 2007).

Patients also disclosed that they sometimes might withhold information from professional health workers for fear of being denied the medicines especially in cases of non-adherence. The concealment of information from professional health workers also at times relates to being given treatment options in terms of prescriptions that are not available at the health facility at the time including even essential drugs as panadol, septrin etcetera. Other views expressed in the FGDs were that often a times, some prescriptions are not affordable to the clients and instead of telling the medical health workers about the untreated symptom, they may tell the Expert Client who sometimes may devise a cheaper trial remedy, which he himself may have tried for similar signs and symptoms.

Tensions in Caring Relations

Some of the challenges and tensions that presented themselves in the implementation of this initiative relate to the control of knowledge of the professional health worker vis a vis the Expert Clients and the general clientele. Questions arose relating to who gives what information to whom and when,

and who has control over which knowledge and why. Generally speaking, some patients had more knowledge on some issues (e.g. nutrition facts, side effects control and management) than some nurses so it creates a clash of expectations. Expert Clients expect respect for what they know but in some cases they know only less or as much as other clients. This knowledge gap often related to one's level of exposure to HIV/AIDS related information and ability to read.

Participant observations from the group counselling sessions revealed that patients generally had high expectations of Expert Clients and at times expect to hear new solutions to old problems. For instance, patients sometimes have more technical questions for Expert Clients than they can answer given their level of knowledge and exposure to related information. This makes Expert Clients to go on an aggressive search for answers to client's questions from all possible sources including trying to penetrate the backstage of professional health workers to get more information. However, this is sometimes to the dislike and discomfort of the professional health workers.

"Sometimes client questions are too technical for us and we need to consult so we go the nurses or clinician or the doctor... though sometimes we may not know how far to go or how to do it and this usually annoys the nurses... they complain that we disturb them with questions at the wrong times, etc but the most important thing is that we seek always to learn so as to help our fellow patients... (FGD with Expert Clients, 20 October, 2007)

The Expert Clients expressed that they always enjoyed being utilised and answering client's questions but also searching for answers to technical questions posed to them by fellow clients thus:

"It feels empowering for us when patients seek answers from us. It brings us some feeling of respect and prestige to know that we are actually being utilised as experts"

"...it also feels good to search for answers and always learn something new that is helpful for us all about our condition" (FGD with Expert Clients, 20 October, 2007)

a) Acceptance and legitimacy

The Expert Clients agreed that they are constantly confronted with issues of acceptance and legitimacy as new entrants within the traditional hierarchy of clinical health service delivery in the clinical space.

“Since the beginning the nurses here often joke that we are the ‘adopted children of chronic medicine’ and they (the health professionals) are the born and trained children of medicine” (FGD with Expert Clients, 20 September, 2007)

This metaphor can have two different meanings. An adopted child may be privileged above others that at least they have a home to stay plus some other defined privileges. But depending on the mood and manner in which one says and/or is perceived may also carry negative connotation. It may also be a reminder to Expert Clients that they have no entitlements e.g. in terms of ownership to whatever is found in the home (clinical space), therefore one ought to watch themselves in terms of what they do and say when and how.

b) Overshooting boundaries within the clinical space

Currently there is a policy requirement for PLWA to be involved in every area that concerns their health (MoH 2005) in fulfilment of the GIPA principle. However, this is not backed by guidelines on institutionalising or operationalising their recruitment into the clinical space. There were general feelings and agreement among all medical care providers and even among clients themselves (see outgoing section) that Expert Clients as PLWA often overshoot their ‘boundaries’.

“...despite its advantage of restoring faith in the medical profession, HIV/AIDS treatment using HAART has done our profession some harm as well. Because of the complexity of HAART treatment and care, we have new entrants in the clinical affairs called the Expert Clients who I must say have been very helpful. But you know as time goes on and especially when there are no proper streamlined guidelines things begin to be problematic. (In-depth interview with HIV clinic Clinical Officer, July 2006)

“Our Expert Clients sometimes want and pretend to know more than we – the experts on HIV/AIDS treatment...quite often this leads to some discomfort and a clash in expectations” (FGD with nurses, October 7, 2007)

“They [Expert Clients] are too inquisitive and often overstep their boundaries. We have to be careful sometimes what we say or do because they are unaware of professional medical practice and ethics ... there have been cases like the drug-stock outs case and where a patient died due to lack of second line regime, the placebo patient case etc.

In all cases emotions flared beyond reason and we were accused of deliberately wanting to kill our patients by our friends the Expert Clients. In turn they misrepresented us by misinformation to the patients and the tensions were obvious and our respect became at stake” (in-depth interview with senior nurse, October 20, 2007).

This clash of expectations creates uncertainty and an inertia that may get in the way of progress and improvement in terms of trying to establish service delivery partnerships with lay providers and the community so as to improve access and delivery of care.

c) Complementary or conflicting roles

Expert Clients are seen as mediating the relationship between the clients, doctor and clinicians and by so doing, they continuously seem to subsume the roles of nurses who occupy the lower cadre in clinical medical care. Whereas they should be looked at as complementing clinical care on the one hand, they have on the other hand been looked at like a new category of entrants in the clinical space that may threaten the existence and the roles of nurses in chronic care.

In the HAART era, since medical knowledge is more than ever an open market, the nurses felt that the involvement of the Expert Clients in the clinical space may compromise their roles in the long run. Some medical health workers described sometimes being caught up in a situation where they uneasily carry out their work simply because the clients knew too much.

“The Expert Clients are always too eager to see, to know and to learn from us at the same time which is not bad. However they sometimes have inappropriate technical information... given that the HAART information market is open to the general public, it is difficult to control what and how to tell and not to tell patients. In reality some information like the case of mercy killing of an agonising patient or placebo treatment of a dying patient who has failed on the available HAART regime, unavailability of a next line drug regime, convincing someone that HAART cannot work on them when it has worked on other familiar people, etc. are things that need to better be left to the medical care professionals. (in-depth interview with doctor, October, 2006)

This issue is made complex given the lack of confidence resulting from an absence of updated knowledge of HAART treatment (MoH 2005: 39), but also a resentment about the very presence of these lay providers who are seen

as watchmen to medical practice in the clinical space. Furthermore, the fact that Expert Clients learn and reveal information that health professionals would rather not reveal to patients. The outcome of these revelations is often accusations and resentment among the patients and their family caregivers about the medical care workers who at times would be perceived as accelerating suffering instead of relieving it.

“ there are sometimes accusations of killing our own patients by denying them HAART treatment or having given them a wrong dosage. This is frustrating especially well knowing that I am supposed to be giving life and this is the correct impression patients must always have of us their providers...however, sometimes you find these Expert Clients discussing with patients some technical information, which they have may be overheard but which patients must not learn of especially that they may not understand it in medical terms. This sometimes alarms the patients and the effects of which both Expert Clients and patients cannot handle...and as a medical care provider this puts me in a difficult position” (In-depth interview with a clinician, September 20, 2006).

d) Misuse of power and undermining of authority outside the clinic space

From the informal conversations, there were strong sentiments among medical care health workers that Expert Clients were sometimes undermining their authority and that this might cause real conflict situations in the long run. When I returned to the field in December 2007, these feelings had become open resulting in an Expert Client being sent away from the clinic. It is alleged that Fred (*pseudonom used here*) had for long been posing as a medical care worker in the community and soliciting money from unsuspecting patients while inviting them to come to the clinic for cheaper CD4 tests on days when this was not happening (people were bled for CD4 count only on Mondays by JCRC), or for cheaper drugs like septrin (as this often run out at the clinic and patients were required to buy from outside the clinic – which was expensive) and on the day of appointment he would disappear. This left the medical workers with the discomfort of explaining to the angry patients how one of their own could engage in such an activity. Fred was subsequently expelled.

e) Accountability and allegiance

Expert Clients were often reminded to pay their allegiance to the health facility

authorities where they were employed by following the instructions as given by the professional health worker staff and that they were accountable to the HIV/AIDS clinician in-charge. However, tensions arose earlier with regard to the loyalty of the Expert Clients who attached great importance to the plight of fellow clients.

“Often, you have to act in the interest of the patients because they trusted you as their helper and watchman and to argue their case especially when caught in a difficult situation. For instance these “basawo” [health professional care providers] sometimes come late and then some complain that they are too tired to either see a patient or have the patient put on direct admission and they will send such a patient to the Outpatient Department with his file to start lining up again after having lined up the whole day at the HIV clinic waiting to see either a doctor or a clinical officer or a nurse in-charge.”

From the in-depth interviews, Expert Clients reported that they were actually more accountable to fellow patients than to the medical care health workers. This is mainly because Expert Clients and these patients view each other as *“balwadde banaffe* [fellow sufferers]” and thus having common interests. But even more, Expert Clients’ sometimes felt that the health system in away manipulates their plight since they work a lot and are not paid anything for their good will.

Discussion: Implications of Findings and Way Forward

Conceptualising Expert Clients in terms of their support function shows that through training and practice, Expert Clients gained confidence, hope and substantially lessened the workload of health professionals. Expert Clients acquired new roles from being advocates and intermediaries of care at the clinic to extending beyond the clinical care context such that they act as a bridge between the clinical set up and the community. Expert Clients are not only able to give peer support, counselling and encouraging adherence to other clients, they gained more confidence and better knowledge sharing skills, hence they act as role models giving hope to clients and family caregivers. They go out of their way and make home visits and sometimes offer material support as well as referral of patients to other care organisations and consequently, many people have been encouraged to test for HIV. These findings compare with health status and health service utilisation outcome measurement of self-management programmes in high income countries where, evaluations of self-management programmes have shown improvements in the core self-management elements

like increased knowledge, skills and sense of self-efficacy from the patient's perspective (Barlow et.al. 2000, Bodenheimer et.al. 2002, Tang et. al. 2005, Stone et.al. 2005, Rosal et.al.2005, Kober & Van Damme 2006).

The findings show that the scaling up of ART and subsequent introduction of Expert Clients as a new care arrangement within the traditional health clinic in resource limited settings has opened up the clinical space as some pseudo space where at least in principle, the patient has a voice in care. There is a great degree of patient expression within the clinical space as can be read in the approved and implemented proposals (the porridge proposal, the window project the FIDA project) resulting from patient voice for a different form of care than what is being offered, a kind of agitation that is rather unique in chronic health care to the HIV/AIDS treatment discourse. That patients propose and systems adopt, is a shift in the care discourse of the health system in Uganda i.e. from the conventional top-down organisational implementation approach to a bottom-up approach. This shift also points to the gradual attempt to shift from the acute care model to the chronic care model in resource poor settings and key here is patient expression in care. In high-income countries, where the 20th century saw a shift from acute to chronic care models, a central component of all models for chronic disease care is the altered relationship between patients and health service providers (see Kennedy et al. 2004, 2005, Jardine 2005, TAC 2006, WHO 2006). For the effective management of a chronic disease it is deemed essential that the patient assumes an active role in its management (Shaw et al. 2004, Jones 2004), which is a departure from the traditional 'medical paradigm' where the patient is seen as a passive recipient of care and treatment from the medical doctor. But I must caution here that for either settings it is important to carefully consider the logic and mechanism generating factors. Involvement of patients in high income countries stems from the logic of the need for every patient to self-manage their chronic condition whereas, the logic and emphasis on involvement of patients in low income countries stems from the need to curb the problem of scarce human resources and relieving the workload burden of professional health workers, in other words, the need for patients to be engaged in care delivery for the sake of fellow patients. It is a privilege with power bringing about inequalities among patients. However, the Expert Client initiative may create resistance from patients especially if they feel that Expert Clients lack in proper knowledge to give answers to the kinds of questions that patients may pose to them especially given the high medicalisation of the HIV/AIDS treatment.

Because HIV/AIDS disease and its treatment has been highly medicalised within the public health approach to care, I argue that the Expert Clients initiative as a new care arrangement is a channel to an emerging process of de-

medicalisation, popularisation and domestication of ART within a constrained and resource-limited healthcare setting. For instance, Expert Clients became clinical care providers without any rather formal training in western medicine and engaged and intervened in care using a highly complex treatment at different points including, giving advice to fellow patients to adhere to this complex drug regime which would be seen as the prerogative of the medical personnel who have received formal training in the kinetics and complexity of drugs. Additionally, Expert Clients became advocates for treatment outside the clinic through the new roles they acquired beyond the clinic and, they also became negotiators and intermediaries for better care within the clinic, for example, when they escort and help negotiate for attention or admissions for fellow clients at the outpatient department, their suggestions of new projects and ways of doing things within the clinic. The findings reveal clearly that there is striking divergence between the content of the training programme and the Expert Clients roles. Such results have implications for training of the Expert Clients. Ideally, a comprehensive training programme should be designed to prepare Expert Clients to be competent in the roles they are expected to fulfill. The study participants identified need for the will and leadership between managers, clients and clinicians to make things change through creation of an open forum where all stakeholders can work together, learn from and feel appreciated eg 'create and belong to a convention of carers' so as to minimise apprehension. Their suggestions seem to come from an awareness of the enormity of work involved in chronic care and the fact that they each are insufficient to provide all the care needed. Hence there is a great awareness that they all need each other in the caring process to be able to effect and sustain chronic care. However, from the lessons drawn above, this new awareness would require employing mechanisms to build trust and confidence in the entire health care system if the delivery of care for people with chronic conditions is to succeed.

Several recommendations have been proposed by the clientele and professional health workers about how to minimise the existing tensions. They proposed the need for a clear elaboration and understanding of roles and responsibilities for all stakeholders in the clinical space vis a vis the emerging chronic care needs. However, since these have not been institutionalised, a key policy issue arises here: how the caring role of Expert Clients can be institutionalised and operationalised within the healthcare system of Uganda, a question requiring further exploration. For instance, with reference to the Expert Clients providing material support to fellow clients, it may be advantageous to have definitive roles as a way of having clear expectations. However creating very strict responsibility and role boundaries may also be disadvantageous in a way that there is less flexibility.

Conclusion

This study has shown that to conceptualise the involvement of PLHA as Expert Clients in the clinical space as work (support function), improves outcomes for HIV positive individuals as well as the community, while crucially reducing the workload of chronic HIV/AIDS care for medical personnel. While the objective of expert patient programmes for chronic diseases in high-income countries is not in the first place a reduction in health service utilisation, there is some evidence that expert patient programmes do reduce health service utilisation while improving health outcomes (Kober & Van Damme 2006).

Exploring this aspect in the context of the current study has shown that Expert Client programmes do hold great potential for the context of chronic ART care in resource-constrained settings.

Additionally, by exploring into the emerging relationships I have highlighted the tensions arising in care, which has allowed for an understanding of PLWA professional involvement as Expert Clients. The implication of the findings here is that whereas caregiving can be an immensely enriching experience, one that immeasurably deepens human connections, it can also create crushing burdens, devolving into mutual punishment. There is no way to eliminate the core of responsibility and obligation embedded within the caregiving relationship. If the provider or the Expert Clients as a caregiver is not morally, emotionally, and educationally well prepared, then caregiving can become a frustrating experience and, for those involved, an intrusion and a threat rather than a helping connection.

Even medical caregivers can become so stressed by impossible demands that they are unable to give the care they would otherwise be able to offer, and their frustration can turn to undifferentiated anger, affecting their performance and inevitably leading to the denial of comfort to patients and to the health workers themselves.

Nonetheless, the meaningful involvement of PLWHA as an integral part of the health care team can be useful to support the implementation of the National AIDS Program strategic plan in fostering sustainable chronic care in a resource poor setting. But this would mean establishing a conducive environment where each party involved in the clinical space is educationally and emotionally prepared, and the contributions of each party appreciated. Whereas patients need to air their voices and these voices need to be heard, they should be accompanied with somekind of framework that operationalises and supports the functions and interactions of all parties.

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