Scaling up HIV treatment, care and support for injecting drug users in Vietnam

Lisa Maher\textsuperscript{a,*}, Heidi Coupland\textsuperscript{a}, Rachel Musson\textsuperscript{b}

\textsuperscript{a} National Centre in HIV Epidemiology and Clinical Research and School of Public Health and Community Medicine, University of New South Wales, Sydney, Australia
\textsuperscript{b} Albion Street Centre, Sydney, Australia

Received 25 May 2006; received in revised form 10 December 2006; accepted 11 December 2006

Abstract

Background: People living with HIV/AIDS (PLWHA) in developing countries are rarely consulted about ways to promote their health and well-being. This study sought to identify and understand, from the perspective of PLWHA, challenges and opportunities for improving access to HIV treatment, care and support in Vietnam, a resource-limited setting with an epidemic driven by injecting drug use.

Methods: PLWHA trained in participatory research methods completed fieldwork and data collection and co-facilitated focus groups with injecting drug users (IDUs) in Ho Chi Minh City. Qualitative data were analysed in Vietnamese and English using an inductive approach to code and compare content and identify key themes.

Results: Results suggest considerable barriers to scaling up in this setting. Against a backdrop of punitive government policies, including mandatory detention of IDUs and sex workers, and widespread stigma and discrimination, many PLWHA lived with the fear of discovery and the threat of abandonment. Lack of confidentiality, limited financial resources and restricted access to essential medications provided powerful disincentives to health service utilisation.

Conclusions: Opportunities for scaling up lie firstly in expanding access to confidential HIV counselling and testing. However, in the absence of affordable, quality care and access to anti-retroviral therapy, IDUs are unlikely to see testing as worthwhile. Efforts to scale up also need to address structural barriers including stigma and discrimination, poverty and institutional capacity. Finally, PLWHA in Vietnam are a significant but underutilised resource and consideration should be given to overcoming barriers to building confidence and capacity within affected communities.

© 2006 Elsevier B.V. All rights reserved.

Keywords: HIV/AIDS; Injecting drug use; Treatment; Care; Support; Vietnam

Introduction

The first case of HIV was diagnosed in Vietnam in 1990 (Nguyen, Le, Phan, & Wolfers, 2000) and reported infections have roughly doubled each year since 1994 (Borghese et al., 2001). By the end of 2005, an estimated 260,000 adults and children were living with HIV and cumulative AIDS-related deaths were estimated to be 13,000 (UNAIDS, 2006). Fifty to sixty percent of those reported to be living with HIV in Vietnam are injecting drug users (IDUs) (WHO, 2005). While overall HIV prevalence among IDUs has been estimated at 32 percent, infection rates of up to 90 percent have been observed in some areas (Nguyen, Nguyen, & Trinh, 2004).

The epidemic in Vietnam appears to consist of three inter-related sub-epidemics (Borghese et al., 2001). The first, and most advanced, epidemic is concentrated in older male IDUs in southern and central Vietnam. Ho Chi Minh City (HCMC), has been the epicenter with prevalence in IDUs ranging from 1 to 84 percent (WHO, 2006a). The second, more recent epidemic is among younger male IDUs in northern Vietnam and the Red River Delta where prevalence rates
of up to 74 percent have been reported (Nguyen, Hoang, Pham, & Detels, 2001). There is also a third epidemic emerging among female sex workers (FSW) in the southern provinces, many of whom also inject drugs (WHO, 2005). In HCMC, the site for the current research, prevalence of HIV in FSWs has been reported at 23 percent (WHO, 2006a).

Research suggests that it is possible to provide anti-retroviral therapy (ART) in resource-limited settings and to achieve adherence and treatment outcomes comparable with those in the developed world (Orrell, 2005; Meng et al., 2006; Nemes, Carvalho, & Souza, 2004). This has served to focus the research agenda in relation to ART in these settings on barriers to, and facilitators of, adherence. Treatment costs (Crane et al., 2006; Kumarasamy et al., 2005), lack of adequate physician training and healthcare infrastructure (Meng et al., 2006) and the effects of stigma and discrimination (Meng et al., 2006; Kumarasamy et al., 2005; Krain & Fitzgerald, 2005) have been identified as barriers to adherence. A primary care orientation and access to community-based supports (Meng et al., 2006; Jaffar et al., 2005), ease of use of the medication regimen (Orrell, 2005), belief in the benefits of ART (Kumarasamy et al., 2005) and concern for family well-being (Crane et al., 2006) have been found to facilitate adherence in resource-limited settings.

IDUs remain under-represented among those receiving ART in both developed and developing countries (UNAIDS, 2006) and some evidence suggests that adherence may be undermined by drug use (Stein et al., 2000; Lucas, Cheever, Chaisson, & Moore, 2001). While the literature does not support the assumption that IDUs are inherently less capable of adhering to complex medication regimens (Ammassari et al., 2002; Puch, Cerbone, & Gerstein, 2003; Ware, Wyatt, & Tugenberg, 2005; Open Society Institute, 2004), active IDUs receiving ART are more likely to be adherent when prescribed opioid substitution therapy (OST) (Moatti et al., 2000).

PLWHA in developing countries are often viewed as ignorant or indifferent about their health and are rarely consulted about ways of promoting their health or improving their well-being. At the Paris AIDS Summit (1994), a strong commitment was made to Greater Involvement of People Living with HIV/AIDS (GIPA) in response to the global AIDS epidemic. The GIPA Principle calls for the meaningful participation of PLWHA in policy-making, program design and implementation, community mobilisation, and evaluation (UNAIDS, 1999). In particular, GIPA acknowledges the critical role of PLWHA in reducing stigma and discrimination related to HIV/AIDS through peer education and support, advocacy and public education (Asia Pacific Network of PLWHA, 2004).

The need to scale up access to ART as a “global health emergency” (WHO, 2006b) by building the capacity of human resources and systems within affected countries has provided the impetus for a shift towards greater responsibility for PLWHA and their networks in the response to HIV/AIDS. Inclusion of “civil society organisations” (CSOs), consisting of any non-government or private sector group, including PLWHA, has been identified as an integral component of this process and the Global Fund to Fight AIDS, Tuberculosis and Malaria now insists on the inclusion of CSO representatives on all grant proposals (UNAIDS, 2006). However, at the country level, more is needed to make these policies a reality. In some instances, “collaboration between governments and CSOs is more often akin to tokenism than real commitment” (UNAIDS, 2006, p. 206). Strong political leadership, heavy government investment, pragmatic and strategically focused policy, and massive public education campaigns have been identified as key elements of successful mobilisation of PLWHA (UNDP, 2004). Donor agencies have also taken influential positions to bring about national legislative reforms conducive to the involvement of CSOs, including PLWHA (Cornman, Grimm & Rana, 2005; Global AIDS Program, 2006). The “Three Ones” principle recommends a single national AIDS action framework, co-ordinating authority and country-level monitoring and evaluation system, as essential for creating a supportive environment for CS activities (UNAIDS, 2006).

In 2005, Vietnam received approximately US$60 million from a number of international agencies to assist with scaling up HIV treatment support and care (WHO, 2005). However, of the estimated 34,000 adults aged 15–49 years in need of treatment in 2005, only 3,000 had initiated treatment by the end of 2005 (WHO, 2006b). Failure to meet World Health Organisation “3 × 5” targets aimed at providing ART to 11,000 people by the end of 2005 (based on 50% of estimated need), has been attributed to the cost of anti-retrovirals (ARVs), lack of health system infrastructure and limited human resource capacity (WHO/UNAIDS, 2006). First-line ARVs cost around US$260 per person per year for the locally produced generic product and around US$545 for branded ARVs (WHO, 2005).

To date the establishment and support of PLWHA associations and funding for advocacy targeting stigma and discrimination in Vietnam has been limited (UNAIDS, 2002). While government policies increasingly recognise the importance of PLWHA involvement in responding to the epidemic (Socialist Republic of Vietnam, 2006) and considerable donor funding is now focused on capacity building in this area (WHO, 2006b), there remain significant impediments to widespread involvement of PLWHA, particularly IDUs and FSWs. The challenges inherent in implementing high-cost interventions like ART in resource-limited settings like Vietnam are self-evident. However, aspects of the current political landscape also raise questions about the feasibility of fulfilling Vietnam’s commitment to GIPA. Since 2001, IDUs and FSWs have been the targets of punitive government policies involving mandatory detention in “rehabilitation” camps or 05 and 06 centres (Human Rights Watch, 2003). Against such a backdrop, stigma and discrimination have been identified as major challenges to halting the spread of HIV (Borghese et al., 2001).

Using the GIPA principle as a starting point, the pilot project reported here was implemented as part of a regional
initiative to identify needs and build capacity for HIV/AIDS treatment, care and support. The current paper explores these issues from the perspective of Vietnamese PLWHA, bringing to the “scaling up” debate the perspective of affected communities.

Methods

As part of a pilot project designed to build capacity for HIV/AIDS care and support, the project sought to recruit and train eight to ten PLWHA Counterparts to conduct a needs assessment of PLWHA in HCMC. Selection criteria included that Counterparts reside in District 10, the local government administrative unit where the project was based, be in reasonable health with capacity for involvement on a daily basis, and possess basic literacy skills. The manager of the “Ban Giup Ban” (BGB or “Friends Help Friends”), a government funded peer support group for PLWHA, was responsible for identifying and recruiting Counterparts, in consultation with the HCMC AIDS Committee and the in-country Project Co-ordinator. Nine PLWHA, all current or former IDUs, subsequently completed training in participatory research methods covering research ethics, qualitative research methods, data collection techniques (fieldwork, in-depth interviews, focus groups, free listing, mapping and role-playing), and data analysis and interpretation.

Initial data collection involved community-based fieldwork and narrative data collection. Narratives were recorded in story and interview format (n = 45), many with accompanying photographs. Field notes included personal reflections on the fieldwork process. At the conclusion of the fieldwork phase a debriefing workshop was conducted. Issues raised by Counterparts included the need to maintain participant confidentiality during fieldwork, particularly when attempting to access PLWHA. Counterparts also reported that many participants were sad, regretful and resigned to the fact that they were going to die. In these situations, Counterparts reported providing emotional support and making referrals to the Ban Giup Ban peer support group.

The second phase of data collection involved conducting five focus groups with a total of 38 PLWHA. Separate groups for IDUs, younger IDUs, older IDUs, women and FSWs, were held at convenient locations including a traditional medicine center, a district health center and a condom café targeting IDUs and sex workers. Groups were approximately 1.5–2 hr in duration and participants were given a small stipend of 37,000 VND (approximately US$2.50). Focus groups were tape-recorded and simultaneously transcribed in Vietnamese. After each focus group, Counterparts reviewed notes and simultaneous transcriptions and identified key themes. Following data collection and preliminary analysis in country, tape recordings, along with field notes and narrative data, were transcribed in full and translated into English and subjected to further thematic analysis by the authors.

Results

Participants highlighted a range of barriers to scaling up HIV treatment, care and support which were coded and classified according to three main themes: family and community responses to HIV/AIDS, health system responses and health care worker (HCW) attitudes towards PLWHA.

Family and community responses to HIV/AIDS

As well as dealing with the physical burden of their disease, PLWHA in Vietnam also need to manage the psychosocial aspects of HIV infection that impact upon everyday life. One of the major decisions PLWHA must make is whether to disclose their serostatus to their families. Fear of disclosure is directly related to the stigma associated with HIV and injecting drug use. PLWHA who were IDUs commonly referred to themselves as “social evils”, reflecting a more general tendency to link HIV with the “social evils” of drug use and prostitution.

Generally speaking, the doctors treated me in a normal way, but their eyes showed that they still tried to keep some distance because we are social evils anyway (Quoc, 34 year-old male).

The close epidemiological associations between HIV, injecting drug use and sex work in Vietnam (Maher, 2004; Tran, Detels, Hien, Long, & Nga, 2004) serve to exacerbate pre-existing stigmas attached to “social evils”. In particular, HIV is synonymous with injecting drug use and IDUs are often labeled HIV positive by association.

In general people know that we are IDU and they guess that all of us are HIV positive and they’re afraid of us (Female participant, Focus Group 5).

Stigma not only adheres to the individuals or groups with the discrediting characteristic, but also sometimes to families (Goffman, 1963). In Vietnam, not all families understand about HIV infection and fear can sometimes be stronger than love. Families may fear infection and/or stigma and discrimination or they may not know how to look after the positive member. Isolation or abandonment of an infected family member was not uncommon and was sometimes justified as a form of “prevention” or “protection”.

Now I am a street person because my family put me out. I have a six-year-old child who lives with my mother (Female participant, Focus Group 4).

I used to have a lot of friends in the neighbourhood, but now nobody wants to be with me. My elder sister has a lovely baby daughter, but she doesn’t allow me to hold the baby or take her anywhere in the neighbourhood. When I kissed the baby because it smiled like a doll, my sister
or abandoned. Participants were conscious of the impact of the “secondary stigmatisation” of their serostatus on families, neighbours and friends.

My sister sells fruit and if the people around know that I am HIV positive nobody will come to my sister and buy fruit (Tran, 27 year-old male).

Focus group and narrative data indicated that PLWHA who chose not to disclose their HIV status to their families lived with the fear of discovery and the threat of being rejected or abandoned.

We were diagnosed HIV/AIDS positive last year. I tore the result paper to keep it away from my family and my younger sister dared not to take the test for fearing of getting the disease. She said she would rather hear nothing than realize the truth. Just let it be (Son, 23 year-old male).

Disclosure of positive serostatus was often met with a response consistent with PLWHAs expectations of rejection.

My mother was very sad and my father blamed my mother and me. He [lectured] me in such an angry voice. He scolded me, “You are a bad child! You’d better die too, away from my eyes . . . I feel too ashamed to live when having an HIV/AIDS positive daughter”. (Chau, 35 year-old female).

While family provided a crucial source of care and support for some participants, many reported little in the way of support.

I am around 25 years old. I do not hope to receive any assistance from my family any more. Now, my life depends on my fate. I live on selling anything collected in the city pavements. When I feel sleepy and tired I can sleep everywhere. But I have to avoid one street where my family is living and I used to live happily there (Toan, 25 year-old male).

Participants’ accounts highlighted the importance of education for family and community members regarding transmission for both family support and reducing the impact of stigma and discrimination.

At first my family stayed away from me because they didn’t understand about transmission, but after that the people working here told my family and my family did not stay away anymore (Female participant, Focus Group 5).

Health system responses to HIV/AIDS

User-pays health care

Prior to 1986 Vietnam had a centrally planned economy and a system of universal health care. Since the introduction of the Doi Moi or Open Door policy, authorities have attempted to shift the costs of health care to users at provincial, district, village and ward or commune levels (Wolffers, 1995). Within HCMC there are four main levels of government health care facilities potentially accessible by PLWHA. Each district has a number of Ward Health Stations (WHSs) that, in theory, provide basic primary care, counselling, medications and referrals, free of charge. The next level consists of District Health Centres which have a diagnostic capacity and stock a more extensive range of medications available for purchase. The next level, district hospitals, provides inpatient care and treatment and tertiary hospitals provide specialist care and treatment.

HIV/AIDS places significant burdens on families, communities and health care systems. While PLWHA come from all social strata, those who are impoverished or marginalised are most vulnerable. Middle-class families may have savings or investments to cover the costs of care, but low-income families have little or no financial resources and are less likely to have the support systems or capacity to cope with HIV/AIDS. There is often a significant loss of family income due to reduced productivity of both PLWHA and their carers, as well as the costs incurred by secondary stigmatisation. For many PLWHA, this makes the monetary cost of their disease crippling.

I have a problem with money. Testing is very expensive and there are so many tests to take and many medications to buy (Female Participant, Focus Group 4).

This situation is compounded by limited access to medications at the WHS or primary care level where they are provided free of charge. PLWHA with common opportunistic infections (OI) may be referred to secondary or tertiary care institutions to access appropriate treatment. This pushes up the cost of care and promotes self-medication. Although mechanisms are ostensibly in place for indigent PLWHA to receive free health care, the process for procuring these benefits is cumbersome and acts as a deterrent to many PLWHA. Once approved, patients receive an “examination booklet” that entitles them to access free health care. However, this was often a case of too little, too late.

After three or four months, my brother’s disease got more serious and could not eat and drink. His body was swelled and could not move. He coughed much and always tired. We were given a patient treatment booklet which reduced the fee for our difficulties and were referred to higher medical organization but my brother died for suffering from serious tuberculosis because we had not money (Khanh, 50 year-old male).
Despite being eligible, most participants had not registered for this booklet. For those participants who had not disclosed their serostatus to their families, the risk of having their confidentiality compromised outweighed the potential benefits of the booklet.

I’m afraid that my husband and child will read the booklet and know everything about me (Female participant, Focus Group 4).

Moreover, for PLWHA, particularly IDUs, who are homeless or living on the streets, negotiating the health bureaucracy and producing the required documentation to receive health services free of charge is extremely difficult.

In my circumstance I don’t know what to do if I have a serious illness because my home is on a corridor under a bridge and my meals are leftovers in market (Khoa, 44 year-old male).

Witnessing the fate of others only fuels the sense of hopelessness experienced by this group of particularly marginalised PLWHA.

I myself have witnessed two people die. At first they lay on the street and they had diarrhea and coma, and the people around informed the police and the People’s Committee, but nobody knew whose job it was, so my friends died, and the police came and took them away (Male participant, Focus Group 3).

**HIV testing and diagnosis**

Voluntary counselling and testing for HIV not only promotes prevention, but also serves as an entry point for treatment, care and support (WHO/UNAIDS, 2006). At the time the study was conducted there were 17 tertiary level centres for HIV testing in HCMC, none of which were located in District 10. While anonymous testing sites providing free HIV testing, counselling and information have since been established in Vietnam (Thinh, Bain, Giang, Mandel, & Lindan, 2002), these facilities were not available in HCMC at the time of the study.

Many PLWHA reported from personal experience that test results were often given without empathy, consideration or pre and post-test counselling.

No one gave me counselling. Two days after the test I came to take the result, a nurse in the testing department passed me the result. Having a look at the result, I came home. Nobody said a word. Only when I asked the nurse whether I had disease, all she said was “yes”, giving me some more words that I should not continue using drug any longer (Khoa, 26 year-old male).

Post-test counselling, where available, usually consisted of general advice, including information about how to prevent secondary transmission, how to live a healthy life and the importance of ceasing drug use. Participants stated that they were rarely provided with practical information on how to stop using drugs or how to access services, information or support.

They only advise. There is no instruction how to stop using. And they advise more on how to live a safe life and to keep others safe too, not to interact with too many people (Male participant, Focus Group 3).

While Vietnam’s national HIV/AIDS strategy, adopted in 2004, endorses methadone treatment, failure to initiate OST remains a crucial weakness in Vietnam’s response to HIV (Maher, 2004). Pilot methadone programs have been established in Hai Phong, Hanoi and Khanh Hoa but progress has been slow and there is little prospect of widespread roll out (UNAIDS Technical Working Group, 2005).

Some participants, particularly older IDUs and those tested in “rehabilitation centers”, reported not being informed of their test result and only learning of their positive status by default or from family members.

I once had a high fever, and my family hurriedly took me to ______ Hospital, where the doctors told my parents that I am positive. When I heard positive, I didn’t know what it is, but later I began to know something when my father said in an angry voice, “You go to hell! Your AIDS has made me run out of money.” (Truc, 22 year-old female).

Participants expressed serious concerns about lack of confidentiality in relation to HIV. Lack of confidentiality adversely impacts upon the uptake of voluntary testing and the decision to seek care and support. Our data suggest that patient confidentiality is rarely observed, particularly at the local level where both the WHS and the BGB maintain “lists” of PLWHA.

[T]he BGB came to my home, informing me about my HIV infection and then consoling me and told me to join the club . . . In 2000 I joined the District BGB and was in charge of the secretarial work. Reading the list of HIV positives in my ward I found my name (Phu, 46 year-old male).

Those at risk of HIV infection, particularly IDUs, will not present for testing if they fear the stigma and discrimination that accompanies disclosure. Moreover, in the absence of affordable care options, PLWHA are unlikely to perceive any benefits to learning their HIV status. Quality post-testing services, such as referral networks for both HIV and opioid substitution treatment, are essential to facilitating uptake of voluntary counselling and testing.
Access to medications

The limited availability of affordable medications is also a problem experienced by PLWHA in Vietnam. WHSs have a limited range of basic medications available free of charge but these are often unavailable (see also Wolffers, 1995). Many elect to avoid the formal sector and self-medicate.

If I’m ill, I go to a pharmacy. Going to the Ward Health Station is just a waste of time (Nhat, 33 year-old male).

Limited access to affordable medications from services where PLWHA also have serious concerns about confidentiality, made some participants question the benefits of accessing WHSs.

I have some friends who are HIV positive and their names are on the list controlled by the Ward Health Station. They could only just receive some normal medications such as paracetamol. . . . So I think why we should go to such places [and risk] being revealed our secrets? (Dao, 47 year-old male).

I think it would be better to go to the Ward Health Station, but I want to avoid public attention, so I treat myself by using medicine bought from chemists according to what I know (Trang, 31 year-old female).

Avoidance of the formal health care system could have devastating consequences for PLWHA.

I had a friend who was ashamed and afraid of public opinion, so he didn’t go to the Ward Health Station, and it was too late when he was taken to hospital. He died last month. (Nghia, 24 year-old male).

When PLWHA need medications that are not stocked by WHSs, particularly ART, doctors usually provide prescriptions or tell them which medications to buy from the pharmacy at their own expense. For many PLWHA, particularly current IDUs, this option is beyond their reach.

What makes me sad now is that the doctor’s prescription for stopping my HIV/AIDS cost us no less than some million dong, but how can my parents afford it because they earn so little from their coffee shop? (Trung, 21 year-old male).

Participants’ attitudes towards the expenses associated with ART were particularly noteworthy. Their expectations for the future were typically modest and, within the context of the current user-pays system, ART was seen as unaffordable and therefore unrealistic.

In my opinion to have specific medication [ART] is impossible in Vietnam because we cannot afford them. I think we should have some counselling for them [PLWHA] at first and then give them medications for common diseases such as opportunistic infection (Male participant, Focus Group 3).

That most participants did not expect access to ART may reflect internalisation of their status as “social evils” and concomitant self-stigma. However, it may also reflect Vietnamese pragmatism in response to perceptions that restricted access to health care represents the reality of Vietnam’s lack of economic prosperity.

We have to be satisfied with it because our country is still poor so we should not demand modern medical facilities and all specific and cheap medication for HIV positive people (Quoc, 34 year-old male).

When access to health care is restricted, people seek care outside the formal system. Since the introduction of a user-pays health system in Vietnam, there has been a rapid increase in the number of pharmacies and drug stands. Wolffers (1988) has shown how, in developing countries, pharmaceuticals may provide a metaphor for political and economic transformation. In Vietnam, health advice is rarely seen as value for money and medication may be the only concrete good exchanged between the provider and consumer (Wolffers, 1995). A survey of eight provinces in 1992 reported that 21 percent of Vietnamese self-medicated (Wolffers, 1995).

In the open [door] time, people’s lives are better. With a little money we can buy medicine at the pharmacies. If needing inject[ion] I just have the street nurses do [it] (Minh Khoi, 44 year-old male).

Many participants described turning to pharmacists and traditional healers, as well as using traditional practices such as coin rubbing, for symptomatic relief. This can lead to delayed presentation, making attempts to treat or prevent opportunistic infections more difficult.

Many HIV positive people, due to their inferiority complex and the fear that other people will know about their disease, dare not go anywhere, especially the Ward Health Station, for examination, so when their opportunistic illnesses become serious, it is too late for treatment, and if treatment is possible, it will be very expensive (Hai, 41 year-old male).

By not accessing the formal health care system, PLWHA may also be receiving inappropriate medication or missing out on education and information about their condition. They may also misdiagnose themselves and take medications which may be harmful to them. While, given their fears, the decision to self-medicate may seem logical and justified, the long-term impact upon health, quality of life and survival is unknown.

Resort to self-medication using pharmaceutical preparations available without prescription creates a system
vulnerable to exploitation. The pharmaceutical market in Vietnam is largely unregulated with little capacity for attention to issues such as rational prescribing and quality use of medicine. Fieldwork visits to pharmacies and the pharmacy market in HCMC revealed that most Western medications, including some ARVs, are available over the counter to those who can afford them. In Vietnam anyone can open a pharmacy and there have been several high profile cases where health care workers (HCW) have been caught selling donor-funded drugs on the black market (Wolffers, 1995).

The health care system should take more control over the medicines sources and origin on the market as well as its price so that it is reasonable for the people. Do not let the people who only run after profits, ignore user’s benefit then sell bad quality medicines with high price like is happening nowadays (Dao, 47 year-old male).

Providing care and support for PLWHA

Access to care and support was the most immediate and tangible issue identified by PLWHA. As noted previously, stigma and discrimination pushed many positive IDUs away from families and onto the streets. For this group, peers are often the sole source of care and support. The BGB peer support group, which operates under the guidance of Provincial AIDS Committees, provides counselling, homed based care and support, education for families and assistance with administrative requirements. Many participants highlighted the need for more services like the BGB that address PLWHAs needs for care but that also reflect their concerns about stigma and discrimination. BGB peer workers were seen as being “in the same shoes”, thereby offering something unique to PLWHA.

When I was sick and it turned to late HIV infection, the BGB member like Mr ___ dropped by and took care of me. Thanks to the support of the BGB members forced me to eat, I ate and survived. We help each other as we are in the same shoes. No help from the ward health stations (Male participant, Focus Group 3).

In principle when we are in hospital we are supposed to be visited by people from the district and ward station levels and they should come to us in order to give us care and support but in reality we got almost nothing. Only the BGB members help HIV positive people (Tien, 33 year-old male).

Participants’ positive responses to the Counterparts, who were current or former IDUs, also suggest that the peer support model may be of particular value for this group of PLWHA and has the capacity to generate forms of belonging in an environment of stigma and discrimination. More PLWHA clearly need to be trained and mobilised in order to expand peer-based care and support in Vietnam, particularly for HIV positive IDUs. However, a significant barrier to the expansion of peer-based services is the capacity of PLWHA to take on this role. Experience has shown that without access to ART, peers also succumb to AIDS and have a high attrition rate.

Health care worker attitudes

Stigma and discrimination remain very common in Vietnam, “even among health care workers involved in HIV/AIDS prevention and care” (Borghese et al., 2001, p. 6; Khuat, Nguyen, & Ogden, 2004). HCWs’ concerns about the risk of HIV transmission through casual contact can lead to the adoption of excessive measures and negative attitudes (see also Ha & Ickovics, 1996).

Once I got a problem with my hand, it bled, my hand bled. I asked a friend to phone to the Ward Health Station to ask a doctor to come and give me wound care but they did not come. Finally I went to the Ward Health Station and asked for help but they said no because they knew that I am HIV positive (Male participant, Focus Group 1).

It was seen through the attitudes of the nurses. They feared of touching me. For I was aching all over, I had to lie in the patient-trolley. But they shifted their responsibility to one another and asked my family to take me to the ultrasound room. They pulled my patient-trolley talking to my older sister that “Many young people nowadays involve in drug, I am afraid of being infected by them when working here because 80 percent of IDUs become HIV/AIDS positive. If I had such descendents, I would abandon them all”. Although I was aching, I felt upset when hearing her words (Son, 23 year-old male).

While misconceptions about HIV transmission have been associated with the stigmatisation of PLWHA (Dab, Moatti, Bastide, Abenheim, & Bruent, 1989) they cannot be considered in isolation as an underlying cause. Participants also emphasised the pervasive effects of “social evils” campaigns on HCW attitudes towards IDUs, particularly the conflation of HIV with drug use and sex work.

I found the nurses and pharmacists staring at us. I felt hurt due to an inferiority complex because I knew for sure that those nurses looked down upon us social evils, not like when they talked to businessmen such as directors, managers (Phu, 46 year-old male).

Some participants felt that HCW attitudes differed depending upon their exposure to, and experience of, positive people. Personal interaction has been identified as an important factor in reducing discrimination (Bermingham & Kippax, 1998). In general, participants felt that doctors and other HCWs who specialised in HIV medicine, worked in HIV wards or who had a counselling role with PLWHA,
showed more compassion and empathy and provided better service.

It depends on each person’s heart, education and the doctors doing social work they usually work with HIV positives, they understand the patients’ psychology while doctors working in hospitals understand almost nothing about HIV positives (Male participant, Focus Group 2).

Discrimination against PLWHA often manifested in the quality of care they received, which many participants felt was lower than the standard received by other patients. Some participants felt that they had been treated inappropriately or inadequately and were not referred to other services when they should have been.

Because of the inferiority complex to be HIV/AIDS positive and the fear of being rumored by my neighbors, I am afraid of going to the Ward Health Station. Moreover, I examined there once or twice, they only gave me some analgesics or antipyretic medication such as paracetamol or some multivitamin such as B1, B6, B12, . . . and cotton wool (Minh Khoi, 44 year-old male).

Even if I had money I wouldn’t go. When I had some exam of my shingles they looked at me very strangely. It seemed that they wanted to stay away from me. I feel sad and ashamed. That’s why I don’t want to go there again (Lanh, 29 year-old male).

Discussion

This project provided an opportunity for PLWHA in Vietnam to describe their experiences of living with HIV/AIDS and to identify and assess their needs for treatment, care and support. While some participants acknowledged positive interactions with individual HCWs, the data presented here suggest that, for the most part, interactions between PLWHA and the health care system are negative.

Decision making by PLWHA in relation to HIV-related health care was dominated by the need to avoid the stigma and discrimination associated with being branded both an IDU and HIV positive. Trust in the health system and its workers was undermined by a profound lack of confidentiality, a situation that is at best, unethical but also questionable in terms of human rights. While there is much that can be done to enhance institutional capacity, particularly at the local level, the willingness of PLWHA to access the health system will ultimately be determined by the perceived costs and benefits of accessing care, particularly the costs associated with stigma and discrimination.

There is a need for community education programs that aim to counteract negative community attitudes towards PLWHA in Vietnam. However, greater efforts are also needed to address discrimination within the health system and to de-link HIV/AIDS and “social evils” in policy, legislative and educational initiatives. As recently as 2003, the Vietnamese government issued a policy stating that prostitution and drug use were the primary causes of the HIV epidemic (Khuat et al., 2004), highlighting the contribution of official discourses to sustaining HIV-related stigma and discrimination (Khuat et al., 2004). Vietnam has yet to create an appropriate legal and policy framework to reduce stigma and discrimination and to foster the creation of an enabling environment for those affected by HIV/AIDS. At the very least, punitive government policies in relation to vulnerable groups are counterproductive (UNDP, 2004). Regardless of the challenges inherent in managing the tensions between law enforcement and public health priorities, drug control practices should reduce the HIV risk to IDUs and conform to international human rights standards (UNAIDS, 2006).

The data also indicate that Vietnamese HCWs continue to fear HIV transmission through occupational exposure and casual contact. This may be due to a lack of adequate knowledge or an inability to protect themselves. The public health system in Vietnam is clearly under-resourced and universal precautions may be seen as a luxury the system cannot afford. HCWs would clearly benefit from ongoing access to basic training which incorporates information on HIV, patient confidentiality, infection control and stigma and discrimination. In Thailand, the involvement of PLWHA as “co-providers” of care has been responsible for de-stigmatisation and positive changes in the attitudes of HCWs towards the role of PLWHA in treatment, care and support (Kumphitak et al., 2004).

Building the capacity of the health workforce is an essential part of enhancing health service provision for PLWHA. Scaling up HIV treatment and care is all too easily translated into acquiring technical infrastructure, expertise and medication at considerable cost and at the expense of developing local, people-based initiatives that promote health service engagement and utilisation. While seeking to shape the attitudes of HCWs and PLWHA to challenge stigma and discrimination offers less tangible results than funding a state-of-the-art clinic, it represents an investment in sustainable development and a broader, contextually informed framework for scaling up efforts.

The poverty and marginalisation currently experienced by many PLWHA in Vietnam also presents significant challenges to improving access to HIV testing, treatment and support. For IDUs in particular, the costs of health care, in addition to those associated with drug dependence, represent a significant barrier. Participants also emphasised the need to address restricted access to affordable medications for OIs. While ART was seen to be beyond the realm of possibility for most participants, access to treatment for OIs may significantly improve the quality of life for PLWHA and in some cases, prolong their lives. Only when accessing services offers hope for the future, will HIV testing and treatment become more necessity than liability.
Results highlight many areas in which appropriately and collaboratively developed interventions could benefit both PLWHA and the health care system. Participants’ positive experiences with peers providing information, support and care suggest scope for further involvement of peer-based organisations. However, while the government of Vietnam continues to reiterate its support for involvement of PLWHA, this aspect of the evolving response to HIV/AIDS in Vietnam remains in its infancy. While donor agencies increasingly fund non-government organisations to train PLWHA volunteers to perform specific aspects of service provision (UNAIDS, 2006), and to advocate for greater involvement of PLWHA at all levels of program development, implementation and monitoring (Global AIDS Program, 2006), there has been no significant increase in domestic budget allocations targeting this essential component of scaling up efforts (Socialist Republic of Vietnam, 2006).

Lessons learned from other resource-poor settings, particularly within the region, provide a starting point from which to review and further develop existing policies in Vietnam. In a range of countries in Africa, Latin America, Asia and the former Soviet Union, PLWHA have been involved in projects aimed at facilitating uptake of HIV testing, reducing stigma-related obstacles to scaling up access to treatment, and extending the reach of prevention and harm reduction activities (UNAIDS, 2006). In Indonesia, CSOs are involved in drafting provincial regulations to determine budgeting for the AIDS response, and are active in service provision and monitoring activities (UNAIDS, 2006). Experience in Thailand has shown what can be achieved with strong political leadership that facilitates broad-based co-operation between key government agencies, CSOs, the media and the private sector (UNDP, 2004; Ford, Wilson, Bunjumnong, & von Shoen Angerer, 2004).

Conclusion

Saving the lives of PLWHA by providing ART will go a long way towards addressing the humanitarian crisis of HIV/AIDS in Vietnam. However, the data presented here highlight some of the problems that “scaling up” ART will not address. Access to treatment will not, in and of itself, compensate IDUs and their families for the stigma and discrimination they experience nor will it guarantee that the benefits of treatment outweigh the burdens of adherence. While ART roll out has the potential to decrease stigma as HIV/AIDS becomes normalised as a result of increased health outcomes and improvements in quality of life, the powerful nexus between HIV and “social evils” in Vietnam may prove difficult to dismantle. Strategies that address the social and structural dimensions of HIV/AIDS are also needed to ensure the response to the HIV/AIDS crisis is broad-based and sustainable. The success of HIV/AIDS prevention, care and support will depend on the creation of an enabling environment which promotes quality of life for PLWHA and their carers. Within such environments, people are not afraid to seek information, testing or treatment.

Ways in which harm reduction can be implemented in Vietnam without sacrificing cultural beliefs and values should also be explored. Promotion of a public health approach will require review of the current status of HIV as a “social evil” (Borghese et al., 2001). In light of human rights concerns and high recidivism rates, current policies such as the mandatory detention of drug users and sex workers are fundamentally at odds with public health.

In Vietnam, PLWHA are a significant but under-utilised resource. The data presented here suggest that PLWHA, particularly current or former IDUs, experience considerable stigma and discrimination and there is little sense of a partnership between affected communities and the health care system. A genuine commitment by government to fostering the development of peer-based organisations is required to provide mechanisms for advocacy by, and greater involvement of, affected communities in responding to the epidemic.

Acknowledgements

We are grateful to everyone who contributed to the success of this project, especially the PLWHA Counterparts and the PLWHA participants, Tran Thinh MD, Tran Minh Gioi MD MPH, Thuong Duc Quang, Ho Thi Hien MD, the Ho Chi Minh City Health Department and Provincial AIDS Committee, and the University of New South Wales/Albion Street Centre project team (Ali Arancibia, John Arneil, Trish Bullen, Margie Ewing, Julian Gold, Ari Rotem and Alexandra Wilson). This project was funded by AusAID.

References


