

**“I Wish I Had AIDS”:**

A qualitative study on access to health care services for HIV/AIDS and diabetic patients in Cambodia

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Volume 2, No. 1 (2012) | ISSN 2161-6590 (online) DOI 10.5195/hcs.2012.67| <http://hcs.pitt.edu>



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## Abstract

Financially stricken Cambodian patients with diabetes and HIV/AIDS typically encounter multiple, serious barriers to effective care. This process may extend over many years and involve numerous rounds of diagnosis and treatment as the disease progresses from initial symptoms to longer term complications. Living with both the impact of the disease and this ongoing struggle for care can severely disrupt the everyday life of both sufferers and their families.

Our retrospective study adopted qualitative research methods to collect data from HIV/AIDS and diabetic patients enrolled and not enrolled in treatment programs at varying institutions in urban and rural settings. Using purposive sampling techniques, a total of 25 HIV/AIDS and 45 diabetic patients were recruited. Semi-structured and open-ended interviews were used to collect information on patient experiences of different phases in the on-going process of seeking care and treatment. The findings indicate that both HIV/AIDS and diabetic patients encounter multiple supply- and demand-side barriers to care at different stages of their illness. More strikingly, our research findings suggest that supply-side barriers, for example rationing systems or targeting strategies that limit access to free treatment or social assistance, are substantially higher for diabetic patients. This perceived inequity had a profound impact on diabetic patients to the extent that some “wished they had HIV/AIDS”.

These findings suggest that there is an urgent need to widen the focus of health care to address the substantial and increasing burden of disease resulting from diabetes and other serious chronic disorders in Cambodia and many other low/middle income countries.

*Keywords: Cambodia; the Poor; access to health care; chronic disease; HIV/AIDS; diabetes*

## “I Wish I Had AIDS”:

A qualitative study on access to health care services for HIV/AIDS and diabetic patients in Cambodia

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### 1. Introduction

Studies on access to health care tend to principally focus on supply-side factors including the quality, volume, and price of services. In their review of interventions to reduce barriers to access, Ensor and Cooper (2004) identified that there are numerous demand-side factors such as distance, lack of information, opportunity cost as well as cultural and social barriers. Hardeman et al. (2004) pinpointed four main barriers limiting access for those with acute illness in Cambodia. These were: financial, geographical, informational and intra-household. A similar study on access for acute illness among the poor identified that physical access; ability to pay; knowledge of assistance schemes; personal beliefs and perceptions of need and quality of health care; lack of trust in public health care facilities; and socio-cultural practices of health and treatment were also major factors in determining access to health care (Annear et al., 2006). Those with chronic diseases might be expected to encounter increasingly complex barriers given the need for long-term care and treatment. The WHO (2003) review of international evidence on adherence to long-term treatments for chronic diseases indicated that the ability of patients to follow treatment plans in an optimal manner is frequently compromised by multiple and diverse barriers related to social and economic factors, the health care system, characteristics of the disease, characteristics of therapies and patient-related factors. The picture of health access, therefore, is a complex one of many variables. Chronic conditions create special challenges for health systems originally designed to deal with acute and infectious diseases (Adeyi et al., 2007), particularly in low and middle income countries undergoing economic and epidemiological transitions (Dummer and Cook, 2008; Abegunde and Stanciole, 2008; King et al., 2005; Abegunde et al., 2007; Miranda et al., 2008; Posse et al., 2008). Barriers to long-term care and treatment (LTC) also exist and are well documented in affluent societies (Schoen et al., 2008). However, efforts to document the complexity and multi-dimensionality of such barriers to LTC in low-income and developing countries are limited and fairly recent to say the least (Miranda et al., 2008). It is clear that these barriers can have very serious consequences in terms of delayed treatment, inappropriate healthcare-seeking behaviors, poor adherence to treatment regimes or even a decision to forego treatment.

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Schoenberg et al. (1998) explore lay perspectives on the origin and management of non-insulin dependent diabetes among older women in the United States. They point out that the management of disease and adherence to medication is strongly associated with patients' perceptions as to the aetiology of diabetes. Alberti et al. (2007) likewise focus on primary care management of diabetes in Tunisia, a middle income country, and identify numerous barriers that may potentially influence disease management including the availability of medication at the health centre; provider incentives; financial constraints; patient compliance and attendance, as well as clinician workload.

Weidle et al. (2006) consider adherence to antiretroviral therapy in a home-based AIDS care program in rural Uganda. Their study suggests that the two major barriers encountered were difficulty in accessing transport to health centres and the requirement to pay for therapy. A similar study (Nam et al., 2008) on adherence in urban Botswana, examined the role of psycho-social factors. This found that factors such as acceptance of HIV-status; the ability to avoid internalizing, stigmatizing attitudes and identification of an encouraging confidante were associated with good adherence. A recent paper by Posse and colleagues (2008) reviews 19 articles and abstracts from 1996-2007 on barriers to access antiretroviral therapy in developing countries. It identified the most common barriers at the population level as the lack of information about antiretroviral therapy, perceived cost for ART and stigma attaching to HIV/AIDS. At the health care delivery level the main barriers were distance to facilities; lack of coordination across services and limited involvement of community in the program planning process.

Although it may be convenient to distinguish supply- and demand-side barriers to care, a patient's experiences of both their illness and the health care delivery system may be deeply entangled. As pointed out by Lawton et al. (2004), not only may different types of health service delivery influence the ways in which patients think about and manage their disease but over time the perceptions they have about their disease can come to influence their expectations of, and preferences for, services. Health care can be seen as simply one aspect of the overall experience of living with a chronic disease, composing its complex reality and experience. Exploring such experience from the patient's perspective may thus help us understand the complexity of the problems they face.

The aim of our study is to explore and document the different types of barriers to care and treatment at different phases of illness experience reported by financially disadvantaged Cambodian patients with HIV/AIDS or diabetes. By comparing these two diseases, we aim to identify differences and similarities in those experiences. We define a barrier to health care as any factor or circumstance that either prevents or hinders a patient from receiving the (modern) health care that they perceive as necessary or prevents a provider giving the care they consider appropriate. Health care will be taken to include diagnosis, treatment and management of the disease.

The subsequent section of our paper presents the analytical framework for the study. This is followed by discussion of the methodology employed for data collection and analysis. The findings are divided into five main themes according to the proposed framework. The final section provides a discussion of the findings and draws conclusions linked to policy implications.

## II. Analytical Framework

The analytical framework used for this study views chronic disease experience as a continuum of distinguishable phases. This approach dates to Chrisman (1977:353) who defined such a process in terms of: symptoms; care seeking; provider consultation; treatment and adherence. The intention was to capture the experiences of patients and the multiplicity of problems encountered over the course of their illness through patient illness narratives embedded in their social and cultural contexts (Farmer, 1994; Garro, 1994; Mathews et al., 1994; Hök et al., 2007). Here we focus on four states, labeled as: the road to proper diagnosis; seeking medical treatment;

accessing social care and support, and adherence to care and treatment (figure 1).

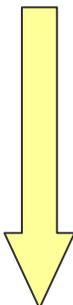
Phase	Continuum	Problems encountered
The road to proper diagnosis		Obtaining correct diagnosis Accepting disease status
Seeking medical treatment		Problems in locating and accessing effective treatment
Accessing social care and support		Problems in obtaining social care and support
Adherence to care and treatment		Problems with adherence

Figure 1: phases in accessibility continuum

Phase one covers the period from initial symptoms to a diagnosis of diabetes or HIV/AIDS which is proposed by a provider and accepted by the patient. Phase two involves gaining access to treatment from a medical provider. Phase three concerns the search for necessary social care or support, which might range from counseling to physical or financial assistance. The final phase involves the patient attempting to develop a successful ongoing coping strategy based on adherence to treatment regimes and support mechanisms.

### III. Methods

The study was conducted in two sites: Phnom Penh (an urban setting) and Takeo province (a rural setting). In Phnom Penh, interviewees were selected from patients enrolled in a free care program at the Centre of Hope, also known as Norodom Sihanouk Hospital. This charity hospital is an important provider of treatment and care for both HIV/AIDS and diabetes patients in Phnom Penh. Similarly, in Takeo, interviewees were selected from patients enrolled in a free care program at the chronic disease clinic co-managed by the referral hospital and MSF Belgium. Again, this facility provided care and treatment for both disease groups. The rationale for selecting patients already enrolled in treatment programs at these facilities was simply that these patients had been through the various disease phases. Since they had already overcome many problems to get to where they were, their stories were expected to provide more detailed insights compared with those who were not yet in the final phase of the disease continuum.

Interviews were also conducted based on snowball sampling (Bernard, 1988) with people who considered that they had HIV/AIDS or diabetes but were not using the above facilities. It was difficult both in practice and in terms of maintaining ethical research standards to locate HIV/AIDS patients outside the system, as they typically concealed their status. It was easier for the researcher to locate diabetic patients not in the treatment programs because diabetic patients tend to know other sufferers in their community. Initial samples were obtained by locating a key individual working as a not-for-profit socio-medical service provider or as a traditional healer for either HIV/AIDS or diabetes. This individual was asked to contact beneficiaries or clients to ask if they were willing to participate. If the answer was positive, the researcher met with each individual to explain the purpose of the research and confirm their consent.

A semi-structured interview questionnaire was used, focusing on: perceptions and understandings of chronic diseases and how patients recognize the symptoms of their illness; social and psychological factors influencing care seeking and treatment; financial burdens on households; distance and means of travel to health care facilities; information barriers to receiving appropriate care and treatment; and how patients managed and controlled their diseases.

Interviews were also carried out with two other groups. The first consisted of ten health care providers, who were questioned on access barriers related to the supply side of the health sector, their underlying causes, and how they might be addressed. The second group comprised five key NGO staff members. They were asked to explain their roles and policies in terms of health care delivery to the poor and, as above, to provide their perceptions as to barriers, causes and suggestions for addressing them.

All interviews were conducted in Khmer by a native Cambodian researcher trained in the field of medical anthropology. Interviews were transcribed and analyzed using qualitative techniques to search for patterns; themes; word repetition and local terminology and concepts emerging from the interviews.

### Study limitations

This study suffers some limitations. The sampling procedures clearly do not permit inferences to any larger population. The aim is primarily to provide detailed information and in-depth understanding of the experiences of specific patients that could not be captured in a large quantitative survey. A further limitation is that the data collection was carried out in late 2005 and therefore the situations presented have possibly changed.

## IV. Findings

### Patient characteristics

70 people participated in the study, 25 diagnosed with HIV/AIDS and 45 with diabetes (table 1). All of the former had received medical treatment. Those in Phnom Penh had attended the Center of Hope (6) or national hospitals (7), and all those in Takeo the MSF chronic disease clinic (12). Among the diabetic patients, 38 had received treatment. In Phnom Penh, 16 had enrolled in a treatment program provided by the Center of Hope (6) and Kossamac Hospital (10). In Takeo province, 17 were receiving treatment from the MSF clinic, while five others attended the Center of Hope in Phnom Penh. Another seven diabetic patients in Takeo were self-treating at home, using both modern medicines bought from private pharmacies and traditional remedies. 17 of the HIV/AIDS patients reported living with the disease between 1 to 3 years and the remaining 8 for more than 4 years. Of the diabetic patients, 6 had been diagnosed less than 1 year previously, 10 between 1 and 3 years, and 29 more than 5 years.

	HIV/AIDS		Diabetes	
	Phnom Penh	Takeo	Phnom Penh	Takeo
<b>Number of patients</b>	13	12	17	28
Male	7	7	7	10
Female	6	5	10	18
Age range	24-35	24-40	35-64	32-70
Median age	30	34	51	54

<b>Number of year after diagnosis</b>				
<1 year	0	0	1	5
1-3 years	7	10	6	4
4-5 years	1	0	2	8
>5 years	5	2	8	11
<b>Current place of care or treatment</b>				
Center of Hope (Phnom Penh)	6		6	5
MSF (Takeo)		12	7	10
National hospitals in Phnom Penh	4			
NGOs	3		10	
Private clinic/self-treatment			1	6

Table 1: Participants of study

### Stage 1: The road to proper diagnosis

For both HIV/AIDS and diabetic sufferers at the early stages of their disease, their perception and interpretation of symptoms and severity strongly influenced their attempts to obtain a diagnosis. Most assumed alternative causes of their symptoms. The diabetic patients tended to attribute blurred vision; tingling and burning of the fingers; numbness of the feet; continuous thirst; sleeplessness; frequent urination and weight loss to magical manipulations and initially sought diagnosis from Buddhist monks and other traditional healers:

I was sick with many symptoms and I did not know what the cause was. I went to a traditional healer to find out what was wrong with me and I was treated with traditional medicine ... The traditional healer at first did not tell me that I had diabetes but he simply treated me for a while. After that I went to a private clinic in town for a blood test and the results showed my blood glucose was very high. They said I had diabetes. (PLWD #8 at the MSF clinic in Takeo.)

The HIV/AIDS patients also tended to attribute their symptoms to other diseases and depending on their severity typically sought palliative treatment for a period of time:

At first I did not know that I had HIV. I thought I had appendicitis and I spent a lot of money to treat myself. (PLHA #12 at the MSF Takeo clinic).

Only when symptoms persisted or worsened did patients seek diagnosis at a health care facility. Simply treating symptoms and delaying diagnosis often led to a worsening of their condition and also had financial implications.

I got sick in 2001. At first I had diarrhea for four months and got very skinny. I was treated with IV fluid at a private clinic near my house and also with traditional medicine. But my condition did not get any better. I was treated by three different private doctors for three years, but with all these three doctors I was never tested for HIV. I spent a lot of money on these doctors: as a result I sold two plots of land and one motorbike to pay for my treatment. In total, I spent about 10 million Riel [around US\$2,500]. (PLHA #4 at the MSF clinic in Takeo.)

Being very skinny was perceived and understood as an obvious indicator of HIV/AIDS. It was not appreciated that rapid weight loss is a possible consequence of diabetes.

I tested for HIV in April 2004. The reason I decided to get the test was that my friend saw I was very skinny so she suspected that I had HIV/AIDS and suggested that I should go for the test. (PLHA #4 at the Center of Hope)

When I became ill my weight went down to 57kg. Everyone thought I had AIDS because I became very skinny. My friend who works as a HIV/AIDS counselor at Takeo clinic suggested that I should go for an HIV test. I went to a private clinic in Takeo for diagnosis but I did not have HIV/AIDS. (PLWD #9 at the MSF clinic in Takeo).

A major barrier to obtaining a correct diagnosis was the limited diagnostic abilities of health providers, particularly those in the private sector in rural areas. The lack of appropriate technology to undertake medical tests coupled with the simple absence of knowledge among providers, often led them simply to treating a patient's symptoms or incorrect diagnosis. This tendency was often compounded by perverse financial incentives, given that providers were reluctant to turn away paying customers. One diabetic patient described his experience:

I was sick in 1997 with symptoms such as urinating 10 times a night, cannot eat, and thirsty. My wife decided to take me to a private clinic for treatment. The doctor did not diagnose me; he just treated me with injections ... I did not ask to be injected but it was the doctor who wanted to give me an injection and IV infusion mixed with Vitamin C. (PLWD #7 at the Center of Hope.)

A number of patients obtained multiple diagnoses. In the case of HIV/AIDS this was related not only to patients' assessment of the validity of a given diagnosis but also to their resistance to accepting that they had the disease:

I first went to the Red Cross health center for the test and it was positive. I became unconscious when I heard the result. I did not want to believe the result so I decided to go to the Russian Hospital for another test, and the result was positive. I still did not want to believe it. Then I went to Calmette Hospital for the third test and it was positive again. (PLHA #13, currently not on a treatment program, in Phnom Penh).

Some reported delaying diagnosis through fear of stigmatization:

I know that my husband had died from AIDS. But I was afraid to get tested because I was scared other people might look down on me" (PLHA#5 at the MSF clinic in Takeo).

This tendency to deny their disease status did not apply to diabetic patients. Most patients did not associate the disease with social stigma and tended to both accept and reveal their diagnosis, even if it had been obtained from traditional healers or they had learned about the symptoms from other community members with the disease.

I knew I have diabetes symptoms for eight years because people in my village who had diabetes described similar symptoms to me. They told me to taste my own urine to find out if I really had diabetes. I tasted it and it was very sweet. Then I was sure that I had diabetes. But I also went for diagnosis at a private clinic. (PLWD #5, currently not on a treatment program, in Phnom Penh.)

However, a lack of trust in providers, especially in private clinics in rural areas, was sometimes important, mainly for HIV/AIDS patients.

I first got tested in a private clinic in Phnom Penh but I did not believe in the result. I spent about US\$20 on the first test. Then I got my second test also in a private clinic in Phnom Penh and again I was afraid that the clinic had lied about the result. In 2002, when I began to get seriously ill, I decided to test again in Takeo hospital in 2003 and I tested positive for HIV. (PLHA #1 at the MSF clinic in Takeo.)

## **Stage 2: Seeking medical treatment**

Patient perceptions as to the curability of their disease affected their healthcare seeking behavior. The majority of HIV/AIDS patients understood that there was no cure, even with modern medicine (although this could prolong the life of sufferers). This perception has changed from an earlier period when it was believed that HIV/AIDS could be cured using traditional medicine (Khana, 2001). For example, one HIV/AIDS patient stated:

I first tried to find traditional medicine to cure my disease because my brother-in-law who was the doctor told me that my disease was not serious yet, so I could find traditional medicine to take first. I got the traditional medicine but I did not really want to take it because people told me HIV could not be cured by traditional medicine. I spent about 200,000 Riel [US\$50] on traditional medicine. I did not get better, so I decided to come to MSF for treatment in 2003. When I came to MSF I just gave them the result of my test and they took me in right away. (PLHA #6 at the MSF clinic in Takeo.)

On the other hand, the majority of diabetic patients believed that the disease could be cured permanently with traditional remedies though not with modern medicine. Knowledge relating to different kinds of traditional medicine or about traditional healers who could treat diabetes often came through word of mouth from peer-patients, relatives or other community members.

I was told by my brother-in-law about traditional medicine to cure diabetes; I went right away to find it. I took the traditional medicine and it got better (PLWD #7 in Takeo, currently not enrolled on treatment program).

As a result, most diabetic patients initially tended to seek out traditional remedies, sometimes in combination with modern medicine. Several reported that they had chosen the latter approach because traditional remedies could complement modern medicine to make the treatment more effective and cure the disease permanently. In other cases, the belief that traditional remedies could cure diabetes resulted in patients delaying the use of modern medicine following diagnosis and/or compromising their adherence to an effective treatment regime at a later stage. These findings, moreover, bear a striking similarity to those of a recent study of diabetic patients in Ghana (de-Graft Aikins, 2005).

Psychological factors were also found to influence patients' decisions in seeking treatment. Knowing that they had to live with a disease that could not be cured, many patients were overcome by hopelessness. For example, one HIV/AIDS patient did not attempt to obtain medical treatment for one year after diagnosis because he was sure that even with treatment he would not live very long and it was therefore a waste of money. Diabetic patients also felt hopeless when they knew that they had the disease. But in their case it was more related to not knowing where to find the treatment and care they needed. HIV/AIDS patients encountered fewer barriers in finding facilities that provided appropriate treatment free of charge. Most obtained information on treatment from health care providers

through referral mechanisms, NGOs and civil society organizations networking with medical institutions and government to provide medical treatment and care.

Reliable information on diabetes was much more difficult to obtain. Most sufferers said that their main source of information was other community members and diagnosed diabetic patients in their peer-group. There is no referral mechanism comparable to that for HIV/AIDS. As one patient stated:

For diabetes treatment, no one would know where to find it, unlike for HIV/AIDS, all people know of a place that provides treatment' (PLWD#1 in Phnom Penh).

Because they did not know where to go for appropriate affordable treatment, many diabetic patients resorting to shopping around for whatever was available and within reach of their financial means. This would typically involve purchasing medicine at a pharmacy, seeking treatment at a private clinic, or obtaining traditional remedies.

When asked where they would first go for modern medical treatment, the two facilities most frequently mentioned by both groups of patients were the Center of Hope in Phnom Penh and the MSF chronic disease clinic in Takeo. These two institutions were identified by diabetic patients as the only institutions providing inexpensive and effective treatment in the whole country and some patients were found to have traveled very long distances to seek care:

When I heard from other people that they provide treatment for diabetes for free in Phnom Penh through a lottery, I went there right away. I came from Takeo every day to Phnom Penh by taxi and rented a house in Phnom Penh, which cost me US\$10 per night, so that I could take the lottery very early in the morning and go home in the afternoon. I persevered for four months until one day I was lucky and got selected. Since then I have received medical treatment for my diabetes at the Center of Hope. It has cost me altogether about US\$300 including transportation and food (PLWD #1 at the Center of Hope but living in Takeo).

However, given the limited financial and human resources these facilities cannot meet the overwhelming demand for services, particularly from diabetic patients. Both have consequently introduced rationing systems in order to maintain the quality of health care provided. As indicated above, the Center of Hope has opted for a lottery system for diabetic patients, while MSF apply geographical (catchment area) restrictions. At present all HIV/AIDS patients are nevertheless accepted into treatment programs at both institutions. At the time of study, 3-4 health workers at the Center of Hope were treating more than 3,000 diabetic patients. At the MSF clinic 3,876 patients with HIV/AIDS, diabetes, hypertension and other chronic diseases are cared for by 20 full-time staff (Janssens et al., 2007). Furthermore, HIV/AIDS patients receive treatment free of charge whereas diabetic patients have to pay a fixed fee per consultation of US\$1.50, which includes the cost of drugs and diagnosis. The medical staff themselves considered the current situation highly inequitable.

Patients likened the lottery system at the Center of Hope to playing a game with very little chance of winning. This was particularly true for poor patients who had no financial or other means facilitating access:

When I knew that I had diabetes I wanted to be treated at the Center of Hope because people who also had diabetes told me that the Center of Hope is free and has good medicine. I know it is not easy to get into the Center of Hope since you have to take the lottery and the chance of being selected among the 500 patients is like picking a needle from the bottom of the ocean. (PLWD #9 in the Boeung Kak slum in Phnom Penh).

I went to take the lottery several times but I could not win, and since it is far and I don't have money for transportation I stopped going. When my son is free I ask him to take me there, but he does not have much time to take me as he also has to work. (PLWD #4, currently not enrolled on a treatment program, Anglong Kagan.)

The rationing system creates a particularly heavy burden for elderly patients, who often have to depend on family members for financial and social support while hoping that eventually they will be accepted into a care program. Some patients try to bypass the rationing system by lying about their residence or begging staff to treat them as special cases. As one patient stated:

After two months I could not get into the Center of Hope, and my son told me to go to Takeo clinic. When I got there I told the doctor that I was from Phnom Penh. The doctor said they did not accept people from Phnom Penh anymore. I was scared that I would not get any treatment, so I had to beg, telling him that I went to the Hope Center for two months but did not get it. The doctor then let me in. (PLWD #13 at the MSF clinic in Takeo.)

A number of the diabetic patients had tried numerous times, some over a two to three year period, to get into a treatment program, but without success. Eventually they gave up entirely on the system and resorted to private providers or one of the other alternative treatments described above. Paying for medication out of pocket at a private clinic can be costly, placing a heavy financial burden on households.

For three years I bought medicine from a private clinic to treat my disease. Then I had no more money to buy medicine ... I spent about US\$30 per week on medication. I sold my productive land for US\$1,800 to treat my disease (PLWD #3 at the Center of Hope but living in Takeo.)

I became poor because of my disease. I sold everything to take care of myself. Now I don't have any more money. My children support me, but when they didn't have money to help me I stopped buying the medicine because I don't want to borrow money any more from other people. I don't want to have debt. (PLWD #7 in Boeung Kak.)

When they could no longer afford to pay private doctors, patients continued to search for other alternatives, looking for free treatment as the ultimate goal:

After I was diagnosed to have diabetes at the private clinic, I wanted to be treated at the Center of Hope because people told me that they had good medicine that can treat diabetes, but I could not get in because I was unlucky with the lottery. Then I heard on the radio that there is a traditional herbal treatment at Lybunarith that can cure my disease. I went there and bought the medicine ... then I went to a private clinic and the doctor gave me Glucofa and it cost me US\$10 per month. (PLWD #10 in Phnom Penh, currently not on a treatment program).

### **Stage 3: Accessing social care and support**

Access to social care and support, for example advice, counseling and financial assistance, should be an integral component of the long-term management of chronic diseases. It may be provided through formal or informal (family, friends, associates, etc.) mechanisms. The social care provided by the Center of Hope and MSF

Takeo for HIV/AIDS patients included counseling, education, fee exemption, food and home-based care. However, for diabetes, only counseling and education were provided. The limited formal social care service provided to diabetic patients was perceived as highly inequitable by users.

I don't know why there is no NGO providing social support to diabetic patients like they provide to HIV/AIDS patients. Here at Takeo clinic, diabetic patients have to pay 6,000 Riel [US\$1.50] for the service, whereas HIV/AIDS patients don't have to pay but instead receive money and support. (PLWD #9 at the MSF clinic in Takeo.)

The study interviews exposed strong feelings of envy which occasionally lead them to express what might otherwise be considered unthinkable attitudes:

I now get treatment at Takeo clinic but I do not have any social support from any NGO. I still have to pay 6,000 Riel [US\$1.50] for medication every month. But it is not the same with PLHA, they get rice every month and don't have to pay anything for medicine. They even receive money for transportation to the clinic. But for people with diabetes, no one helps us. So I think if I had AIDS it would be better. My husband thought I was crazy to say this, but this is true. (PLWD #6 at the MSF clinic in Takeo.)

I do not receive any social support from any organization. We diabetic patients tend to say that HIV/AIDS patients are lucky because they have an NGO helping them but for us we don't have any support; instead they charge us for medicine. Honestly, I wish I had AIDS more than diabetes. (PLWD #6 at the MSF clinic in Takeo.)

Social stigma can be a barrier to informal care. The majority of the HIV/AIDS patients were currently receiving both medical treatment and social support from a formal system. However, some, particularly those not enrolled in a treatment program, expressed a sense of being rejected by other members of their community. As one HIV/AIDS patient stated:

People in the community discriminate against me: they are disgusted with me because I have sores on my body; they do not even want me to take a bath near their place. But my husband still takes care of me. My husband tested three times already for HIV but he told me that he was negative. (PLHA #5 in Phnom Penh.)

Community attitudes were generally sympathetic towards those with diabetes. However, several male patients reported psychological distress due to lack of support from their spouse:

My husband left me because I don't have any more money to treat myself. When I still had money my husband stayed and took care of me, but when I could not make any more money and all the savings were gone, he decided to leave me. I have no one to take care of me. (PLWD #12 in Anlong Kagan.)

By depending on family financial resources for health care expenditures, some diabetic patients began to develop a sense of guilt because of the burden they were placing on the household. This was illustrated by one older diabetic patient:

I live in Phnom Penh but I receive treatment at the MSF clinic in Takeo. I am too old to come by myself, so my children have to take me every month for follow-up. Sometimes I ask other people to take me but I have

to pay for gasoline and food. I depend on my children and relatives to take care of me. (PLWD #14 at the MSF clinic in Takeo.)

#### **Stage 4: Adherence to care and treatment**

A study conducted by Janssens et al. (2007) of chronic disease patients at the MSF clinics in Takeo and Soknikum (Siem Reap province) indicated that only 3% of HIV/AIDS patients on HAART (highly active antiretroviral therapy) were lost to follow-up in the first three months, as compared with 29% of diabetic patients. Although many of the HIV/AIDS patients in the present study experienced side effects from their medication, this did not seem to limit their determination to continue with a treatment that offered them the chance to live a long and relatively normal life. Another important factor promoting adherence was effective communication between patients and providers. Most HIV/AIDS patients said that they had been informed by doctors about the possible side effects of the medication and received emotional encouragement from doctors and counselors to continue treatment if they experienced these effects.

I have experienced side effects from the medication, but I never attempt to stop taking it. I try to follow very strictly the advice from the doctor, to not give up and continue to fight the disease. (PLHA #9 in Takeo.)

There may be many reasons for a high dropout rate among diabetic patients. It would again seem unrelated to the side effects of medication as few patients in the present study complained of such effects. Cost of treatment is undoubtedly important. As pointed out by Rubin (2005), even among diabetic patients in America, medication costs can affect adherence. In low-income countries most patients simply cannot afford to pay for medication for the rest of their life without formal or informal financial assistance. Lack of means led some patients in the current study to cease treatment, temporarily or permanently, or reduce dosages to make medications last longer.

Psychological problems, including stress and depression, which have previously been found to mitigate against adherence (Peyrot et al., 2002), may also be important. In some cases a vicious cycle appeared to have developed, with a number of patients suggesting that follow-up visits with doctors increased their level of anxiety and despair because they had failed to adhere to that doctor's advice.

Earlier studies have shown that a patient's perceptions relating to susceptibility to illness, severity of illness and treatment efficacy also appear to be correlated with adherence (Haynes, 1979; Becker and Rosenstock, 1984). Confusion as to which drugs would prove most effective seems to have been a major factor in this instance. Little attention has been paid by the health sector to educating people about prevention or treatment and patients typically have limited knowledge of the disease. In this study, the majority of patients knew that modern medicine could not cure diabetes and could only help to reduce blood glucose. However, a number shared drugs or bought them from other patients without medical advice. Others, as previously discussed, used prescribed medications in combination with traditional remedies in the belief that their complementary actions could cure the disease. As one patient expressed:

I am taking traditional medicine now because I want to be cured. I am taking both medicines, they complement each other. It doesn't matter which one does it as long as I can be cured of the disease. (PLWD #7 in Boeung Kak.)

Several diabetic patients stopped taking modern medicine under the influence of other patients who reported that their condition had improved after taking traditional medicine.

Someone told me that traditional medicine could cure my diabetes forever. They told me to take 1kg of pure palm sugar (without chemicals), mix it with 1kg of sour fruit and let it soak for a while then drink it. If I do that my diabetes will be cured. This is what they did and they don't have diabetes any more. I also wanted to try this, but I want to wait a little bit more until I finish with modern medicine, then I will try it. I want my disease to be cured. I have a hope that my disease will be cured. (PLWD #8 receiving treatment at Kossamac Hospital, Phnom Penh.)

All the HIV/AIDS patients in this study knew that they would remain on treatment for the rest of their lives. This went against the findings of an early study that many people with HIV used traditional medicine not only to alleviate symptoms but as a potential cure (Khana, 2001). The study suggested that patients often interpreted 'prolonging life' with 'curing'. At that time confused messages about AIDS and its treatment were prevalent, with different sources often in contradiction. The situation has changed radically. In parallel with the greatly increased availability of free modern medicine, information on both the nature of its disease and its treatment has been broadly disseminated through multiple communication channels.

Almost none of the HIV/AIDS patients mentioned lifestyle changes as a barrier to adherence. On the other hand, the diabetic patients frequently said that the need for such changes was proving a major obstacle to bringing their disease under control. Understanding and adhering to food restrictions posed the most serious challenge.

Sometimes I cannot follow food restrictions: the doctor told me not to eat a lot of rice. But how can I not eat a lot of rice if I come from work feeling weak and hungry? When I feel tired from work and hungry, I have to eat a lot. (PLWD #22 in Takeo.)

Sometimes I feel hungry and, despite the fact that the doctor told me not to eat a lot and not to eat sweet things, I cannot control myself, so I have to hide and eat sweet things. (PLWD #25 at the MSF clinic in Takeo.)

Most patients knew that modifying their diet and eliminating certain kinds of food was necessary but found this very difficult. One patient made an explicit comparison between HIV/AIDS and diabetes in terms of diet restrictions:

I think that having diabetes is worse than having AIDS because with diabetes you have to restrict your diet, cannot eat anything. But people with AIDS can eat anything with free will ... Now I only eat green bananas and dried bread. And if I eat rice I cannot eat noodle, and if I eat need noodles I cannot eat bread. (PLWD#7 in Takeo.)

## V. Discussion

The HIV/AIDS and diabetic patients included in this study reported multiple and complex barriers to accessing effective health care and treatment at different stages of their illness. Apart from the physical and emotional damage inflicted by their illness, many faced considerable direct and indirect costs of care and/or loss of income, both because of the limitations on their ability to work and the additional demands placed on other household members who provided care. There is substantial evidence that these health-related financial burdens can

drive the households of such patients into debt and eventually into poverty (Meessen et al., 2003).

Following their initial awareness of an ongoing medical problem, most patients sought diagnosis and treatment in the formal or informal private sector. Both groups of patients tended to 'shop around', mainly concerned to find treatment for their immediate symptoms rather than to seek a reliable diagnosis. In general, their experiences suggest that they encountered a largely unregulated market for health care (Bloom 1998), in which providers were more motivated to make a profit than provide proper diagnosis and treatment. This typically led to high health care expenditures on medicines or traditional remedies which, at best, simply alleviated symptoms. Many patients failed to obtain a correct diagnosis until the diseases had worsened considerably, and sometimes suffered severe complications. They were almost never referred to existing public sector facilities where appropriate care might have been obtained. Substantial financial burdens were incurred by patients in both categories at this early stage of their illness. This is in line with another recent study on AIDS and indebtedness in Cambodia, which found that among 327 patients reported to have AIDS related debts, 179 (54.7%) had fallen into debt before they were diagnosed (Ir Por, 2007).

When patients finally moved on to treatment and care, diabetes patients seem to have encountered the greater difficulties. Overall, HIV/AIDS patients had easier access to free care and treatment at well organized institutions such as the Center of Hope, the MSF clinic and public hospitals. Diabetic patients identified a lack of appropriate information, limited availability of quality health care services and substantial financial barriers. The limited access to affordable treatment and social assistance (i.e. the rationing system of the Center of Hope and the targeting strategy of the MSF clinic) engendered a considerable sense of envy and injustice among this group, who perceived that more resources and assistance were available for HIV/AIDS patients.

Poor adherence was also more common among diabetic patients than HIV/AIDS patients. This seemed to relate to the fact that life-style factors are often central in bringing diabetes under control. Alongside routine medication regimes and regular follow-up visits to medical providers, the willingness and capacity to monitor blood glucose levels, observe food restrictions, control bodyweight and cope with social pressures that may encourage inadvisable behavior are extremely important in the management of the disease. Effective social support mechanisms have a very important role to play in encouraging what may be substantial lifestyle changes for many diabetic patients (de Alba Garcia et al., 2007). Because diabetes has not been well understood by society at large, and because governments have generally failed to allocate resources to raising public awareness, such support mechanisms are often absent or ineffective.

The study also found that the knowledge-base of HIV/AIDS patients has changed radically since the earlier 2000s, with most reporting that they had appropriate information about the disease and its treatment. Diabetic patients, on the other hand, had received conflicting information about their disease and its treatment and care. The ideas persist that diabetes is not a deadly disease like HIV/AIDS and that it can be cured if the right medicine is found (Men, 2006). Because patients perceive that modern medicine can *only* help prevent their disease from getting worse and make them feel better temporarily, many still resort to traditional remedies in search of a permanent cure. This perception influences their health-seeking behavior and can complicate their treatment outcomes. At present, national and international efforts to support those suffering from diabetes in Cambodia fall woefully short of what is required. Indeed, the situation has recently worsened substantially as resource constraints have forced the Chronic Disease Center in Takeo to close its diabetes program entirely and the Center of Hope to end enrollment of new diabetic patients. While the implications of providing long-terms care for the millions suffering from chronic disease in such a poor country may be daunting, this is not a challenge that can be ignored (Horton, 2007).

The relatively successful efforts to support those suffering from HIV/AIDS should not be seen as a unique exercise in global cooperation but should rather inspire similar efforts on behalf those suffering often equally damaging diseases. There is an increasingly urgent need for governments, international agencies and national

institutions to move on from an understandable preoccupation with HIV/AIDS to address a range of chronic diseases which are becoming the major cause of morbidity and mortality in many developing countries (Nishtar, 2007).

## Acknowledgements

First of all, the researcher would like to thank most sincerely all respondents who agreed to committing their valuable time and energy when sharing their stories of illness and other important information. The researcher would also like to thank health care staff at both the Center of Hope and the MSF clinic in Takeo for their efforts in bringing participants for interviews and for their own participation in the study. Moreover, the research is deeply indebted to the Center of Hope and MSF Takeo clinic for their collaboration and assistance. This study is an output of the EuropeAID project, “Increasing the relevance and effectiveness of HIV/AIDS prevention and care among youth through a Cambodia-Thailand partnership”, (European Commission, EuropeAID, Health/2002/045-809) a project supported by the European Commission. The final writing up of this paper was financed by POVILL (Protecting the rural poor against the economic consequences of major illness: A challenge for Asian transitional economies), a project funded by European Commission.

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