“I Wish I Had AIDS”: Qualitative Study on Access to Health Care Services for HIV/AIDS and Diabetic Patients in Cambodia

Men, Chean R.

3rd ICIUM 2011

Antalya, Turkey
November 14-18, 2011
Introduction

- In order to access medical care, poor people may have to overcome various kinds of problems, including lack of appropriate health information, financial burden, health care system barriers, cultural and social barriers, psychological distress, and so on. Such problems can lead patients to delay treatment or improper health-seeking behaviors or even the decision to forego treatment.
Objectives of the study

The objectives of this study were:

- To identify the different types of barriers poor patients affected by HIV/AIDS and diabetes encounter in accessing care and treatment.

- To compare HIV/AIDS and diabetes patients’ experiences in seeking treatment and care through the different stages, which can help us understand the complexity of the problems related to both the demand-side and the supply-side system.
## Analytical framework

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the phase</th>
<th>code</th>
<th>Types of problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No proper diagnosis, patient doesn’t know</td>
<td>1</td>
<td>Problem in getting proper diagnosis</td>
</tr>
<tr>
<td>2</td>
<td>Diagnosis is clear for the patient</td>
<td>2</td>
<td>Problems in access to medical treatment</td>
</tr>
<tr>
<td>3</td>
<td>Receiving medical Treatment Or getting social care</td>
<td>3</td>
<td>Problems in access to social care and support</td>
</tr>
<tr>
<td>4</td>
<td>Accepted into an integrated program of medical treatment and social care</td>
<td>4</td>
<td>Problems in access to integrated program</td>
</tr>
<tr>
<td>5</td>
<td>Control, loss of control, regaining control</td>
<td>5</td>
<td>Problems with adherence</td>
</tr>
</tbody>
</table>
Methodology

- Study design
  - Retrospective study
  - Qualitative method

- Site: urban and rural setting

- Sample selection
  - Patients *not enrolled* in care or treatment program (N=14)
  - Patients *enrolled* in care or treatment program at Center of Hope or MSF (N=56)
  - Health care providers (N=10)
  - NGO personnel (N=5)

- Study limitation
## Patient characteristics

<table>
<thead>
<tr>
<th></th>
<th>HIV/AIDS</th>
<th>Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Phnom Penh</td>
<td>Takeo</td>
</tr>
<tr>
<td><strong>Demographic info</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Age range</td>
<td>24-35</td>
<td>24-40</td>
</tr>
<tr>
<td>Median age</td>
<td>30</td>
<td>34</td>
</tr>
<tr>
<td><strong>Year having the disease (after diagnosed)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>1-3 years</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>4-5 years</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td><strong>Current place of care or treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Center of Hope (Phnom Penh)</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>MSF (Takeo)</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td>National hospitals in Phnom Penh</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>NGOs</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Private clinic/self-treatment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Findings
Stage 1: Barriers in access to proper diagnosis

- Interpretation of symptoms leads to prolonging diagnosis

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 MSF clinic in Takeo.)

- Reliable source of information on diagnosis:
  - HIV/AIDS patients were more aware of facilities for testing, particularly at public health care facilities than diabetic patients
  - No information disseminated, most diabetic patients relied more on other sources or methods of diagnosis, such as through peer-patients and traditional techniques

- Poor quality of health services in making accurate diagnoses and lack of trust in providers particularly those in the private sector led patients to have multiple diagnoses
Stage 2: Barriers to accessing medical treatment

- Knowledge and perception of curability of disease:
  - Majority of HIV/AIDS patients understand that HIV/AIDS could not be cured, whereas diabetic patients perceived that diabetes could be cured permanently, especially with traditional medicine or a combination of both modern and traditional medicines.

- Institutional policy as barrier to medical treatment
  - The rationing strategy of Center of Hope and the policy of the MSF Takeo clinic to enroll only patients living in the coverage area, but these policies apply only for diabetes patients, not HIV/AIDS patients.

  - Since poor diabetic patients knew of only these two institutions providing free or cheap treatment of high quality, they would spend a great deal of resources and energy trying to get into the programs, like playing a game with very little chance of winning.
Stage 2: Barriers to accessing medical treatment (cont.)

- **Financial and opportunity costs as barriers to accessing treatment**

- Because of the limited availability of care and treatment for diabetes in the public health sector, diabetic patients often sought out treatment at private clinics or pharmacies, paying from out of pockets.

- Paying for expensive medicine at private clinics out of pocket can be costly, leading households into poverty. As one patient stated:

  > 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 anymore from other people. I don’t want to have debt. (PLWD #7 in Boeung Kak.)
HIV/AIDS patients experienced fewer barriers to social care and support from formal institutions than diabetic patients.

There was a feeling of envy among diabetic patients regarding the unequal resource available for HIV/AIDS.

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 MSF clinic in Takeo.)

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 MSF clinic in Takeo.)
Stage 4: Life-style change as barriers in bringing the disease under control

- Most PLHA said that they had been informed by doctors about the possible side effects of the medication; emotional encouragement from doctors and counselors helped them to go on taking medicine despite the many side effects they experienced.

- Perceptions and believe of the curability of chronic diseases influenced both health-seeking behavior and adherence to care and treatment.

  *I think AIDS cannot be cured but I can live longer with ARV. Now I have stopped using traditional medicine completely because the doctor told me not to take any other medicine without his advice, and also because I myself don’t want to take it any more because it cannot cure the disease.* (PLHA #8 at MSF Takeo.)

- Understanding and adhering to food restrictions and physical exercise was a major factor in the ability of patients to bring their diabetes under control.

  *I think that having diabetes is worse than having AIDS because with diabetes you have to restrict your diet. 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 noodles I cannot eat bread.* (PLWD#7 in Takeo.)
Stage 4: Cost of medicine as barrier to 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. As stated:

  *The biggest obstacle for me in treating my disease is lack of money to buy medicine. The medicine that I buy from the pharmacy costs about US$7 per box which is too expensive for me. So I have to preserve it to make it last longer; I now only take one pill in the evening or only take it when I don’t feel well. But the doctor told me to take it three times a day. If I do that I will finish the medicine really fast. So, by taking one pill in the evening or taking it when the disease causes me problem, I can keep one box for one whole month.* (PLWD #17 in Takeo who stopped going to the MSF clinic.)

- Travel costs were another factor, affecting patients’ ability to go for regular follow-up visits with health care providers.

  *I have to travel from Phnom Penh to the MSF clinic in Takeo in order to get medication. I spend each time about 30,000 riel [US$7.50] on transportation, food and service. My condition is still the same and if I do not get better next month, I will stop coming here. I will go back to the private clinic. Even though I pay very little for medication here I still have to pay a lot for transportation and food to come here every month.* (PLWD #13 at MSF clinic in Takeo.)
Conclusion

- This study found that poor HIV/AIDS and diabetic patients encountered multiple and complex problems throughout different stages of illness experiences.

- It was found at diagnosis stage both HIV/AIDS and diabetic patients were shopping around to find treatment for the symptoms mostly at the private sector rather than seeking a correct diagnosis.

- When patients finally moved from the diagnosis stage onto treatment and care, they were confronted with different problems and barriers to accessing appropriate health services. This was particularly the case for diabetic patients. For HIV/AIDS patients, access to treatment and care was not as problematic, since health care services and social assistance were more available.
Conclusion (cont.)

- The perception and knowledge that patients have regarding the curability of diabetes influenced their health-seeking behavior and complicated their treatment outcomes, especially for diabetic patients.

- Poor adherence was more common among diabetic patients than HIV/AIDS patients at the management stage of the disease. Diabetic patients continued to experience more and more complex problems than HIV/AIDS patients with regard to adherence to care and treatment.

- Some of these problems included lack of effective communication between health care providers and patients, difficulties in adhering to lifestyle changes, lack of social and psychological support, and financial constraints.
Study implications

- 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 diseases in Cambodia and many other low/middle income countries.

- The current health care systems have had greater success in dealing with HIV/AIDS than with diabetes. This success owes to global and local efforts in the fight against HIV/AIDS.

- The question is how can we bring the successful lessons from the HIV/AIDS case to other chronic diseases such as diabetes and hypertension, diseases which are affecting the population on a larger scale?

- Thus what is needed is public policy, resources and cost-effective intervention in order to prevent the burden of chronic disease and also to make health equitable for all.