July 2006: Evaluation of MoPoTsyo Program impact after one year: Qualitative Study[1]

By

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[1] This evaluation was carried out in July 2006 by persons who are independent from MoPoTyso Patient Information Center. All field interviews were conducted by Cambodian students at Faculty of Social Sciences after which data analysis and report writing was done by a researcher qualified in the field of medical anthropology. (PhD candidate, with a Masters in Anthropology from an American university in the USA), who is also unpaid board member of MoPoTsyo;

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1. Purpose of the Evaluation

The evaluation was done to understand the impact of the intervention on the beneficiaries, people with diabetes, one year after MoPoTsyo's intervention had started in the poor communities. The evaluation meant to give answers to the question whether MoPoTsyo Patient Information Centre has impact on the patients in the poor communities, and if so what the impact is on the control of their blood glucose levels, their understanding and knowledge of diabetes and their health expenditure and their well being overall. Also the researcher wanted to find out what patients suggest to MoPoTsyo for the future.

The evaluation was done using qualitative and quantitative measurements.

This report contains only the ***qualitative*** findings.

The qualitative study was done to complement the quantitative study by investigating the perceptions and feelings of the patients before and after they joined the program. Thus the qualitative part of the study aims 1) to examine from the patients' point of view their feelings in terms of physical, financial and social support before and after becoming a registered member of MoPoTsyo, 2) to understand if and how they feel they are in control of their disease and if the disease is still interfering with their productivity, 3) to explore how the patients perceive the information given by the peer educators and what benefits they think they have received from MoPoTsyo.

2. Methodology

2.1 Research sites

The research was conducted at two locations which lie both within Phnom Penh Municipality: At Anlong Kangan, a resettlement area which is far from Phnom Penh city centre and at Boeung Kok area, a slum area which lies in the heart of Phnom Penh city behind the railway station around a heavily polluted lake. Both sites are populated with mostly poor urban households. There exist different statistics with regards to the numbers of people actually living there, due to a high degree of in- and out migration, house-owners who have changed their house into many small rooms that they rent out to poor people who are not registered, to seasonal factors such as the planting season and all kinds of temporary employment opportunities. MoPoTsyo's peer educators go alley by alley in the slum from hut to hut (often nothing more than a shack) trying to meet the people living there to explain about diabetes symptoms, how to test for high sugar in the urine, and to talk about healthy lifestyle issues. After one year, they had not completely finished the whole area under their responsibility. The table below provides the total numbers of people that were encountered by the MoPoTsyo's peer educator in three slum areas during the first year until the date of the evaluation (July 2006).

Table 1: Number of Household encountered by MoPoTsyo to detect diabetics;

	encountered by MoPoTsyo peer educators during year 1
Anlong Kangan	2,725 people in 779 households
Sras Chork (BK-lake)	3,874 people in 910 households
Boeungkak 2	1,006 people in 247 households
Total	7,605 people in 1936 households

MoPoTsyo started to work in those two areas in July 2005. Therefore, this evaluation was conducted after the first full year of the operations.

Table 2: Diabetics identified by MoPoTsyo's peer educators

Area	**July – Dec 2005**	**Jan – June 2006**	**Total diabetics found**
Anlong Kangan	20	36	56
Sras Chork slum	40	22	62
Boengkak II slum	0	37	37
Total	**60**	**95**	**155**
per month	*10*	*16*	*13*

2.2 Sample selection

During the first 12 months, MoPoTsyo found 56 diabetic patients in Anlong Kangan and 99 diabetic patients in the Boeungkok area, in total 155 diabetic patients on the sampling frame list from which interviewees were selected.

In order to make the sample representative of the total population the researchers purposively selected 15 patients from the list of all diabetic patients registered at MoPoTsyo during the first year of its implementation, using particular inclusion and exclusion criteria of which MoPoTsyo reported that they may play a role in how beneficiaries respond to the opportunities offered by MoPoTsyo's intervention. These criteria include age, sex, literacy level, weight, HbA1c, place of treatment, poverty status, residential area, how long they have been enrolled in the MoPoTsyo program, life style change, whether they are hypertensive, and if they have to inject insulin. The criteria are classified in opposition. These criteria were used to classify patients in three slum areas covered by MoPoTsyo, which was done by examining the patient's record and by asking MoPoTsyo staff to help score the patients according to these criteria. 52 patients were identified based on those criteria, and finally 15 patients were further selected from the 52. The table below shows the list of criteria of the 15 patients selected for the qualitative study.

Table 3: The inclusion/exclusion criteria and the profile of 15 interviewees :

Categories	N	Categories	N
Young age	7	Old age	8
Illiterate	12	Higher education	3
Men	6	Women	9
Needs to lose weight	8	No weight problem	7
HbA1c went down a lot	9	No progress in HbA1c	5
Treated at Kossamak	7	Treated by Center of Hope	4
Very Poor	7	No poverty problem	8
Place of residence Anlong Kangan	8	Place of residence BKK SrasChok	7
Long time MoPoTsyo	13	Short time MoPoTsyo	2
Only life style changes	5	Life style change + drug treatment	10
has Diabetes for quite some time	11	New: discovered by MoPoTsyo	4
Has also hypertension	7	No hypertension	8
Injecting Insulin	4	Non insulin injecting	10

2.3 Data collection process

In-depth interview technique was used to interview patients in this study. The interview focused on main questions: 1) How do they feel and what situation do they have before and after joining MoPoTsyo program; 2) Do you feel your are in control compare to before, that is, do you feel healthy compared to before you joined the program?, 3) Is this disease still hindering your productivity, daily functioning?, and 4) Is MoPoTsyo beneficial for you in term of financial, education, emotional support, and so on ? All interviews were conducted in Khmer.

Information was recorded using tape recorder and note-taking. All interviews were transcribed for data analysis. We used qualitative data analysis techniques to look for main issues emerging from the interviews — by looking at patterns or themes that are relevant to the research questions stated above:

3. Findings:

The findings of this study relate to four main questions 1) How patients feel before and after joining MoPoTsyo intervention, 2) Do they feel that they able to bring the disease under control; 3) If the disease is still interfering their productivity and daily tasks, and 4) what benefit they received from MoPoTsyo intervention.

3.1 Theme 1: Feeling and situation before and after joining MoPoTsyo intervention

From the data several findings were identified that related to the first theme how patients feel and situation they encountered before and after they joined MoPoTsyo. These include emotional/psychological, social and physical differences. One of the most important findings is that patients experienced a dramatic change in the financial issue, when they compare before and after they joined MoPoTsyo.

3.1.2 Emotional/psychological situation

As related to the Emotional/psychological feeling patients have before and after they joined MoPoTsyo was the feeling that they were scared of not knowing what can happen to them or where to go for help. Five out of 15 patients interviewed had the feeling that they were scared they would die, scared of not having treatment, scared of not having anyone to support them. It was mentioned that after joining MoPoTsyo these feeling have changed, that they were not scared anymore. As stated by several patients:

> "Before I was scared that I will die very early but now I am not afraid anymore" (#3, Lou Chheng).
>
> "I was scared of the disease before joining MoPoTsyo but now I am feeling happy and not afraid because now I receive treatment. I get support from MoPoTyso" (#5, Chew Kimly)
>
> "Before I was very stressful, no money, very sick, and depressed but now I feel better and normal again" (#7 Noy Nyoun).
>
> "Now I don't care anymore about my disease. I just wait until the time come whenever time for me to die, I just die" (#6, Som Yon).

3.1.2 Social situation

As for the social issue, only one patient mentioned that her situation has changed as result of joining MoPoTsyo as compared to before. The social problem she encountered before was related to the fact that the family was not able to take care of her because her condition was draining the family resources. As she stated:

> "My husband left me because I did not have anymore money to treat my self. When I still had money my husband stayed and took care of me, but when I could not make anymore money and all the savings were gone, he decided to leave me. I have no one to take care of me. Now I am very thankful for MoPoYsyo who cares about me and I want MoPoTsyo to continue helping me and find the drugs that can cure my disease. (#8 Noy Gyoun)

Thus gaining social and financial support from MoPoTsyo has helped the patient to feel that she is not alone and there is someone caring for her.

3.1.3 Financial situation

The changes in their financial situation after they join MoPoTsyo, played a crucial role in patients' feeling on how they cope with their disease. The financial burden created not only emotional distress but also could plunge the household into debt, which resulted eventually into poverty. One factor that can lead into high expenditure for their disease was that the patient spent money treating all kinds of symptoms of diabetes but not the disease itself because they did not know that they have diabetes.

> "Before I spent 60$ per month to treat my disease. I spent a lot of money ($200-$300), and I even borrowed $100 from money lender with the interest of $10 per month. After joining MoPoTsyo I spent less than before, about 50000 riel (4000 riels is 1 USD) per month buying medicine at Kossamak hospital" (#5, Kimly).
>
> "I had spent a lot of money in the past to treat the disease, but now less than before since I registered with MoPoTsyo" (#3 Lou Chheng)

One of the treatments that were most quoted by patients is IV fluid injection. However, it was not clear whether the use of IV fluid injection was demanded by the patients themselves or it was prescribed by the providers. From other studies, it was found that most injections occurring in health care facilities are related to the provider's prescription behavior, not so much related to the patient's preference for injections (Men 2006, MoH 2003). Getting IV fluid injection is more expensive than simple oral medication. As stated by the following patients:

> "I spent more money before, but now spend less. Before I had borrowed money to get IV fluid injection" (#1, Van Dy).

> “I spent a lot of money for my heart problem ($1200)—my family helped with the money. I borrowed money, 1 million riel (is USD 250) from a local authority from Kompong Cham province for medical treatment.... I spent a lot of money buying medication—injections and oral (70,000 riel per day), and for injections it cost me $10 per injection.... After I entered MoPoTsyo I spent less money (#4, Seng Kunthea).
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> “I spent less money for diabetes now as compared to before joining MoPoTyso. In the past I spent two times what I spend now. I borrowed money for medical treatments, especially getting IV fluids. I Borrowed 100,000 riel with 20,000 monthly interest, and I spent this money for food and medication (#6 Sre Pou)
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> “Before I joined MoPoTsyoMoPoTsyo I spent a lot of money to treat my disease. I sold all my land and all the gold that I have. It was about $10,000. When I ran out of money, I stopped treating myself and decided to move from Kos Kong to Phnom Penh. All the money I spent on my disease was from my own money, not through borrowing from anyone. Only recently, I was so really sick that I borrowed $50 with interest ($2.5 per month) from a neighbor to buy IV fluids to treat. After I entered MoPoTyso, I spent less than before. Before this, I spent about 1 million riel per month (USD 250) for my treatment in Vietnam and Thailand. (#8 Noy Ngouy)

Thus, patients who have had diabetes for a long time tend to express the feeling that they were happy after joining MoPoTsyo because they spent less money now for their disease compared to before. As mentioned by one patient, “Now I feel happier than before. I spend less money” (#12 Chhun Chheng).

The reduction of expenditure for medical treatment shows is a dramatic result directly related to the effectiveness of MoPoTsyo’s intervention. However, the intervention of MoPoTsyo can also have a negative outcome in term of financial issue of the patients. This relates to the fact that they were told by MoPoTsyo that they were not treating their disease appropriately. This feeling of having to spend money to get treatment or feeling the pressure by MoPoTsyo to get appropriate treatment was expressed by three patients.

> “There is no difference before I joined MoPoTsyo and now. Before MoPoTsyo I spent about 15, 000 riel per day to buy medicine at the pharmacy, and some time I spent about $100 for treatment at a private clinic. The money I have for treating my disease comes from my own savings. I earn about $30 per month. Sometimes I have to borrow money to buy medicine for treatment. So, compared to before, now I still spend the same amount of money, even a little more than before” (#9, Seng Dara).

For patients that just discovered that they have diabetes through MoPoTsyo also have negative feeling toward spending money on their disease. Because they did not know that they have diabetes thus they did not spend anything on the disease before they joined MoPoTsyo. This relates to the inability for the patient to find money to pay for medication on top of the daily expenditure for food and other necessities. Learning that they have diabetes meant that they have to find extra money to pay for treatment. In such cases, some patients refused to treat themselves with the modern medicine, and resort to home remedies that cost less.

> "Before entering into MoPoTsyo program I did not spend any money on my disease because I did not know that I have it. Now that I know, I have to spend the money on medicine every month. So I spend more money than before. Now I have stopped taking the medicine because I don't have the money. I just take traditional medicine instead. Now I don't care anymore about my disease. I just wait until the time come whenever time for me to die, I just die (#7, Som Yon).
>
> "Compared to before, I feel that there is nothing different about myself. I did not spend any money to treat my disease before because I did not know I have it, but now that I know, I still don't spend any money on it. When I feel a little bit sick, I just do the coining and it get better" (#10, Sra).

3.2 Theme 2: Feeling that they are in control of their disease

Having their disease under control is one of the most important outcomes, a benefit that MoPoTsyo's peer educators tried to make all patients receive. Factors in bringing the disease under control can be related to both the ability of the peer educator to "counsel" (persuade the patients to follow the main instructions and also the personal willingness of the patients to change their lifestyle). Other factors such as having monitoring tools to measure their blood glucose daily, knowledge about food restrictions and the desire to eat, social pressure in social events, adhering to medication, follow-up visits to medical providers, and "seeking for a diabetes - cure" play important roles for the patients in bringing the disease under control.

3.2.1 Regular blood glucose monitoring

Two patients mentioned that having MoPoTsyo's peer educator to check their blood glucose every week free of charge has made it easy for them to know the status of their disease, thus can easily control their disease. As one patient mentioned:

> "Now I can check my blood glucose every week. Having the *peet*[2] (MoPoTsyo) in the community made it easy for me to test my blood every week for free, before

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[2] "Peet" is referred to someone who has modern medical knowledge and/or practice, which include nurse, medical assistant, doctors, lab technician, and midwife. Thus, when the patient referred MoPoTsyo as peet, this means that the patient thinks the peer educator have modern medical knowledge and practice. This in

> this I have to go to private clinic to get the test and spent about 1000 riel each test". (#1, Van Dy).

3.2.2 Following food restriction and changing eating pattern

Understand about and adhering to food restrictions is a major factor in the ability of the patient to bring their disease under control. Although most patients understand food restriction plays an important role in controlling their disease but they find it the most difficult thing to do. This is because they know about kind of food they can and cannot consume but the desire to eat "rice" or to have "sweet thing" can sometime make the patient unable to control their disease.

Six patients in the study expressed the feeling that they have the disease under control because they are able to follow instruction from the peer educator on food restriction and regular exercise. The following statements show how patients recognize that the result of changing their eating patterns and restricting on consuming "sweet things" and doing exercises improved their disease condition.

> "I feel I am in control of the disease because I follow the diet not eating sweet thing and exercise, so I feel better (#1 Van Dy)
>
> "Before my eyesight was blurred but when I started to follow food restrictions as told by *peet* from MoPoTsyo I felt that my eyes got better (#5, Chew Kimly).
>
> "Right now I feel that I have my disease under control because I am restricting myself from eating things with a lot of sugar. I now can keep my blood glucose very low at 70, 71 or 69 (=mg per dl). (#12)

Education provided by the peer educator helped to change patient's eating pattern, thus helped them to control their disease. As mentioned by one patient, "Compared to before, I now know a little bit about food restriction; before I did not know any thing about what food to eat and not to eat" (#9).

Thus, following instructions and restraining oneself from eating "sweet things" and not eating too much were perceived by patients as having the ability to control their disease, which gave them the sense that their disease situation improved. As one patient expressed, "I have hope that in the future my disease will be cured, but if not cured, at least I can live long as long as I follow the instruction of MoPoTsyo (#10).

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some way has put the status of peer educator above the patient. This status can put the peer educator in a good or bad position: good position in a sense of having status that is well respected in the community and bad in a sense that people in the community can demand him/her to provide medical treatment or advice on medical matter.

However not all patients were able to control their disease through restricting their diet or able to overcome the desire to eat “sweet things.” Three patients expressed that although they were told by the peer educators about controlling their disease through food restriction, but they were unable to restrict themselves. As mentioned by one patient, “Sometime I was unable to restrict to the food that I was not suppose to eat” (#4). The desire to eat the forbidden fruit such as durian was so strong that the patients sometimes have to give in to their temptation despite the fact that they know the consequences that would follow. Examples are provided in the statement below:

> “I was told to not eat sweet thing like durian, but then I was so hungry that I ate it. After I ate I felt that my eye sight became blurred and I was sick again” (#13).
>
> “When I ate durian my blood glucose goes up to 200 [mg/dl]; my eyes got blurred and I felt the numbness in my fingers” (#14).

3.2.3 The change from rice to beans and the assocation with “strength”

As relating to the changing diet of patient, five patients were still in doubt about the benefit of changing from rice to bean. They were not clear about the different between rice and bean. One of the most common complaints patients made related to eating beans as compared to rice was that beans did not give them the same strength after eating. As stated:

> “I cannot follow the food restriction especially eating beans because bean does not give strength like rice (#3).
>
> “Not follow recommendation about eating beans, because believing that beans does not provide strength to be able to work (#7).
>
> “Eating beans help to lower the blood glucose from 400 to 200, but afterward I felt weak. I know that eating beans can reduce the blood glucose but I don’t want to do it because it does not give strength and not delicious (#12).

Given the fact that rice has been the main diet of the people in Cambodia and that people have been eating it for all their life, thus to simply change to eating beans is not quite an easy switch. Patients simply do not know how to eat it and do not favor the taste. One patient mentioned as followed:

> “They told me to eat beans; it hard for me to follow. I used to eat good rice from Battambang. But now I have to change everything that I like to eat (#13).

3.3.4 Physical exercise

Another component of the educational message provided by the peer educators to the patient that links to bringing the disease under control is the physical exercise.

> “Now I can control my disease by exercises and by eating the right food. Before MoPoTyso I did not know how to exercise to control my disease, but now I have to take care of myself by exercise and restricting certain foods (#8).

However, doing physical exercise has shown more difficult for four patients. The problem of not being able to perform physical exercise was due to several reasons. The lack of time for physical exercise was more related to the opportunity cost that the patients have to take care of family matters. For example, one patient stated:

> **“**I was told by the peer educator to exercise 10-15 minutes everyday to control my disease, but I don’t have time. I have to care for my grandchild. But I do housework, so it is like exercise” (#13).

Laziness was mentioned by one patient (#6) as reason for not doing daily exercise to control the disease.

Inability to perform exercise due to physical weakness caused by the disease itself was also mentioned by two patients.

> “...not able to exercise because weakness in the legs” (#3)
>
> “...don’t have the energy to do exercise because my knee is getting weak” (#12).

3.3.5 Social pressure or obligation as obstacle for controlling the disease

The ability to control the disease can also depend on the social support patient received within their social environment. Since diabetes has not been well understood by the society and not enough public awareness has been raised about diabetes, patients can have difficulty in controlling their disease when they are in a social environment. For example a monk cannot inform the people beforehand that he has diabetes, thus when people make offering such as coca-cola (very common gift) or fruit juice drink during the ritual ceremony, he cannot refuse to take it. And because monk is forbidden to eat food in the evening, the only way to have energy to perform the ceremonies is to drink something that can give energy. As stated by one patient who is a monk:

> “I am not able to control the disease completely because being a monk it is difficult when it comes to social obligations. Especially drinking coco-cola and energy drinks in the evening, but I do drink less than before (#2 Seak Sot).

One patient, who is not a monk, also expressed the difficulty in controlling the disease in the social environment. This again has to do with the patient not being able to inform other people about their disease and the perception of the patient that there is no social support provided to them by the society.

> "Sometimes I am not able to follow the instructions of the peer-educator on the food restrictions because of social conditions—like when I am traveling or staying at other people's house I have to eat what they offer me—I was afraid to tell them that I have diabetes because they don't understand it" (#4).

Getting social support from family such as financial support also play an important role for the patient to control their disease. Especially for patients that are at their old age. Having financial support to buy medicine on a regular basis is crucial for the patient to control the disease. This problem was mentioned by one patient:

> "Because I don't have enough money to buy modern medicine, I feel that I have to take the traditional medicine. I would like to take modern medicine because it is easier to take than traditional medicine.... But now my son cannot make anymore money so he does not bring anymore medicine. The traditional medicine is also expensive (20,000 riels (=5 USD) per bag), so I cannot afford anymore to buy either modern or traditional. They (my children) gave me some money but not enough to buy modern medicine" (#13).

3.3.6 Adherence to medication and follow-up visit

Adhering to medication was also mentioned by patients as a way to control their disease. In this evaluation study, there were only 2 out of 15 patients talking about having difficulty with adherence to medication. This problem of adherence was due to the side-effect of medication. As mentioned by one of the patient:

> "The medicine is too strong for me, so I am not taking it regularly as I was told by the doctor. The doctor told me to take three times a day, but I can only take two times a day because it is too strong that it made me have diarrhea (#14).

Another problem in controlling the disease encountered by one patient was the inability to have a regular follow-up visit with the doctor. This particular patient recognized that the importance of having follow-up visits at the doctor was to know if her disease has getting better or getting worse. As she mentioned:

> "I don't visit the doctor that often because I am too busy making a living. I am a widow so I have to work to support the family" (#7).

3.3.7 Experimenting with traditional medicine to search for cure

All patients mentioned that they have learned from the peer educator that diabetes cannot be cured, that it is a life-long disease. Although patients believe in this message provided by the peer educator, they still search for the possibility to cure their disease, and this possibility is traditional medicine. Because patients know that modern medicine can only help to keep their disease from getting worse and only make them better temporary, so they sort to traditional medicine for permanent cure.

> "I was told by another diabetic patient who took traditional medicine for her disease that now she did not have the disease anymore. I then tried it my self, and I found my eyesight got better" (#4).

> "Someone told me about a traditional medicine that can cure my diabetes forever. They told me to take 1 kilogram of pure palm sugar (without chemical), mix it with 1 kilogram of sour fruit and let it soak for awhile then drink it. If I do that my diabetes will be cured. This is what they did and they don't have diabetes anymore. I also want 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 hope that my disease will be cured (#12)

Thus by experimenting with traditional medicine, which often they got the information from other patients who have taken the medicine themselves served as a proof to the patients that the traditional medicine was indeed efficacious. This information can be a faulty one, but what matters most for the patients is that the desire to search for other alternatives to cure where modern medicines has failed to do so. This perception can have negative consequences for the patient in a sense that this makes it difficult for the patients to bring their disease under control because they do not understand that to have their disease under control is a matter of managing it.

3.4 Theme 3: Disease interferes with their productivity and daily tasks

When asking the patients to compare if the disease is still interfering with their productivity and daily tasks before and after they joined MoPoTsyo program, the two most occurring themes that emerged from the interview were the ability to work to earn income and ability to walk.

3.4.1 Ability to work and perform daily tasks

There were three patients mentioning that since they have diabetes, the disease did not interfere at all with their productivities. However other patients experienced that their disease has interfered with their productivity to some degree.

Having the ability to work normally as compared to before they joined MoPoTsyo was mentioned by four patients. The ability to work normally means that the patients were able to continue in their work occupation and perform their daily tasks like they were before they had the disease. One patient (#4) who just recently had been discovered by MoPoTsyo as diabetic describes that she was not even able to carry water or wash clothes before but now she does a little bit of that back again. Another patient who had diabetes for 4 years mentioned that before joining MoPoTsyo the disease caused her to have blurred vision, caused her to feel weak and unable to do any work, but now her condition has improved and she can work normally. As she stated:

> “Before, this disease disturbed me a lot like blurred eyesight, feeling weak, and cannot do any work, but now after I received treatment I can work like normal” (#5)

Another patient who also has diabetes for 4 years mentioned similar thing:

> “Before I spent money to hire a servant to do all the tasks, but now I have to do it myself. I can do a little bit of work at home as normal (#13).

The ability to walk was mentioned by 5 patients as something that they would not imagine to gain it back after joining MoPoTsyo. Gaining ability to walk normally again has been expressed by the patients as life-changing experience. As described by one patient:

> “Before joined MoPoTsyo, I cannot do anything for three years because I could not move my arms and legs and could not walk. Now I can walk better than before, I can ride bicycle. I don’t feel anymore the numbness in my hand and legs (#14).

Although most patients found that after entering into MoPoTsyo program their physical ability to work and perform daily tasks improved, some other patients still found that their disease interferes with their productivity. Four patients mentioned that they were not able to work anymore because of the disease. For example, one patient (#3) described that the disease has prevented her from working to earn income for the family because the disease was causing her to feel weak, dizzy and often hungry.

Another patient (#9) mentioned that the disease was causing him a lot of problems, and when it got bad he had to stop working for one week or two. This has made him depressed because of not being able to earn income.

3.5 Theme 4: Perceived Benefits received from MoPoTsyo

Another important aspect of this study was to identify what are the perceived benefits, material and/or immaterial, that the patients received from MoPoTsyo program and what are the results of these benefits for the patients, and what they are still lacking. In the interviews, the researchers were very cautious in asking the question that did not make the patients think that the question was trying to elicit on the material benefit. It was important to ask patients to state whatever benefit they received from MoPoTsyo that they perceived to be valuable and that it helped them to deal with their disease.

3.5.1 Types of benefit

The data from the interviews shows that patients were able to state both the material and immaterial benefit. The material benefits that were mentioned by patients include medication, monitoring of blood glucose, bean and rice, IEC materials, and financial benefit, not that MoPoTsyo given the money but the benefit that they spend less money than before they joined the program.

However all patients tend to mention on the <u>immaterial benefits more than the material one</u>. The immaterial benefits include education about the disease, lessons on how to control the disease, information on medication, and emotional support provided by the peer-educators. The following statements provide examples of the benefit patients received from the program:

- "It is important that this NGO comes to educate us about diabetes and how to prevent us from having the disease" (#2)

- "Received information about medication from peer-educator, where to buy good and cheap drug" (#6)

- "I received training from MoPoTsyo about blood test and learned how to recognize the drug by looking at the cover. I also learned about physiology, such as about the heart" (#7).

- "Received bean, drug, and monthly checkup" (#8).

- "I have learned about diabetes through peer educator showing picture and told me about the complications that I might have if I don't control it. I was also trained on how to use the machine to measure my blood glucose" (#10).

- "The peer educator (X) came to check my blood glucose and urine, and educated me about food restriction and exercise. The peer educator show picture of human body on the paper and the food pyramid. He came to do the blood test every week" (#12)

- “MoPoTsyo came to diagnose me and gave me confirmation that I have diabetes. They gave me lessons about food restriction and how to take care my self. I have regular check up every week. They told me to do regular exercise. They help me to recognize the correct diabetic medicine, and learn how to perform the test my self. They explain about the complications of the disease by showing pictures” (#14).

- “Receive regular check up with peer educator every week. The peer educator instructed me on food restriction such as eating beans. I also learned about the body and about the disease itself. The training of the peer educator is very good and useful because it helps me to know the level of my blood glucose if it goes up or down. If the glucose goes down then it makes me feel weak, but if it goes up then it makes me have blurred vision. The benefit I get from MoPoTyso is important in that I know about my blood glucose and I know how to control and manage my disease to prevent it from getting worse” (#11)

The last statement made by patient (#11) indicated the perception they have on the quality of information provided by the peer educator. The perception on the quality of information that patients have is a very important indicator not only on the content of the information itself, but also related to the behavior of the peer-educator, the effectiveness of the teaching, the retention of the information, and who should or should not provide the information.

3.5.2 Perception on the quality of information provided by peer educator

Regarding the perception patients have on the quality of information, 4 patients stated that they understood the message clearly and that they believe the information provided by the peer educators. They believed the information because the peer educators themselves have diabetes and that the peer educators appeared to be healthy. As one patient stated:

> “I believe in the information provided by the peer educator because the peer-educator told me that he also has diabetes and he restrict on his diet and follow all the instruction as taught in the lessons and that is why he has better health like normal person. Therefore, I believe in what he says.” (6)

Other patients believe in the information provided by the peer educator because when they tried to follow the instruction on diet and exercise they found a positive result. This notion was expressed by one patient, “The lessons provided by the peer educator is very good, and if I follow exactly what he told me to do I found that it was effective” (#12)

Although most patients contend that the peer educators provide good information, there were questions which remained unanswered. For example, one patient was not sure about why the disease caused him to "have blurred eyesight, lost hair and pressure inside the head" (#12)

Two patients mentioned that the information provided by the peer educator was not enough to understand about the effects of the disease on their bodies, particularly related to retinal problems.

3.5.3 Retention of information

The problem of not able to retain information was also related to the ability of remembering the lessons taught by the peer educators. Four patients expressed that although the peer educator provides good and useful information, the problem in retaining that information was that they were very forgetful. For example, one patient (#10) mentioned that he was able to understand the information during the education session, but afterward when he returned home he forget about the information. This inability to remember the information was explained by the patients themselves that it caused by the disease they have and the many social obligations that they have in their lives. Because they have to take care of family and doing many other daily tasks, they did not pay too much attention in trying to remember everything that was told by the peer educators.

3.5.4 Impression on the peer-educator

The ability to deliver information effectively to the patients was also related to how the patients think about the personality and responsibility of the peer educator toward them. When the peer educator expressed a friendly behavior, patients perceived that he/she was caring for them. Out of the two peer educators, one had expressed the desirable behavior toward the patients and the community at large. When the patients have good impression about the peer educators they tend to listen and feel comfortable in asking for information. The following are some positive impression that patients have toward one particular peer educator:

> "I have good impression on the teaching method of peer-educator (X). I like his behavior because he is friendly and kind" (#1).
>
> "I think he is a good person because he made a lot of effort in helping the community" (#2).

Paying attention to a particular patient was seen as a kind and caring behavior. For example one patient stated, "I like the peer educator because he is very helpful and kind. He is always here if I need him. So I think he is a good person" (9).

The negative aspect of the peer educator's behavior that patients have was related to the peer educator not paying enough attention toward them and not providing enough information when they asked. Not coming to visit the patients at their house frequently was also an expression of not caring for the patients.

> “I don’t really like (peer educator Y) because he asked patients to go to his house to get test, where as (peer educator X) comes directly to the house of the patient. I like (peer educator X) better because he is friendly and work very hard, but (peer educator Y) only comes to see me once a month and he asked patient to go to his house (#5).

Several patients have strong complain about the (peer educator Y) because he did not show that he was caring for the patients and that he found it more convenient by asking patients to go to his place to get blood glucose test and to get education. For example one patient stated:

> “I don’t receive enough lessons from (peer educator Y) because he only did blood glucose test. He did not hold education sessions but told patients to go to his house for the lesson. I have better impression on (peer educator X) than (peer educator Y) because (peer educator X) follows up with me regularly whereas (peer educator Y) rarely comes to visit her” (#6)

3.5.5 Emotional support

Receiving emotional support from the peer educator is considered to be one of the most important benefits patients have from the program. The information provided by and the attention and caring of the peer educators were perceived by some patients as life-saving. In the words of one patient:

> MoPoTyso staff was very caring and provide regular checkup. I am very thankful to him because I was nearly dead but then he came to save my life. Information I received from MoPoTsyo helped me to have strength and it helped me to control the disease from getting worse. My disease is getting better because I have medicine and.... (#8)

The experiences patients have with the peer educator can also influence on how they see the role of non-governmental organization in providing social support for people who affected by diabetes, the disease that was neglected by many other NGO’s in particular and by the society in general. As stated by the patients:

> “I am very thankful to MoPoTsyo who tries to help me all the time. The peer educator is very caring and a good person. I have never seen any NGO like this. If there is no more MoPoTsyo to help me then I don’t know who else can help. I just wait to die (#14).

3.5.6 Lacks and short comings of MoPoTsyo

Although patients found activities implemented by MoPoTsyo beneficial and valuable for them, but nonetheless, MoPoTsyo cannot provide everything and help every patient according to their needs. One patient complained about MoPoTsyo not able to provide monitoring equipment that they can use to monitor their blood glucose on their own, and the need having to wait for the peer educator to come for a visit. Patients were complaining about urgent circumstances when they need to know their blood glucose level, but they have to wait for the peer educator come for weekly visit or that they have to go to the peer educator's house.

Patients who think they need medication but only joined MoPoTsyo in short period of time made the complaint about why MoPoTsyo does not provide free medication. As he stated:

> "I don't feel like attending MoPoTyso anymore because they only do the blood test, and do not give any medicine. So I am getting a bit lazy in attending the session. I buy my own medicine at the pharmacy. I don't understand the purpose of MoPoTsyo, why they have activities here if they don't even provide medicine. There is no meaning to this" (#9)

4. Conclusion

What we can conclude from this study is that there are positive outcomes of the program in several dimensions which include improvement in the health status of the patients, improvement in financial payment for their disease, increasing in awareness and knowledge about the disease, having the confidence that they can manage their disease, and getting the emotional and social support patients through the peer-educators.

As compared to before they entered into MoPoTsyo program, most patients feel that their physical well-being has improved from not being able to walk and perform daily tasks to having the ability to walk again and continue their daily tasks like they normally did before they got the disease. And in terms of their psychological and mental aspects, patients expressed that before they joined MoPoTsyo, they feared early death, feared of not having access to treatment, and feared of not having anyone to support them. However, after joining MoPoTsyo these feelings changed: they feel that they are not scared anymore because they now know that there is support for them and that there is someone who pays attention and cares about them.

With regards to having the disease under control, several factors were identified to relate to how patients attempt to bring the disease under control. These factors include the ability of the peer educator to counsel succesfully the patients, so to persuade the patients to follow the main instructions, and also the personal willingness of the patients to change their lifestyle. Other factors such as having a monitoring tool to measure their blood glucose, knowledge about food restriction and the desire to eat, social pressures in social events, adhering to medication, follow-up visits with medical providers, and seeking for cure also play important roles in how patients tried to control their disease. It was found that most patients acknowledged that they knew about and practiced all the methods in managing their disease, but they have found it difficult to follow some of the lessons, particularly relating to eating beans instead or white rice and the desire to eat sweet things. Another problem some patients encountered in controlling their disease was related to the social environment that they live in, for example the social pressure in consuming food and the lack of understanding in the society about diabetes.

When asking the patients to compare if the disease is still interfering with their productivity and daily tasks before and after they joined MoPoTsyo program, it was found that the few patients still have the disease hindering their productivity and daily tasks, but most patients they found that after joining MoPoTsyo they were able to work normally again.

As regard to the types of benefits that patients received from MoPoTsyo, it was found patients have received both the material and immaterial benefit. The material benefits that patients received include medication, monitoring of blood glucose, bean and rice, IEC materials, and financial benefit in the sense that they spend less money now compare to before they joined the program. However all patients tend to mention on the immaterial benefits more than the material ones. The immaterial benefits include education about the disease, lessons on how to control the disease, information on medication, and emotional support provided by the peer-educators.

Most patients found activities implemented by MoPoTsyo were very beneficial and valuable for them in terms of the knowledge they gained from the peer educators, the ability to have their blood glucose test in the community, the emotional support they get from the peer educators and the medical treatment they need.