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EVALUATION of a PEER-EDUCATION PROGRAM for DIABETES and HYPERTENSION in RURAL CAMBODIA

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List of abbreviations

ADL - activities of daily life
ART - antiretroviral therapy
BMI - body mass index
BP - blood pressure
CBHI - community based health insurance
CHW(s) - community health worker(s)
DBP - diastolic blood pressure
DM2 - diabetes mellitus type 2
FBG - fasting blood glucose
HAI - health action international
HEF - Health Equity Fund
HICs - high-income countries
HIV/AIDS - Human Immunodeficiency Virus / Acquired Immunity Disorder Syndrome
HSP - Health Strategic Plan
IDF - International Diabetes Federation
LAMICs - Low-and Middle-income countries
LTFU - lost to follow up
MDGs - millennium development goals
MoH - ministry of health
MSF - médecins sans frontières
NCDs - non-communicable diseases
NGO - non-governmental organisations
NPCs - non-physician clinicians
PPBR - post prandial blood glucose
RCT - randomized controlled trial
SBP - systolic blood pressure
SSA - sub-sahara africa
TB - tuberculosis
WB - World Bank
WDF - World Diabetes Federation
WHO - World Health Organisation
WP - Western Pacific

Abstract

Introduction: The prevalence of diabetes in Cambodia is high, and the current healthcare system is unable to provide adequate care for the people affected. Where care is available it is often unaffordable and many patients are pushed into poverty because of high out-of-pocket expenditures. MoPoTsyo is a Cambodian NGO providing care for people with diabetes and hypertension by engaging a peer-educator in their own community. The focus of the education is on self-measurement of glucose levels and adaptation of life style, including nutrition and daily exercise.

Method: Our research was performed in Takeo province, one of the poorest provinces in Cambodia, where the NGO has been working since 2007. We used a mixed-method approach: (1) a retrospective before-after study in a random sample of 150 patients in the program for at least 2 years. Basic biomedical data were collected and structured questionnaires were used to assess perceived improvement in health, ability to control the disease and adherence after joining the program; and (2) in depth-interviews with 14 patients and 3 peer-educators were carried out to gain greater understanding of the challenges patients faced before and after joining the program.

Results: A total of 134 patients completed the questionnaires. There was a significant drop in Fasting Blood Glucose (mean drop 42.06 mg/dL; $p < 0.001$) and BP (mean drop 10/7 mmHg; $p < 0.001$) compared to baseline, but not for BMI. Overall, two-thirds of patients reported improved outcomes on the questionnaires, but the in-depth interviews showed that many still faced substantial financial difficulties.

Discussion: Peer support models are especially promising for resource-constrained health systems, where care for chronic condition is often non-existent or of poor quality. The results of our research indicate the potential for peer educator networks to complement professional caregivers, especially where those are scarce, expensive or less effective.

INTRODUCTION

I. Chronic conditions on the rise

Chronic diseases are now the major cause of death and disability worldwide (WHO 2005). Contrary to popular belief, these deaths are not only occurring in the ‘affluent countries’. In fact, low- and middle income countries carry the highest burden. According to WHO, 80% of chronic disease deaths worldwide occur in LAMICs. In 2005, the burden of noncommunicable diseases was assessed in 23 low and middle income countries, showing that they accounted for 50% of their total disease burden (Abegunde *et al.* 2007). Moreover, in these countries, chronic diseases develop at an earlier age than in high-income countries, often resulting in a prolonged period of disability before death (Alwan 2009). The death rates from these potentially preventable diseases are also higher in LAMICs than in HICs, especially among adults aged 30-69 years (Strong *et al.* 2005).

This shift in health problems, away from infectious and perinatal conditions to chronic health problems, poses significant health-threats to all countries (WHO 2002). In addition, low-and middle income countries are faced with a ‘double burden’, since they are still struggling to control communicable diseases, such as malaria and pneumonia, and to improve maternal and child health.

The prevalence of chronic diseases, and the morbidity and mortality associated with them, is only expected to rise in the upcoming decades. By 2020, it is predicted that non-communicable diseases will account for 80 percent of the global burden of disease, causing seven out of every 10 deaths in developing countries (Boutayeb & Boutayeb 2005). Importantly, the concept of “chronic conditions” should go beyond the traditional term “non-communicable diseases” to include several communicable diseases. When communicable diseases become chronic problems, such as in the case of HIV/AIDS or TB, the delineation between non-communicable and communicable diseases becomes artificial. WHO simply defines chronic conditions as “health problems that require ongoing management over a period of years or decades” (WHO 2002). From a health policy point of view it is indeed useful to bring such conditions together under one heading, since the demands they place on patients, families and the health care system are similar and comparable management strategies are effective in addressing them.

Ia. Diabetes

Amongst all the diseases counted as chronic, diabetes is one of the most prevalent and is associated with significant morbidity and mortality. Complications from diabetes, such as coronary artery and peripheral vascular disease, stroke, diabetic neuropathy, amputations, renal failure and blindness are resulting in

increasing disability, reduced life expectancy and enormous health costs for virtually every society. Diabetes is undoubtedly one of the most challenging health problems in the 21st century (IDF 2009)

According to estimations of WHO and IDF close to four million deaths in the 20-79 age group in 2010 may be attributable to diabetes, accounting for 6.8% of global all-cause mortality in this age group (IDF 2009). This estimated number of premature deaths is similar in magnitude to deaths in this age group from several infectious diseases. Moreover, there is evidence to suggest that the prevalence of diabetes in LAMICs is increasing faster than in HICs (Beran & Yudkin 2006). These estimates should be interpreted cautiously, however, since data about the prevalence and mortality of diabetes are difficult to obtain. Estimating the mortality burden is challenging because more than a third of countries of the world do not have any data on diabetes-related mortality and because existing routine health statistics have been shown to underestimate mortality from type 2 diabetes. The estimates in the Diabetes Atlas are calculated on the basis of a modelling approach, the rationale of which can be found in the Atlas (IDF 2009).

Although the exact prevalence data differ from study to study, most authors agree that diabetes is an important public health problem that does not get enough attention from policy makers, researchers and the general public. Not only are chronic diseases not mentioned in the MDGs, but only a few LAMICs have a strong NCDs policy. This is certainly to be regretted since many cases could be prevented by simple health measurements such as physical activity, a healthy diet and not smoking. For those who do develop the disease, good management can prevent complications and thus improve quality of life and life-expectancy (IDF 2009).

Diabetes is determined by both genetic and lifestyle influences. The current diabetes epidemic is undoubtedly linked to the rapid nutritional and lifestyle transition occurring in developing countries, but there is evidence that certain populations are more susceptible to developing the condition (IDF 2009). Non-Euroid populations living in industrialized societies seem to be at greatest risk (Alberti *et al.* 2004).

The reasons for these differences are complex and not fully understood. A correlation between malnutrition in early childhood and fetal life and diabetes in adult life has been suggested (the 'Barker hypothesis'), which could partly explain the high incidence in LAMICs. Others have suggested the hypothesis of a 'thrifty phenotype', in which inadequate nutrition programs the fetus to develop insulin resistance in adult life. (Alberti *et al.* 2004)

Another interesting finding that could help explain the high burden of diabetes in LAMICs is the association between DM2, TB and HIV/AIDS. Diabetes has been associated with a three-fold incident

risk of tuberculosis and it is hypothesised that TB may also increase the risk of developing diabetes. During co-morbid presentation of tuberculosis and diabetes the outcomes of both have been reported to worsen. Antiretroviral therapy for HIV/AIDS has been associated with an increased risk of developing both diabetes and cardiovascular disease. This is an important finding, pointing to the possibility that achieving the goal of universal ART coverage in SSA might cause a substantial rise in metabolic syndrome, diabetes and heart disease (Young *et al.* 2009). More research is needed to better understand the causes of diabetes; the link with urbanisation, early childhood malnutrition, TB and HIV/AIDS and other possible associated factors; to guide health policy in identifying the most efficient preventive measures.

Ib. 'Sweet urine'

The epidemiological transition is well underway in Cambodia. So even while communicable diseases remain substantial threats, the prevalence of diabetes and hypertension is increasing. A 2005 survey revealed a diabetes prevalence of 11% in a semi-urban community and an unexpectedly high prevalence of 5% in a relatively poor, traditional, rural community (King *et al.* 2005). The 2008 activity report of Doctors Without Borders identified HIV/AIDS, diabetes and tuberculosis as the main health problems in Cambodia (MSF 2008).

During the last decade, the Ministry of Health has been focusing on maternal and child health, communicable diseases and primary health care. Chronic diseases have not received much of attention. In the most recent Health Strategic Plan (HSP) of the Ministry of Health however, the need to improve the prevention and management of chronic diseases is acknowledged. It is stated that “efforts have been made to increase the focus on non-communicable diseases, and continued efforts will identify future needs and their financial implications” (MoH 2008). Three strategic priorities for the health sector are identified in the HSP, one of which is to “reduce the burden of non-communicable diseases and other health problems”. Maternal and child health and communicable diseases such as HIV/AIDS and tuberculosis remain the centrepieces of the HSP though. The draft National Strategic Plan for Non-Communicable Disease provides the overarching framework for all NCD planning at the moment.

Thanks to initiatives of the World Diabetes Federation, WHO and the Ministry of Health, at present 8 diabetes clinics offer specialized services, while no diabetes treatment was available before 2005 (WDF 2008). One is in the capital, Phnom Penh, at Kossamak Hospital; the remaining 7 are in provincial hospitals, in some of the larger provinces of the country (Prey Veng, Pursat, Kampong Cham, Battambang, Kampong Thom, Siem Reap and Kratie). However, these hospitals do not provide free care and many patients are unable to pay for their services. As discussed further, there is no government

provision in terms of subsidies or health insurance programmes to cover essential diabetes medications or supplies.

In what follows, we will discuss some problems related to chronic diseases and the kind of health care needed to manage them. We will focus on diabetes because our research was performed with diabetes patients, but it should be emphasized that none of these problems or solutions is limited to this condition.

II. Living with diabetes: problems faced by patients and providers

For people living with diabetes the management of blood sugar is not just a technical matter, but a complex and dynamic personal task (Broom & Whittaker 2004). There are numerous behavioural changes that patients must integrate into their daily lives. Self-monitoring of blood glucose levels, medication adherence and adjustments, regular checks for foot problems, and ongoing dietary and physical activity regimens become every day concerns (WHO 2003). Because diabetes patients are mainly responsible for their own care, they become experts in ‘self-management’. Disease management however, is but one aspect of life, next to employment, family, enjoyment of life and the desire to remain independent. Patients will make trade-offs between strict disease control and overall quality of life and will sometimes decide not to follow treatment prescriptions. Life-long disease management is not only demanding for patients but also very costly, both for the patient and the health care system and many patients in LAMICs are pushed into poverty because of catastrophic health expenditures (WHO 2010).

IIa. Retention and adherence

Even the best medical treatment has no effect if patients do not adhere to it. Access to medications is necessary but insufficient in itself for the successful treatment of disease. Poor adherence to treatment of chronic diseases is a worldwide problem of striking magnitude. For developed countries it averages 50% (WHO 2003), and it is as low as 20% in developing countries (WHO 2002). For example, in one study in the Gambia 73% of patients previously diagnosed with hypertension had stopped their treatment (Van der Sande *et al.* 2000). Poor adherence severely compromises the effectiveness of treatment, thereby worsening health outcomes and increasing health care costs. In the case of diabetes, poor adherence to recognized standards of care has been identified as the principal cause for the development of complications (WHO 2003). We have reached a point that “increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in

specific medical treatments” (Haynes 2001). Unfortunately, adherence problems have generally been overlooked and as a result have received little direct, systematic intervention.

Despite evidence to the contrary, there continues to be a tendency to focus on patient-related factors as the causes of problems with adherence or retention, to the relative neglect of provider and health system-related determinants. Adherence is a multidimensional phenomenon determined by several factors, of which patient-related factors are just one aspect. WHO has identified five dimensions of adherence: condition-related factors, patient-related factors, therapy-related factors, social/economic factors and health system-related factors.

Research has shown that the major reasons for patients dropping out of treatment programs or simply not being able to access care in LAMICs are mainly structural and that defective health systems lie at the heart of the problem. The key barriers to care are unaffordable costs, weak availability of inputs and services, and poor acceptability (the appropriateness of the social interaction that accompanies care), which has been referred to as the ‘access framework’ (Goudge *et al.* 2009).

In a longitudinal study in South Africa, Goudge *et al.* (2009) found that of the thirty-four chronically ill case-study patients only twelve were receiving regular treatment. Livelihoods exhausted from previous illness and death, low income and limited social networks, prevented consultation with monthly expenditure for repeated consultations as high as 60% of income. Interrupted drug supplies, insufficient clinical services at the clinic level necessitating referral and a lack of ambulances further hampered access to care. Poor provider-patient interaction led to inadequate understanding of illness - 34% of patients had no diagnosis reported - inappropriate treatment action, ‘healer shopping’, and at times a break down in cooperation, with the patient opting out of the public health system.

Awah *et al.* (2008) explored the cultural aspects of adherence in Cameroon using qualitative research. They found that the treatment packages offered to patients at clinical encounters were perceived as socially inappropriate and therefore rejected or modified by the patients. They had difficulty coming to terms with biomedical treatment for diabetes and were still seeking permanent cure through traditional medicine. Accepting weight loss as a lifestyle measure was often not accepted because of its association with AIDS. These cultural aspects could potentially help explain the low-retention rates in an intervention done by Labhardt *et al.* (2010) in rural Cameroon. They trained about 130 non-physician clinicians (predominantly nurses) to provide integrated care for diabetes and hypertension in 54 different rural health facilities and assessed the program after 2 years. Although clinical outcomes on FBG and BP improved significantly for treated patients, the overall effectiveness of the program was modest because of limited access to patients and a very high drop-out rate. Among the 349 patients recruited at least 15

months before the assessment, only 18.1% were still in care after one year (recorded consultation \leq 3 months). A regression analysis for identifying risk factors for dropping out yielded no significant result. Socio-economic status and distance to the facility were not included in the analysis however and could have played an important role.

A thorough understanding of the determinants of adherence is necessary to develop interventions for removing the many barriers patients face. Such interventions must become a central component of efforts to improve care. Without a system that addresses the determinants of adherence, advances in biomedical technology will fail to realize their potential to reduce the burden of chronic illness (WHO 2003).

Iib. Iatrogenic Poverty

Besides their major health impact, chronic conditions have serious economic implications because of the high costs of medicines and complications, and years of life lost because of premature death. WHO has stated that “the failure to address the economic repercussions of chronic conditions by revising health policies and health services endangers the economic prosperity of all nations” (WHO 2002) and Alwan & Maclean added that it could impede international efforts at poverty reduction (Alwan & Maclean 2009). They have estimated that total diabetes-related costs constitute between 2 and 4% of GDP in most LAMICs. The overall cost to the health care system of treating patients with type 2 diabetes is on average over 1.5 times higher than per capita health care expenditure and increases 2- to 3.5-fold once patients develop complications (WHO 2003). The impacts on households can be disastrous as well. Globally, 150 million people suffer financial catastrophe every year, while 100 million are pushed below the poverty line; starting a vicious cycle of poverty and ill health (WHO 2010). In the poorest households of some developing countries 15-25% of household income is spend on the treatment of diabetes (Alwan & Maclean 2009). As stated by WHO: “crucially, it is the poor who are really paying the price – both economically and with their health” (WHO & HAI 2008).

These costs could largely be averted by appropriate prevention and management strategies. Abegunde *et al.* estimated that the achievement of a global goal for chronic disease prevention and control – which is aiming at an additional 2% yearly reduction in chronic disease death rates over the next 10 years – would avert 24 million deaths in the 23 LAMICs they studied, and would save an estimated \$8 billion, which is almost 10% of the projected loss in their national income over the next 10 years (Abegunde 2007). Most of these averted deaths and life-years gained would be in low-income and middle-income countries, and just under half would be in people younger than 70 years (Strong 2005).

Availability and affordability of medicines

A substantial proportion of the costs related to treating chronic conditions are attributable to the cost of medication (Mendis *et al.* 2007). Access to medicines is not only important in the case of chronic conditions, but is more problematic in this setting since the supply needs to be ongoing. Although diabetes can be partly treated by life-style interventions, many patients will eventually need medicines to control their blood sugar, and the amount of medicines needed worldwide will only increase in the coming years (Gelders *et al.* 2006). Meeting this rising demand will be particularly challenging for insulin, which is relatively expensive compared to other essential medicines, and needs to be refrigerated. Insulin is essential for the treatment of type 1 diabetes and the lack of availability in many countries contributes to the high mortality of this disease (Alberti 1994). In addition, most patients with type 2 diabetes will at some moment in their disease course need insulin treatment and recent studies suggest that earlier and aggressive treatment with insulin could lower cardiovascular mortality (Swinnen *et al.* 2009). Finally, diabetes treatment also requires syringes and monitoring equipment, such as urine test strips, blood glucose strips and glucose meters (Volman 2008). All this needs to be sold at an affordable price for patients, to avert that they are pushed into poverty because of catastrophic health-expenditures.

In 2003 WHO and HAI developed a standardised method for surveying medicine prices, availability, affordability, and price components in low-income and middle-income countries (WHO & HAI 2008). Since then, a lot of research has been done, but only very few studies have focused specifically on medicines used to treat chronic diseases. Such research is urgently needed to identify the best ways to make medicines available for all at an affordable cost. General findings in the research so far indicate that, although many medicines are often (theoretically) provided free or at low cost in the public sector, their unavailability in reality forces patients to purchase medicines from the private sector or forego treatment if they cannot afford it, making care inaccessible even though medicines are available (Gelders *et al.* 2006; Mendis *et al.* 2007)

Providing medicines at an affordable price for patients in the public sector has a serious macro-economical impact, especially in the case of insulin, which is expensive relative to the total healthcare budget of governments. The purchase of insulins can consume as much as 10% of government expenditure on drugs, this being highly sensitive to the selection of newer analogue insulins as first-choice options (Gill *et al.* 2011). Governments often have to make choices between different diabetes medications because of budget constraints. In addition, insulin has to compete with other demands, in particular anti-retroviral drugs, a choice referred to in literature as 'the insulin dilemma' (Gill *et al.* 2011). In efforts to increase the availability of medicines, the right policy decisions need to be taken regarding the different medications available on the market to ensure that resources are allocated effectively.

Present cost–benefit considerations do not support the general use of analogue insulins, particularly in resource-poor countries and settings. Simple human (or animal) insulins, if properly used, will nearly always suffice (Gill *et al.* 2011). Governments should also be cautious that resources are not drawn away from other necessary aspects of diabetes care, such as education, self-management and healthcare providers.

The price of insulin could be lowered by tendering for generic preparations from sources conforming to Good Manufacturing Practice, as suggested by the International Insulin Federation. They further encourage the introduction of a Prequalification Scheme, as already exists to ensure quality for anti-retroviral, anti-TB drugs, anti-malarials and asthma treatments. This, in combination with more effective resource-allocation between the different types of insulin and other diabetes medication, could make money available for other essential aspects of diabetes care or for protection of the poorest from financial hardship (Gill 2010).

Another important issue here is the role of international funding. By using the term ‘insulin dilemma’, it seems that governments in LAMICs have an actual choice between buying antiretrovirals or insulin. In reality, they often lack the money for either of these and rely on donor money instead. By earmarking their donations, donor countries make the choice between antiretrovirals and insulin, making the ‘insulin dilemma’ a fiction at country level. The 60,000 people in Cambodia with HIV/AIDS receive 60% of healthcare loans and donations, while non-communicable diseases receive just 1% of donor contributions; despite WHO estimates that they cause seven out of 10 deaths in the Western Pacific region (Van Pelt 2009). This focus on certain diseases creates inequality between different patient groups. In a qualitative study in Cambodia, patients that suffered from diabetes said they ‘wished’ they had AIDS instead of diabetes, because patients with AIDS get more attention from NGOs, free medication and other benefits (Men 2007).

Protecting households from poverty

As mentioned before, chronic diseases are pushing many families into poverty. Direct, out-of-pocket payments are the main cause of catastrophic spending and the greatest obstacle to moving towards universal coverage of health services (WHO 2008a). Evidence shows that raising funds through required prepayment is the most efficient and equitable base for increasing population coverage (WHO 2010). This works best when prepayment comes from a large number of people, with subsequent pooling of funds to cover everyone’s health-care costs. Decisions will have to be made however in terms of who should pay, how much and when, if payment should be compulsory, and what to do with those who are too poor to contribute. Even when funding is largely prepaid and pooled, there will need to be tradeoffs between the

proportions of the population covered, the range of services to be made available and the proportion of the total costs to be met (WHO 2010). The government of Cambodia has opted for a pro-poor approach by introducing a Health Equity Fund, as discussed further below.

Iic. Human resources for health

A sufficient, well trained, and appropriately deployed health workforce is essential for the effective implementation of any health programme, but comprehensive chronic disease prevention, care, and management make especially heavy demands on the health workforce due to the range of interventions and the extended duration of contact with services. Many current models developed in HICs to care for chronic diseases are very intensive in their use of skilled medical and paramedical staff. Low- and middle-income countries have acute shortages of skilled health workers, with overconcentration in urban areas and poor retention rates due to insufficient pay, unfavourable working conditions, and ill health. WHO's 'Health for All' standard of one doctor per 5 000 population is still far from reality in many countries (Kober & Van Damme 2006). In addition, the existing health workforce does not have the skills that are needed to meet the emerging health needs of the communities they serve. There have been new commitments to training for health workers, but these efforts have been driven by the urgent need to scale up access to disease-specific services and have therefore focused mainly on in-service training for HIV/AIDS, tuberculosis, malaria, and vaccine-preventable diseases (Samb *et al.* 2010). Countries should urgently invest in training health workers for the management of chronic diseases.

Iid. Defective health care systems

Health care for chronic conditions is inherently different from health care for acute problems, and in this regard, current health care systems worldwide fall remarkably short. The acute care model still drives the organization of care throughout the world, even in the most economically developed countries (WHO 2002). A WHO survey in 2001 revealed that in most parts of the world, governments do not have policies for preventing or managing non-communicable diseases (WHO 2002). Of the 167 countries surveyed only 43% reported having a Diabetes Control plan. Health policies and plans are outmoded; instead of integrated, population-based care that emphasizes patients' needs, policies and plans often promote models of acute, episodic care, which results in fragmentation and waste to the system. The retrospective reimbursement of providers without regulation (e.g. fee-for-service) is typical in many health systems and stimulates inefficiency on the service delivery side. When health care workers are reimbursed proportionate to the volume and cost of services they deliver, they are effectively economically "punished" for engaging in innovative, health promoting clinical practice (WHO 2002). In addition, the lack of financial reimbursement for patient counselling and education seriously threatens adherence-focused interventions (WHO 2003). Care is misdirected with resources mainly allocated towards the

provision of highly technological biomedical interventions, neglecting the potential of primary prevention and health promotion to prevent up to 70% of the disease burden (WHO 2008a). Such technological interventions mostly make use of skilled health professionals, thereby increasing the burden on the limited workforce in LAMICs. In addition, the potential role of patients and community health-workers is neglected.

Without change, health care systems will continue to grow increasingly inefficient and ineffective as the prevalence of chronic conditions rises. Health care expenditures will continue to escalate, but improvements in population's health status will not. The current system in Cambodia is just one of the many examples where the health care system fails to provide quality care to patients with chronic conditions at an affordable cost.

Cambodia, 'Kingdom of Wonder'

Cambodia is one of the poorest countries in South-East Asia (Meessen 2008). Life expectancy at birth is 62 years, under-5 mortality rate is 89 per 1000 live births and maternal mortality is 461 per 100 000 life births. Cambodia had a turbulent recent history and is still in a process of recovery and rebuilding. International negotiations culminated in the signing of the Paris Peace Accords in 1991, which paved the way for the 1993 UN-supervised general elections. After this period, Cambodia was able to establish a rudimentary national health system and made progress in key areas, most notably child health (Grundy *et al.* 2009)

Although economic growth has been impressive over the last fifteen years, not everybody benefited equally. Around 35% of the population still lives below the national poverty line and as in most transitional countries; inequality has increased, most notably within the rural population (WB 2006). As far as the health sector is concerned, the country has been engaged in an extensive reconstruction and development of its public health system since the early nineties (Hill 2004). For an overview of health policy developments in Cambodia between 1996 and 2008, see appendix I.

Despite recent initiatives to strengthen health service delivery, there are still some important problems, both on the demand and the supply side. Many patients are unable to pay for health services and there is a general lack of trained health professionals, especially in rural areas.

Cambodian health financing has been dominated by out-of-pocket spending since user fees were introduced by the government in 1997. Total annual health expenditures in Cambodia are US\$37 per capita, of which \$25 (68%) is private, out-of-pocket expenditure. While user fees have allowed ensuring a decent income for staff in well-managed hospitals, they present a major financial barrier for the poorest (Meessen *et al.* 2008). About one third of the population is too poor to pay for health care in the public or

private sectors and resorts to a range of traditional healers and other unqualified (and often dangerous) private service providers. This results in large differences in health status between socioeconomic groups (MoH 2008).

Although overall mortality rates have improved since 2000, the gap between mortality rates of the richest and poorest is increasing – rising from twice as high in 2000, to three times as high in 2005. Persistently high maternal mortality rates (461 per 100 000 live births) provide further indication of fundamental inequities in the health system. The under-five mortality rate is almost three times as high in the poorest socio-economic groups as compared to the wealthiest socio-economic groups. (Grundy *et al.* 2009)

On the supply side, there are large inequities in human resource distribution across Cambodia, with medical doctors and other trained professionals concentrated in cities and larger towns (Grundy *et al.* 2009). There are only 1.6 physicians per 10 000 population (compared to a regional average for the Western Pacific of 14) and 8.5 nurses and midwives (WP average 20.8), well below the WHO standard (WHO n.d.). Of those remaining in rural areas, ongoing concerns regarding the quality and distribution of staff persist (Grundy *et al.* 2009). In addition, there are low levels of salary and incentives for staff working in the public health sector, further preventing effective delivery of health services.

In response to the health barriers and access inequities outlined above, the Ministry of Cambodia decided in its Health Strategic Plan to invest in social health protection, using a pro-poor approach in contrast to universal measures. Interventions are focused on targeting resources to the poor and groups with special needs and to areas in greatest need, especially rural and remote areas, and urban poor (MoH 2008).

There are currently four ways in which public health care is financed:

- user fees: revenue for health facilities (these however do not cover the costs made by the facilities. The remaining is paid by the government, mostly using donor money)
- health equity fund: protection for the poor,
- community based health insurance: risk-pooling for informal sector-workers above poverty line,
- social health insurance: universal coverage to wage earners formal sector.

The ultimate objective of the government is to bring all prepayment schemes under a common Social Health Insurance umbrella (MoH 2008).

The health equity fund (HEF) was introduced to remove financial barriers to care for the poorest. The HEF model is straightforward: the main idea is to request no payment from poor patients (as in any waiver), but to ensure nevertheless that the hospital is compensated for each poor patient it admits (Hardeman *et al.* 2004). The policy is achieved by putting aside substantial resources for poor people and establishing a third-party payer arrangement to ensure that the scheme is accurate in its targeting. In all

hospitals where such a scheme was established, use by poor people rose dramatically (Meessen *et al.* 2006). Health equity funds in Cambodia try to address the issue of participation costs; to respond to the fact that ‘free’ health care services (no user fees) are in reality not free because patients still have to pay for transportation and food, and lose precious time (Meessen *et al.* 2008). The benefit package of the HEFs is fairly detailed—besides paying user fees to the hospital, health equity funds also reimburse patients for transport costs. A few schemes also cover food and other expenditures during hospital stay. A social worker is often employed by the health equity fund to assist the patient during their hospital stay, which is a great help to overcoming barriers, such as stigma and social exclusion, and guarantees that no informal fees are charged, or that patients are not referred to private clinics (Meessen *et al.* 2008).

The HEFs are primarily governed by NGOs and have different benefit packages. Most have focused exclusively on the assistance for poor people admitted by public hospitals and often do not include chronic diseases, nor does the CBHI; except for admission for acute episodes (Annear *et al.* 2006). In a study of financial access to health services for the poor in Cambodia in 2006, Annear found that the likelihood of being in debt for health care was significantly greater for people with a chronic condition (Annear *et al.* 2006). These patients are more vulnerable and more likely to slip through a safety net of financial support for the poor (HEF and CBHI).

Since 2010, there is no longer a hospital that provides free care to diabetes patients. The Centre of Hope in the capital previously did but limited patient admission through a lottery system. Because of inadequate external funding and a demand side overwhelming the supply side they have ceased to provide free care since the end of 2009 (Van Pelt, personal communication).

In addition, the availability and affordability of diabetes medication is low. In the International Insulin and Diabetes Supplies Survey on Cost and Availability from IDF Cambodia, together with Côte d’Ivoire, Mali, Nepal and Togo, reported that people with both type 1 and type 2 diabetes had access to insulin less than 25% of the time. Regarding access to syringes and needles, Cambodia, Costa Rica and Mongolia reported that people with diabetes ‘rarely’ were able to access needles and syringes.

Because of a lack of quality, affordable health care, patients have limited information about their disease, about where they can go for treatment and therefore often engage in healer-shopping. In 2007, Men performed a qualitative study on health care access among HIV/AIDS and diabetic patients in Cambodia (Men 2007). The study population included both urban (Phnom Penh) and rural (Takeo province) patients. He found that, at the early stages of the disease, patients mostly access treatment through the private sector. Patients shop around to find treatment for symptoms rather than seeking a correct diagnosis. This leads to high health care expenditures, often for unnecessary treatment of symptoms and incorrect diagnoses (Rose *et al.* 2002). Moreover, providers treated patients without a first diagnosis and

did not reveal the results of the diagnosis to patients; this was seen as an economic motivation to make a profit from patients. Patients felt that treatment with IV fluid injections meant that providers were more interested in making money from patients than in helping them.

Patients did not get information about the causes and symptoms of diabetes and that it can be partly treated by life-style interventions. Many patients also believed that their disease could be cured. Interestingly, a study conducted in 2000 found that patients with HIV/AIDS believed that it could be cured by traditional medicine; while the patients that were questioned by Men in 2007 did not report such a belief. Many of them reported that they used traditional medicine in the past, but changed to modern medicine entirely after being taken care of in the NGO sector. This suggests that the knowledge and perception of HIV/AIDS have changed because of increased information and the availability of free, quality care. Diabetic patients, however, receive conflicting information about their disease and its treatment and care. The majority of diabetic patients questioned by Men perceived that diabetes could be cured permanently with traditional medicine, but not with modern medicine. This perception surrounding the curability of diabetes influences their health-seeking behaviour and complicates treatment outcomes, as they often combine modern medicine with traditional medicine.

From the above it is clear that the health-care available for diabetic patients in Cambodia is far from optimal. Services for diabetic patients are limited and patients are pushed into poverty because of high out-of-pocket expenditures. Patients do not receive adequate information, making it impossible for them to make informed decisions about their health.

III. Rethinking health care delivery:

patient-centered care, self-management education and peer-education

The worldwide shift from acute to chronic diseases as a primary cause of illness has led to a vast amount of literature about what constitutes qualitative care for chronic diseases. In 2002, WHO published the report 'Innovative Care for Chronic Conditions: building blocks for action' (WHO 2002). According to this report, a health care model that is adapted to chronic conditions is focused on prevention, provides integrated care for a range of conditions, uses health care personnel more effectively, centers care on the patient and the family and supports the patients in their communities.

Whereas successful outcomes for acute health problems can occur with a single health care provider, positive outcomes for chronic conditions can only be achieved when different actors work together (WHO 2002). Optimal management of chronic conditions requires that patients and families, health care teams,

and community supporters combine efforts to achieve continuous care, tailored to the patient’s needs and based on a holistic view of the patient (Ouwens *et al.* 2005).

The ICCC framework uses the idea of a ‘health care triad’, a partnership among patients and families, health care teams and community supporters. It functions at its best when each member is informed, motivated, and prepared to manage chronic conditions, and communicates and collaborates with the other members of the triad at all levels of care. The triad is influenced and supported by the larger health care organization, the broader community, and the policy environment.

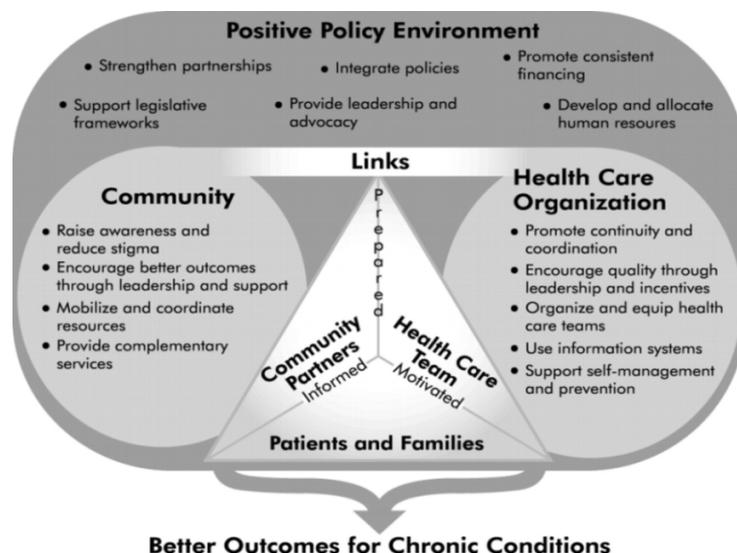


Figure 1 the health care triad.

Source: WHO ICCC report

Integration and patient-centered care are central aspects of innovative care for chronic diseases.

In WHO’s framework, the one follows from the

other, as we can read in the ICCC report: “when the *integration* of the components is optimal, the patient and family *become active participants* in caring for chronic conditions, *supported by* the community and the health care team” (WHO 2002, emphasis added).

Following from what is understood as quality care for chronic conditions, it is clear that primary health care is, in theory, best positioned to address the challenges of chronic disease prevention and management (Beaglehole *et al.* 2008). Chronic diseases in LAMICs also mainly present at the primary health care level (WHO 2002). The renewed international attention for primary health care is thus most welcome, and strengthening primary health care in resource-constrained settings could greatly enhance the delivery of effective, affordable and equitable care for the millions of people living with chronic conditions.

Since primary health care in low-income countries is often provided by nurses working in isolated clinics with limited drugs and equipment, focussing on task shifting and cost-effectiveness is essential when developing management strategies for chronic conditions. More and more examples of care provided by nurses at primary health care level in low-resource settings are being described (Unwin *et al.* 1999; Mamo *et al.* 2007; Gill *et al.* 2008; Kengne *et al.* 2009; Labhardt *et al.* 2010) and it is urgently needed to identify best practices and formulate clear-cut guidelines for policy makers in these settings. In a review of systematic reviews on the delivery of cost-effective interventions in primary health-care, Lewin *et al.* (2008) found several promising health system arrangements and implementation strategies for

strengthening primary health care, but concluded that “the evidence base needs urgently to be strengthened, synthesised and taken into account in policy and practice”. Thorough research on the *cost-effectiveness* of possible strategies is lacking, especially in LAMICs, seriously impeding the translating of these strategies into policy and practice (Lewin *et al.* 2008).

Integrated care: an ill-defined concept

It should be noted that, in the ICCC framework, the concept of integrated care has many different meanings. The one most particular to the management of chronic conditions is integration across disease-boundaries. Chronic diseases place similar demands on the health care system regardless of their cause and comparable management strategies can be used to address them. However, in the WHO report it is emphasized that ‘integration’ does not just refer to the management of different chronic conditions, but also to the integration of each level of the health-care system. As stated in the report: “boundaries among the levels of the system must blur to allow true integration of health care organizations and communities, policies and patients. Patients need integrated care that cuts across time, settings, and providers and patients need self-care skills for managing problems at home. Integration also includes coordinating financing across different arms of health care, including prevention efforts, and incorporating community resources that can leverage overall health care services” (WHO 2002).

These different meanings of “integration” make it difficult to build up knowledge about best practices and cost-effectiveness since many different interventions are labelled as providing ‘integrated care’, making it almost impossible to compare them in a systematic way. In many papers, interventions labelled as ‘integrated care’ actually just refer to the fact that care is provided at primary-health care level (Ouwens *et al.* 2005). With some notable exceptions, there is very little work published on care that is integrated across disease boundaries, despite the coexisting high burden of HIV/AIDS, diabetes and cardiovascular disease in several low-income and middle-income countries (Beaglehole *et al.* 2008). There are some publications on integrated care for diabetes and hypertension (Labhardt *et al.* 2010), but almost none on integrated care for non-communicable and communicable diseases with a chronic course. Janssens *et al.* (2007) reported the experience of the establishment of chronic disease clinics in rural Cambodia, where integrated care was offered for HIV/AIDS, diabetes and hypertension (Janssens *et al.* 2009; Raguenaud *et al.* 2009). They focused on continuity of care, long-term adherence support and social support. The authors reported that adherence-support counsellors, a function that originated for HIV/AIDS care, proved valuable in supporting adherence and lifestyle changes for diabetes as well. This illustrates the opportunity for HIV programmes to both learn from and reinforce other chronic disease programs. In the same line, adaptation of the DOTS tuberculosis programme for chronic disease management has also been advocated (Harries *et al.* 2008; Harries *et al.* 2009).

Diagonal funding

The idea of expanding successes made in the management of one chronic condition to other chronic conditions can also smoothen the artificial dichotomy between vertical and horizontal financing. Efforts in one disease area can strengthen the health system as a whole; thereby improving care for other conditions as well (Ooms *et al.* 2008). Frenk and Sepúlveda have coined the term ‘diagonal funding’, which they describe as “a strategy in which we use explicit intervention priorities to drive the required improvements into the health system, dealing with such generic issues as human resource development, financing, facility planning, drug supply, rational prescription, and quality assurance” (Frenk 2006). Using a diagonal approach is in fact inevitable in the long term, since any vertical approach will at a certain moment hit the ceiling of a dysfunctioning health system with limited supplies, insufficient health workers etc (Ooms *et al.* 2008).

IIIa. Patient-centered care

Since the management of chronic conditions requires lifestyle and daily behaviour change, emphasis must be upon the patient’s central role and responsibility in health care. In the traditional health care model, the focus is on treating the condition, resulting in the provider taking responsibility for care of the problem and consequently taking care of the patient. Patient-centered care implies that the patient is not viewed as a passive recipient of care, but as a partner of the health-care professional in trying to achieve better health. The patient maintains responsibility for his or her health care with help from the provider (Robinson *et al.* 2008). The role of the health care system is to provide patients with the necessary knowledge, skills and motivation to ‘self-manage’ their disease. This can only be done by using a patient-centered approach.

Viewing patients as active partners is especially important in the context of chronic conditions, since patients with these conditions are those that have the most comprehensive expertise in dealing with the condition on a day-to-day basis (Kober & Van Damme 2006). This expertise also makes them the best providers of care. As emphasized by Holman and Lorig (2000), viewing patients as active partners “is not just because patients deserve to be partners in their own health care (which, of course, they do) but also because health care can be delivered more effectively and efficiently if patients are full partners in the process”.

Although uniform definitions of patient-centered care are still lacking the fundamental characters are patient involvement in care and the individualization of care. Effective patient-centered care practices are

communication, shared decision making and patient education. Patient-centered care has been shown to create a positive relationship with the provider, to improve adherence and to lead to better health outcomes. (Robinson *et al.* 2008)

Patients as partners

Patient-centered care has important implications for the role of the health professional and the patient-provider relationship. Assal (1999) has stated that “taking care of a patient with chronic illness implies a profound modification in the physician’s direct relationship with the illness. It becomes necessary to complete this fundamental dimension with another role, quite complex for a doctor, that of *helping the patient manage his treatment on his own*, of guiding him to become independent and responsible” (emphasis added). Medical education in most parts of the world unfortunately does not provide physicians with the necessary skills to take up this supporting role.

Viewing the patient as a partner and equal in the decision-making process touches upon some philosophical issues in medicine concerning paternalism and the role of the physician in protecting the health of their patients. It will be the patient’s preferences, rather than the physician’s, that dictate disease management. This different view on the role of the patient has translated itself into a change in the concepts used when describing patient behaviour in following treatment prescriptions; where previously ‘compliance’ was used, which means merely ‘the extent to which the patient’s behaviour coincides with medical or healthcare advice’ (Sackett & Haynes 1976), we now use ‘adherence’, defined as “the extent to which a person’s behaviour corresponds with *agreed* recommendations from a health care provider” (WHO 2003, emphasis added). For a more detailed discussion of these semantic shifts and their implications for the role of the health care provider, see appendix II.

To effectively assist patients in self-managing diabetes, health care providers will need to understand the process of disease-acceptance patients go through after diagnosis and support them in each phase. They will also need to recognize the importance of health beliefs and accept the fact that patients could set other goals than being perfectly healthy. Disease-management is just one aspect of the lives of people living with a chronic condition and patients may decide that health is not a priority. In a qualitative study on the rhetoric of compliance, one patient said: “do I do everything 100 per cent right and have a miserable time or do I do everything wrong and die of kidney failure in two or three years’ time? It’s a decision that I’m in the process of making now” (Broom & Whittaker 2004).

It is crucial to realise that health is not the same as well-being. For instance, in the case of diabetes, ‘complying’ with the diet can have profound impacts on the patient’s life. Because eating is usually a social event and is always imbued with social meaning, prohibition on rich and sweet foods entail a social loss (Broom & Whittaker 2004). When the pursuit of health conflicts with well-being patients will take

liberties with their diet in order to minimize its impact (Maclean 1991). Another example of this kind of trade-offs patients make is the fact that some patients in low-income countries are not willing to lose weight as part of their treatment package because their friends and family would think they have AIDS. They choose not to follow the proposed treatment because the price, from a social point of view, is too high. Moreover, what is now being considered as 'obese' or 'overweight' has in the past, and is still today, taken as a sign of good health, wealth and vitality.

The most important counter-argument to giving patients equal decision-making power is that it neglects the 'gate-keeping' role of health professionals in minimizing patient harm. Some argue that, no matter how experienced the patient may be, there will always be some knowledge inequality regarding treatment options and their benefits, and that patients should not be given full responsibility over their treatment choice (Kelley 2005). The validity of this argument depends very much on the severity of the disease, the level of understanding of the patient and the relative difference between treatment options. Moreover, the question of who has ultimate responsibility for the well-being of the patient should not be seen as an or/or question, but as and/and. Although there might always be a knowledge gap in terms of biomedical knowledge, it should be emphasized that the knowledge of patients and providers is complementary. Patients have another kind of knowledge, they know how it is like to live with the condition, day by day; what the difficulties are and how to overcome them. The knowledge of both patients and providers should be combined to select the best treatment option. Providers can use their biomedical knowledge to assist patients in making the right choices, in the light of their own goals and health beliefs.

IIIb. Patient empowerment: self-management education

In the case of diabetes, there are numerous behavioural changes that patients must integrate into their daily lives. Self-monitoring of blood glucose levels, medication adherence and adjustments, regular checks for foot problems, and ongoing dietary and physical activity regimens become every day concerns (WHO 2003). In fact, for diabetes, patients and families can be responsible for more than 95 percent of care (WHO 2002). To successfully carry out these tasks, patients need to have acquired the necessary skills and knowledge, have the feeling that they are able to manage their disease (self-efficacy) and feel motivated to do so.

Self-management education is a way to enhance the ability of patients with chronic disease to participate in their health care (Holman & Lorig 2000). Corbin and Strauss have identified three set of self-managing tasks for patients living with a chronic conditions (Corbin & Strauss 1988). The first set of tasks involves the medical management of the condition (i.e. taking medication, adhering to a special diet, ...). The second set involves maintaining, changing and creating new meaningful behaviours or life roles. The final

task requires one to deal with the emotional sequeli of having a chronic condition, which alters one's view of the future. The goal of self-management programs is to provide patients with the necessary skills to adequately fulfil those tasks.

Already in 1999, Lorig *et al.* found in an randomized controlled trial that self-management education led to reduced symptoms, improved physical activity, and significantly less need for medical treatment (Lorig *et al.* 1999a). Since then, a growing body of evidence has been produced supporting that self-management programmes have positive effects on patients' attitudes, self-management behaviour, glycaemic control and the overall quality of life (Bastiaens *et al.* 2009). When self-management and adherence programmes are combined with regular treatment and disease-specific education, significant improvements in health-promoting behaviours, cognitive symptom management, communication and disability management have been observed. In addition, such programmes appear to result in a reduction in the number of patients being hospitalized, days in hospital and outpatient visits (WHO 2003).

Although results so far are promising, a lot of questions remain. Interventions are often not described in enough detail, making comparison and reproduction difficult. This also makes it difficult to ascertain which part of the intervention led to improvements and to understand why patients did or did not change their behaviour during and after the intervention. It is still not entirely clear how self-management leads to improved outcomes (Lorig & Holman 2003). One would expect that changes in behaviour lead to changes in health status, but Lorig *et al.* have found that the association between improvement in healthful behaviour and improvement in health status are weak to nonexistent (Lorig *et al.* 1989). Interestingly, they did find an association between changes in self-efficacy and health status (Lorig *et al.* 1999b), suggesting that "enhanced self-efficacy is at least one of the mechanisms responsible for the improvements in health status demonstrated by those attending self-management programs" (Lorig & Holman 2003). This again points to the importance of patients' beliefs and feelings in the context of chronic conditions.

Secondly, research has been conducted in very diverse health care settings, often with no clear description of the actual context (Bastiaens *et al.* 2009). This makes it difficult to decide whether the intervention could be applicable elsewhere and, if not, in what way it should be adapted. This is particularly important when working in low-resource settings, since most of the available evidence comes from research done in high-income countries. Research available from low-resource settings is often performed in hospital-settings (Acheampong *et al.* 2000; Windus *et al.* 2007) or does not include measurement of glycaemic outcome (Mamo *et al.* 2007).

Finally, follow-up is seldom longer than 12 months, while it is necessary to assess the long-term effects of educational interventions because of the theoretical possibility of a "wear-off" effect. In a RCT for

empowerment-based education for type 2 diabetes patients, Cooper *et al.* (2008) found improvements in HbA1c and BMI after 6 months follow-up, but this was not sustained till 12 months. Self-reported illness attitude and self-monitoring however, did show improvements both at 6 and 12 months follow-up. The same trend was observed in a before-after study consisting of an empowerment-based education program performed by Bastiaens *et al.* (2009), where HbA1c and BMI fell from 7.4% and 29.0 to 6.8% and 28.5 respectively at 12 months follow-up, but rose to 7.3% and 28.8 at 18 months follow-up. Although this could be interpreted as a “wear-off” effect or “educational fatigue”, it should be noted that diabetes type 2 naturally deteriorates over time, something which only comes up in long-term studies. Steady deterioration in HbA1c with time in type 2 diabetes was clearly demonstrated in the United Kingdom Prospective Diabetes Study, and was found in both the intensively treated and control groups (UKPDS Group 1998a).

Recently, a single-centered cohort study of a nurse-led diabetes care program in rural South-Africa, consisting of empowerment-based education and treatment with oral hypoglycaemic agents when necessary, was done with a follow-up of 4 years (Price *et al.* 2011). In the cohort of 80 patients, HbA1c declined till 18 months (from 10.8% at baseline to 7.5%) and then rose to 9.7% 4-years post-intervention, which was still a significant improvement compared to baseline. A subgroup analysis of a cohort of patients who had no drug manipulations (only education) also showed a significant drop in HbA1c. Interestingly, data from the UKPDS study would have predicted a 0.7% deterioration in HbA1c after 4 years, making the observed drop in 1.1% an important achievement. This research is not only valuable because of its long-term follow-up, but also because it was done in a low-resource setting and care was provided by nurses. The authors stated that their study “is the only long-term outcome study of structured diabetes management in rural Africa using objective glycaemic outcomes”. More long-term follow-up studies of educational interventions in LAMICs would be most welcome indeed.

IIIc. Patients as health care providers: peer-education

Because of the shortage of human resources for health in many LAMICs, more efficient use of health care personnel is urgently needed. One option is to use non-physician clinicians, such as nurses or pharmacists. As mentioned previously, more and more examples of care for chronic conditions provided by nurses at primary health care level in low-resource settings are being described, the study done by Price *et al.* being particularly noteworthy. Care provided by non-physician clinicians however, is often still provided at health care facilities, potentially leading to problems of low retention because of distance to the facility. For instance, Geng *et al.* (2010) found that lack of transportation and distance to clinic were the most common reasons for loss to follow-up in Ugandan HIV/AIDS patients. These

structural barriers could be removed by providing care in the community, as suggested by the authors: “alternative models to delivering care such as more dispersed satellite clinics or home-based programs are needed to ensure continuous care”.

Indeed, making use of community resources by training volunteers or using ‘expert patients/peer-educators’ is another way to address the shortage of human resources in LAMICs. Communities can fill crucial gaps in health services that are not provided by organized health care (WHO 2002). Besides leveraging the human resource crisis, using patients in the provision of care empowers them and increases patient-centeredness. Strengthening patients and giving them the opportunity to help each other in dealing with their condition, assisted by the formal health-care system, is what patient-centeredness is all about.

In addition, care provided by patients has the potential of being of better quality than care provided by health professionals, since people living with a chronic condition are those that have the most comprehensive expertise in dealing with that condition (Kober & Van Damme 2006). Peer support can offer the kind of emotional, social and practical assistance for how to achieve and sustain complex behaviours that are critical for managing chronic conditions and staying healthy (Dennis 2003). Indeed, Lorig *et al.* have found from several studies that “peers, when well trained and given a detailed protocol, teach at least as well as health professionals and possibly better” (Lorig & Holman 2003). In fact, the most famous self-management program, the Chronic Disease Self-Management Programme (CDSMP), is lay-led.

Research to date indicates that peer support could be a promising approach for diabetes management (WHO 2008b), but more research is urgently needed. Foster *et al.* (2007) conducted a systematic review of RCTs comparing structured lay-led self-management education programmes for chronic conditions against no intervention or clinician-led programmes. Seventeen trials involving 7442 participants were involved. The interventions shared similar structures and components but studies showed heterogeneity in conditions studied, outcomes collected and effects. Only one study provided data on outcomes beyond six months, and only two studies reported clinical outcomes. They concluded that lay-led self-management education programmes may lead to small, short-term improvements in participants’ self-efficacy, self-rated health, cognitive symptom management and frequency of aerobic exercise. However, they also stated that there is insufficient evidence to suggest that these programmes improve psychological health, symptoms or health-related quality of life, or that they significantly alter health-care use.

With some notable exceptions (Dongbo *et al.* 2003), most evidence on peer support interventions has been generated from high-income, Anglo-Saxon countries (WHO 2008b). Some of the intervention focussed on migrant populations, generating more culturally acceptable variations of existing programs (Uitewaal *et al.* 2004; Choudhury *et al.* 2008; Philis-Tsimikas *et al.* 2011). In a recent RCT, Philis-

Tsimikas *et al.* (2011) evaluated the effect of a culturally sensitive diabetes self-management education program on glucose control and metabolic parameters in low-income Mexican Americans with type 2 diabetes. A total of 207 Mexican-American patients with HbA1c >8% were randomly assigned to the peer intervention or continuation of standard diabetes care. HbA1c improved significantly in the intervention group from baseline to 10 months follow-up, while no significant changes were noted in the control group.

Generalization of conclusions to low- and middle-income countries should be made with caution though. Further research is urgently needed, especially in low-resource settings with long-term follow up and assessment of clinical outcomes.

IV. MoPoTsyo Patient Information Centre

MoPoTsyo is a Cambodian NGO established in 2004 to help people living with diabetes and hypertension¹ to self-manage their condition by engaging a peer educator in their own community. It aims to create *empowered patient networks*, each consisting of 500 to 1000 registered members organised around a team of peer educators. Peer educators provide community members living with diabetes and/or hypertension with reliable information and basic skills. The focus is on self-measurement of glucose levels and adaptation of life style, including nutrition and daily exercise.

A small salaried staff is employed by the NGO to establish and support the semi-autonomous peer-education networks to identify and train new peer educators. The networks organise themselves under a Diabetes Programme Manager (DPM), appointed jointly by MoPoTsyo and the local health authority. The peer educators, who receive six weeks formal training, have themselves recently recovered from years of serious illness and gain the trust of their communities because they can relate personal experience of the effects of poor glycaemic control. Their recovery also leads them to gain credibility. After accreditation, they qualify for basic equipment and supplies, based on reported activities, and are allowed to identify their home as a 'Patient Information Centre' for weekly patient gatherings and education sessions.

Newly qualified educators will screen their community for diabetes. Initial screening is based on adults self-testing with urine strips. The educator counsels those with positive strips and confirms their result using a blood glucose meter. The critical levels used by the NGO are: FBG ≥ 126 mg and/or PPBG ≥ 180 mg. Peer educators are also trained to take a simple patient history using a form which records items including the measurements of FBG, PPBG, BP, urine glucose, weight, and height. Screening will start

¹ Because our research was focused on diabetes patients (with or without hypertension), we will refer to diabetes only in the rest of the text, but it should be noted that everything applies to both diabetes and hypertension patients

within the peer educator's village and be extended over a period of 1 to 2 years to cover an area designated by MoPoTsyo in agreement with local health authorities.

Newly detected diabetics can only become registered members after approval from the DPM, who oversees all peer educators in the health district. The patient's record is then included in a database for follow-up by the peer educator, monthly reporting by the DPM to the health authorities and entry into the local network's own Khmer Open Source database.

New patients have to attend six classes at the home of their peer educator. At the moment, the content of the sessions is mostly destined for new patients who need to learn the basics about diabetes, and cover information about physiopathology, symptoms, long-term complications, lifestyle and medicines and their side-effects. The sessions are however attended by a mix of old and new patients. Patients are encouraged to stop smoking, become more physically active, and to either change or maintain weight. Peer educators discuss nutrition issues using the MoPoTsyo food pyramid which is based on a Glycaemic Index (GI) of locally available food items. Every patient receives a copy. Patients are provided with urine glucose strips each month and are encouraged to use these within three hours of eating to detect after meal glucose peaks. This relatively simple self-testing procedure is easily learned and reasonably reliable provided that kidney function has not deteriorated. Patients are also asked to perform a 24 hour urine test twice a month. All test results are recorded in their self-management book.

If lifestyle changes produce insufficient results within a few months, or sooner if warranted by the patient's condition, peer educators assist patients to obtain an appointment with a specially trained Medical Doctor (MD). This MD is contracted by MoPoTsyo to hold consultations at the local public hospital once per week to initiate or change medical treatments for diabetics. The MD prescribes from a limited list of 20 medicines including insulin, though this is rarely considered appropriate. These medicines are sold to registered patients at a published fixed price by a pharmacy contracted by MoPoTsyo. Initial consultation costs are met by MoPoTsyo's Health Equity Fund. Thereafter, this Fund is available only to the very poor, about 10% of patients, and limited to the cheapest available prescription options. MoPoTsyo will financially assist a patient to buy insulin if glucose levels cannot be normalized by other means.

In May 2011, 3078 people with diabetes were registered with MoPoTsyo. There are 63 patient information centres of which 5 in urban slums. The first rural Diabetes Network started in June 2007 in Ang Roka Operational District in Takeo province. From June 2007 to December 2008, peer educators in the rural areas reached more than 80% of the adult population, with 53,839 using a urine glucose strip after a meal. Of those testing positive, 474 were confirmed as diabetic following a further blood glucose test and all registered with MoPoTsyo. 67% had previously been unaware of the cause of their ill-health.

The retention rate of patients was very high, with only 11% LTFU, of which 3% died, 4% left the area and 4% lost interest (MoPoTsyo, unpublished data).

METHOD

We performed both quantitative and qualitative research in the first rural district where the NGO started working in June 2007 (Ang Roka Operational District, Takeo Province). This district is divided into 10 health centers, each of which is covered by one peer educator. The Health Centre coverage areas, here indicated with codes ARA, ARB, ARC, ..., ARJ. For the quantitative part of the research, we performed a before and after study, comparing health status at baseline with health at time of assessment. To assess long-term impact of the program, only patients in the program for at least two years were included in the research. The patients from ARC were excluded from the quantitative analysis because they didn't have a peer-educator since July 2009. Many of these patients would have been difficult to reach so their group would have been too small in terms of statistical power to serve as some kind of quantitative control group. However, some patients from ARC were included in the qualitative part of the research because they had the unique ability to compare living with and without the assistance of a Peer Educator. There were no other inclusion- or exclusion criteria. From the total of 204 patients that were at least 2 years in the program as of July 2010 and still had a peer educator, a random sample of 150 patients was selected and contacted for participation.

The research consisted of the administration of a structured questionnaire, the collection of a blood sample for laboratory analysis and a short clinical examination. For logistical and organisational reasons, the research was done when MoPoTsyo carried out their 6-monthly assessment. In this assessment the patients come to a central point close to a health center or the house of the peer-educator early in the morning for a short clinical examination and collection of a blood sample. The blood sample is centrifuged immediately and kept in ice, and is transferred to the laboratory when the assessment is finished. During the examination BP, weight, height, pulse and abdominal circumference is measured and written in the patient booklet. Patients unable to travel were visited in their home during the afternoon, so FBG data for these patients are lacking. After finishing the MoPoTsyo assessment, the patients included in our sample were given information about our research and asked oral consent for participation and access to their data in the MoPoTsyo database (see appendix III for the information sheet).

The questioning was done by a team of peer educators from the urban slums, unknown to the patients in the rural areas. The questionnaire was prepared by the researchers on the basis of literature review and subsequently translated in the local language. Upon arrival in Cambodia, the questionnaire was extensively discussed with the team of peer educators to make adjustments in order to improve the cultural sensitivity of the questions.

The questionnaire assessed the relative change in their situation the patients experienced since they joined to program. A visual analog scale was used to depicture the change, ranging from 0 (much worse) to 4 (much better). For the questionnaire, see appendix IV. In the questionnaires three main themes were explored: health, ability to control the disease and adherence. These were subdivided into different aspects. Under 'health', we placed (1) general wellbeing, (2) psychological wellbeing, (3) physical wellbeing, (4) ability to perform activities of daily life and (5) health care resource usage. The 'ability to control' was composed of (1) the feeling of being able to control their condition (self-efficacy), (2) self-management, (3) disease-related knowledge, (4) attitudes towards the disease and (5) disease-related expenditure. Finally for 'adherence', we looked at (1) adherence to medication, adherence to lifestyle adjustments ((2) diet and (3) exercise) and (4) the number of times they check their feet for ulcera.

The data were entered into a database and made anonymous. For baseline data, the database of the NGO was consulted. The statistical analysis was done using SPSS Statistics 19. For statistical significance, p values < 0.05 were regarded as significant. We determined the proportion of the patients who met the recommended targets for FBG, BP and BMI at baseline and at assessment and assessed significance levels by a McNemar test. We used the recommended glycemia (FBG < 110 mg/dl) and BP targets (130/80) for type 2 diabetic patients proposed by the Asian Pacific type 2 diabetes policy group. For BMI, we referred to the WHO cut-off points for Asian populations: 23 to 27.5 kg/m² (defined in the study as overweight) and 27.5 kg/m² or above (defined in the study as obese). Paired-sample T -test was used to calculate levels of changes in mean FBG, while for BMI and BP Wilcoxon signed ranks 2-tailed test was used because these variables did not follow a normal distribution. A logistic regression model was used to assess the following potential risk factors for not reaching treatment targets for FBG, SBP and BMI: age, sex and baseline FBG, BMI and BP. DBP was left out of the regression model because it usually follows SBP.

We calculated a compound score for health, control and adherence. Health and control have a maximum score of 20 while for adherence the maximum is 16. We created a subgroup for adherence that concerns the patients that do not take medicines because they can control their diabetes by lifestyle adjustments ($n = 11$). For them, the question on adherence to medicines is left out and the compound score on adherence has a maximum of 12. Median scores were compared to a hypothetical 'no-change score' (10/20 for health and control; 8/16 for adherence to medication and lifestyle adjustments and 6/12 for adherence to

lifestyle adjustments only) by using a one sample-Wilcoxon-test. We assessed the correlation between these different scores and the correlation between the scores and measured health outcomes, using Spearman correlation.

Qualitative research was used to gain a better understanding of how joining the NGO influenced the lives of the patients, what problems they encountered in trying to control the disease and the role the peers have played in solving them. For this, we performed in-depth interviews in a purposive sample of 14 patients and 3 peer educators, taken out of all patients in the program in Ang Roka District. Patients were selected in consultation with the peer-educators and visited in their homes by the researcher. The interviews were conducted by the main researcher, with the help of an interpreter (not affiliated to the NGO). The interviews were recorded and subsequently written down and translated to English by the interpreter. Patients were asked oral consent before participation (see appendix V). For the analysis, Atlas-ti was used.

RESULTS - Quantitative Analysis

I. Characteristics of study participants and cohort outcomes

A total of 226 diabetic patients were in the program for at least two years in July 2010, of which 22 were excluded because they did not have a peer since 2009. Of the random sample of 150 patients, 7 refused to participate, 2 did not show up for assessment, 6 had moved, 1 had died and 134 patients completed our questionnaire (FIG 2). Patient characteristics are presented in Table 1. Patients were predominantly women (73.7%) and 64.9% were ≥ 50 years old. The median time in the program at the time of assessments was 29 months. When entering the program, 12.7% of patients were underweight, 36.6% were overweight and 12.7% were obese. The median FBG and SBP when joining MoPoTsyo were 170 mg/dl and 132mmHg respectively. Only 2 patients were taking insulin at the time of assessment.

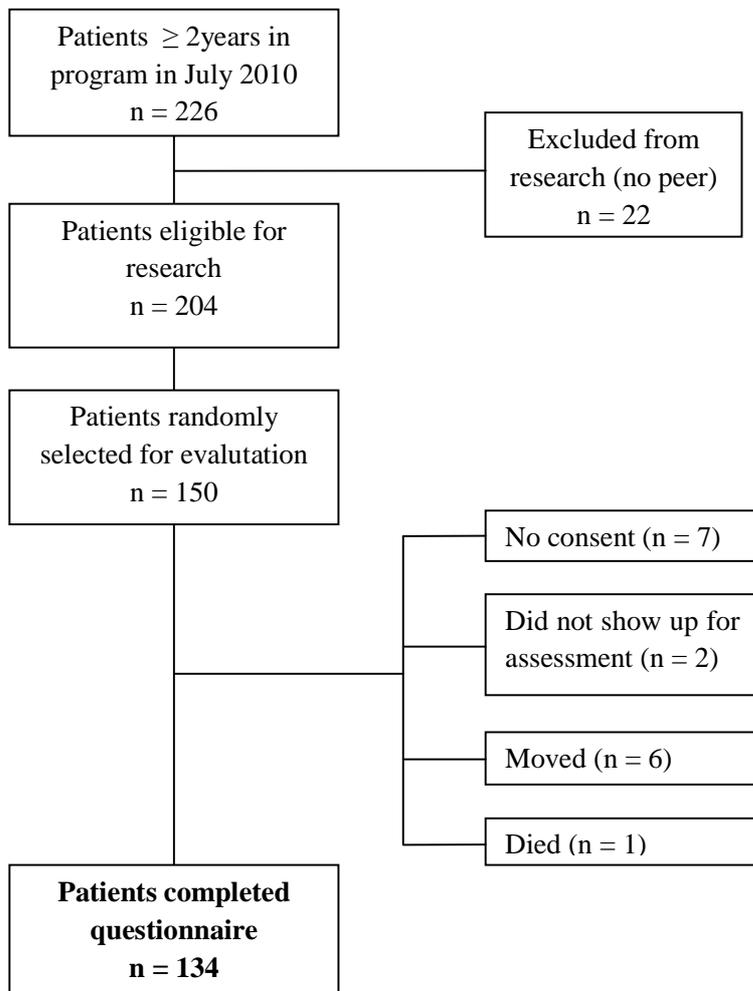


Figure 2 Flow chart

Table 1 Characteristics of patients included in the evaluation

Characteristic	Value
Total number of patients	134
Health Center, n (%) :	
ARA	5 (3.7%)
ARB	18 (13.4%)
ARD	15 (11.2%)
ARE	9 (6.7%)
ARF	3 (2.2%)
ARG	18 (13.4%)
ARH	27 (20.1%)
ARI	17 (12.7%)
ARJ	22 (16.4%)
Months in the program, median (IQR)	29 (26 to 33.25)
Age in years (n = 127), median (IQR)	54 (45 to 61)
Age group in years, n (%) :	
≤ 39	13 (9.7%)
40 to 49	33 (24.6%)
50 to 59	44 (32.8%)
60 to 69	29 (21.6%)
≥ 70	8 (6.0%)
Women, n (%)	98 (73.7%)
FBG on admission (n = 125), median (IQR)	170 (144 to 217)
BP on admission :	
Systolic BP (n = 133), median (IQR)	132 (120 to 142)
Diastolic BP (n = 133), median (IQR)	82 (75 to 95)
BMI on admission, kg/m ² , median (IQR) :	
All (n = 132)	22.9 (20.8 to 25.4)
Male (n = 34)	22.7 (19.5 to 25.5)
Female (n = 97)	23.2 (21.2 to 25.4)
Underweight (BMI ≤ 23), n (%)	17 (12.7%)
Overweight (BMI ≥ 23), n (%)	49 (36.6%)
Obese (BMI ≥ 27.5), n (%)	17 (12.7%)
Insulin, n (%)	2 (1.5%)

BMI = body mass index ; IQR = interquartile range

II. Patients reaching recommended treatment target for FBG, BP and BMI (table 2)

The proportion of patients reaching treatment target for FBG, systolic and diastolic BP rose significantly from 10.2%, 46.5% and 44.2% at baseline to 33.9%, 65.9% and 62.8% at the time of assessment respectively ($p < .001$). For BMI, there was a very small non-significant change in the proportion of patients reaching treatment target at baseline (50.0%) and at assessment (49.2%) ($p = 1.000$).

Table 2: Number and proportion of patients reaching treatment target for FBG, SBP and BMI at baseline and at assessment (FBG <110 mg/dl; BP <130/80; BMI 23-27.5 kg/m²)

		FBG at assessment		
		reached target n (%)	did not reach target n(%)	total
FBG at baseline	reached target n (%)	8 (6.8%)	4 (3.4%)	12 (10.2%)*
	did not reach target n (%)	32 (27.1%)	74 (62.7%)	106 (89.9%)
	total	40 (33.9%)*	78 (66.1%)	118 (100%)

* McNemar test p < .001

		SBP at assessment		
		reached target n(%)	did not reach target n(%)	Total
SBP at Baseline	reached target n (%)	48 (37.2%)	12 (9.3%)	60 (46.5%)*
	did not reach target (%)	37 (28.7%)	32 (24.8%)	69 (53.5%)
	total	85 (65.9%)*	44 (34.1%)	129 (100%)

* McNemar test p < .001

		DBP at assessment		
		reached target n (%)	did not reach target n(%)	total
DBP at baseline	reached target n (%)	43 (33.3%)	14 (10.9%)	57 (44.2%)*
	did not reach target n (%)	38 (29.5%)	34 (26.4%)	72 (55.8%)
	total	81 (62.8%)*	48 (37.2%)	129 (100%)

* McNemar test p = .001

		BMI at assessment		
		reached target n (%)	did not reach target n(%)	total
BMI at baseline	reached target n (%)	55 (41.7%)	11 (8.3%)	66 (50.0%) ^o
	did not reach target n (%)	10 (7.6%)	56 (42.4%)	66 (50.0%)
	total	65 (49.2%) ^o	67 (50.8%)	132 (100%)

^o McNemar test p = 1.000

III. Improvement of mean FBG, BMI and BP from baseline (table 3)

There was a significant drop in mean FBG from 180.5 mg/dl at baseline to 138.4 mg/dl at the time of assessment ($p < .001$). Likewise, the systolic and diastolic BP dropped from 134 mmHg and 84 mmHg to 124 mmHg and 77 mmHg respectively ($p < .001$). The BMI of the patients did not change significantly, from 23 at baseline to 22.8 at assessment ($p = 0.160$).

Table 3 Improvement of FBG, BMI and BP from baseline

	Mean value at baseline	Mean value at assessment	Mean difference	95% CI	Student T-test	
FBG (mg/dl) n = 118	180.5	138.4	- 42.06	[-54.09; - 30.03]	$p < .001$	
	Mean value at baseline	Mean value at assessment	Negative ranks *	Positive ranks *	Ties	Wilcoxon
BMI (kg/m ²) n = 131	23	22.8	48	68	16	$p = .160$
SBP (mmHg) n = 129	134	124	37	89	3	$p < .001$
DBP (mmHg) n = 129	84	77	35	89	5	$p < .001$
* Negative rank: value at baseline < value at assessment Positive rank: value at baseline > value at assessment						

IV. Risk factors for not reaching treatment target for FBG, BMI and SBP (table 4)

We performed a logistic regression analysis to identify risk factors associated with not reaching treatment targets for FBG, BMI and SBP (table 4). For each of these outcomes, a higher value of the outcome at baseline was significantly associated with not reaching treatment targets, even when adjusted for the other variables in the model. Older age (≥ 50 years) in itself was significantly associated with not reaching treatment target for SBP ($p = .038$), but not after adjusting for sex, baseline FBG, BMI and SBP ($p = .107$). Younger age (< 50 years) was significantly associated with not reaching treatment target for FBG ($p = .034$), and even more when put into the multivariate model ($p = .016$).

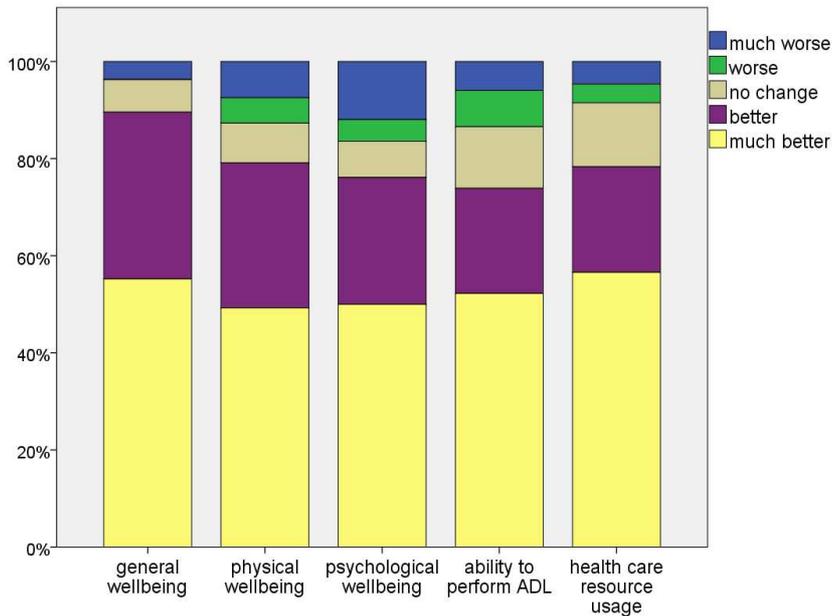
Table 4: Risk factors for not reaching treatment target for FBG, BMI and BP

Factors	Patients not reaching target/ total of patients	OR	95% CI	P-value	aOR	95% CI	P-value
Systolic BP (113 cases included in the multivariate model)							
Sex (n = 129)							
Male	13/33 (39.4)	1					
Female	31/96 (32.3)	0.73	[0.32 – 1.66]	.459	0.73	[0.29 – 1.90]	.526
Age (n = 123)							
< 50	10/46 (21.7)	1					
≥ 50	31/77 (40.3)	2.43	[1.05 - 5.60]	.038*	2.15	[0.85 – 5.46]	.107
FBG at baseline (n = 121)	n/a	1.004	[1.00 – 1.01]	.216	1.01	[1.00 – 1.01]	.131
BMI at baseline (n = 130)							
< 23	20/65 (30.8)	1					
≥ 23	24/65 (36.9)	1.38	[0.64 – 2.73]	.459	2.09	[0.89 – 4.94]	.092
SBP at baseline (n = 129)							
< 130	12/60 (20.0)	1					
≥ 130	32/69 (46.4)	3.46	[1.57 – 7.62]	.002*	2.78	[1.19 – 6.52]	.018*
FBG (109 cases included in the multivariate model)							
Sex (n = 126)							
Male	19/34 (55.9)	1					
Female	63/92 (68.5)	1.72	[0.77 – 3.85]	.190	0.91	[0.36 – 2.35]	.852
Age (n = 120)							
< 50	34/45 (75.6)	1					
≥ 50	42/75 (56.0)	0.41	[0.18 – 0.93]	.034*	0.29	[0.11 – 0.80]	.016*
FBG at baseline (n = 118)	n/a	1.01	[1.00 – 1.02]	.032*	1.01	[1.00 – 1.02]	.045*
BMI at baseline (n = 126)							
< 23	37/63 (58.7)	1					
≥ 23	45/63 (71.4)	1.76	[0.84 – 3.69]	.137	1.04	[0.43 – 2.47]	.939
SBP at baseline (n = 126)							
< 130	40/61 (65.6)	1					
≥ 130	42/65 (64.6)	0.96	[0.46 – 2.00]	.910	0.86	[0.37 – 2.00]	.727
BMI (116 cases included in the multivariate model)							
Sex (n = 131)							
Male	17/34 (50.0)	1					
Female	50/97 (51.5)	1.06	[0.49 – 2.32]	.877	0.70	[0.21 – 2.31]	.558
Age (n = 125)							
< 50	27/46 (58.7)	1					
≥ 50	35/79 (44.3)	0.56	[0.27 – 1.17]	.122	1.049	[0.35 – 3.17]	.933
FBG at baseline (n = 123)	n/a	1.00	[1.00 – 1.01]	.211	1.01	[1.00 – 1.02]	.084
BMI at baseline (n = 132)							
< 23	11/66 (16.7)	1					
≥ 23	56/66 (84.8)	28	[11.01 – 71.23]	<.001*	35.51	[11.61 – 108.61]	<.001*
SBP at baseline (n = 131)							
< 130	33/62 (53.2)	1					
≥ 130	34/69 (49.3)	0.854	[0.43 – 1.70]	.652	0.70	[0.25 – 1.98]	.506

* p values <.05

V. Patients-reported improvement in health, ability to control the condition and adherence

Figure 3 Self-reported improvement in health



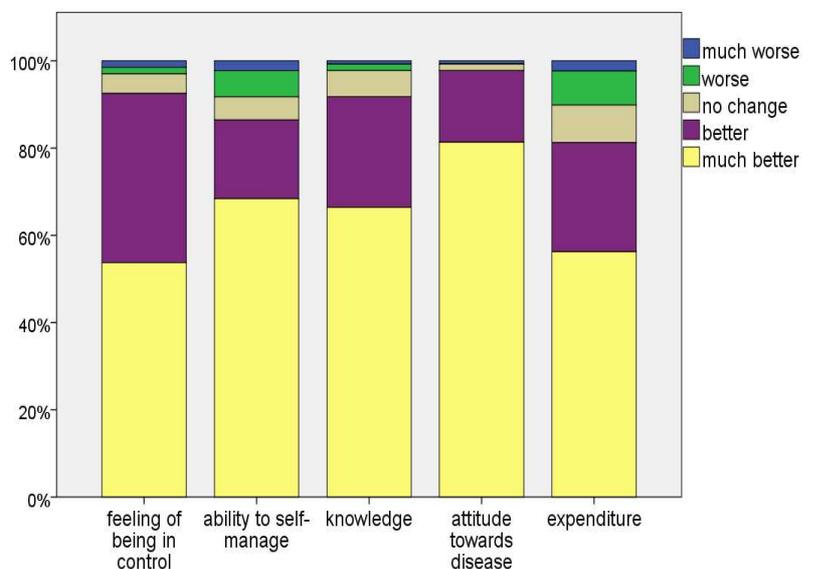
More than two-thirds of patients reported improvement (better or much better) in terms of health (FIG 3), control (FIG 4) and adherence (FIG 5)

The cumulative percentage of patients reporting improvement ('better' or 'much better') for health-related questions were 89.5% for general wellbeing, 79.2% for physical wellbeing, 76.1% for psychological wellbeing, 73.8% for ability to perform activities of daily

life and 75.4% for health care resource usage respectively. Psychological wellbeing was the outcome with most reported negative evolution, with 16.4% of patients feeling 'a bit' or 'much more' sad or anxious than before. This concurs with the findings in the qualitative part of the research, where patients reported feeling much better physically but having worries about the future because they realized they would have to take medicines for the rest of their lives and were not sure they would have the financial capacity do to so.

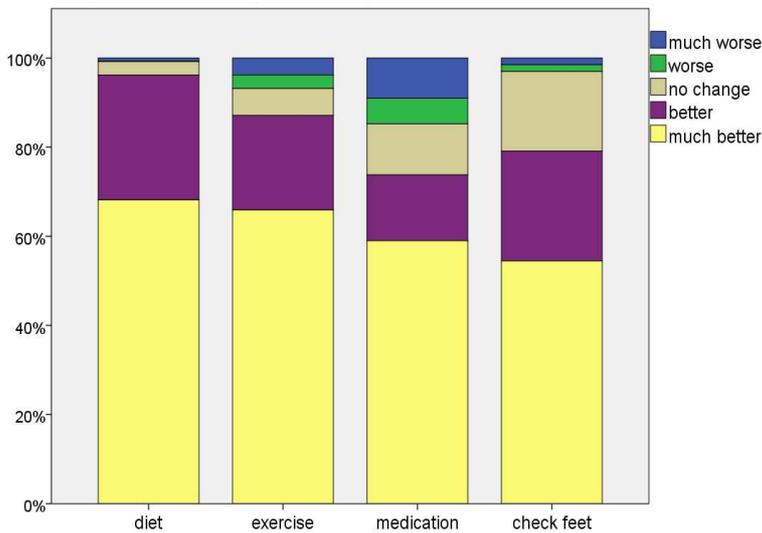
Even more patients reported improvement ('better' or 'much better') for questions concerning a feeling of being able to control their disease. The cumulative percentage of patients reporting improvement ('better' or 'much better') for control-related questions were 92.5% for self-efficacy, 86.4% for ability to self-manage, 91.8% for disease-related knowledge, 97.7% for attitude towards disease and 81.3% for disease-related expenditure respectively. Patients in the in-depth interviews similarly emphasized their

Figure 4 Self-reported improvement in ability to control the disease



increase in knowledge after joining MoPoTsyo and their ability to control their disease simply because of knowing what is wrong and what they can do.

Figure 5 Self-reported improvement in adherence



As for adherence, a total of 94.8% of patients reported to eat ‘a bit’ or ‘much more’ healthy than before they had joined the program; while 67.1% of patients on medication indicated to take their medication ‘a bit’ or ‘much more’ regularly. However, when asked more detailed questions, it became clear that many patients faced problems with following the diet, as discussed in the qualitative part. Exercise is somewhere in between (85.5% reporting ‘better’ or ‘much better’). The lower score than for diet could be explained by the fact that some patients are too busy to do exercise or are unable because of comorbidity, mostly joint pain.

VI. Compound score for health, ability to control the condition and adherence (table 5)

The compound score again shows that patients reported a general improvement in their health (median score 17/20), ability to control the condition (median score 18/20) and adherence (median score 14/16 for patients on medication, and 12/12 for patients on lifestyle adjustments only). These median scores are significantly higher than what would be expected if their situation in general had not changed (health $p < .001$, control $p < .001$, adherence med $p < .001$, adherence lifestyle $p = .002$). It also shows that the minimum score for health (3/20) is much lower than the minimum score for the ability to control the condition (10/20). However, the number of patients with such a low health score is low, since the first quartile is at 13/20. The low score could be because of co-morbidity or because of inability to buy medicines due to financial problems.

Table 5: Compound score for health (/20), ability to control (/20), adherence for patients on medication (/16) and adherence for patients on lifestyle adjustments only (/12)

	Health score (n = 129)	Control score (n = 127)	Adherence score (med) (n = 120)	Adherence score (lifestyle) (n = 11)
Mean	15,64	17,35	13,31	11,73
Median	17	18	14	12
Minimum	3	10	5	10
Maximum	20	20	16	12
Q1	13	16	12	12
Q3	20	20	16	12

VII. Associations between compound scores and between health score and health outcome

There was a significant association between self-reported improvement in health and self-reported adherence to medicine ($r_s = .639$; $p < .001$), as well as with the feeling of being able to control the disease ($r_s = .654$; $p < .001$). We found no significant association between self-reported improvement in health and self-reported adherence to lifestyle adjustments ($r_s = .139$; $p = .793$). These were only a few patients though ($n=11$), with high scores on both adherence and health. In addition, there was a significant association between feeling of being able to control the disease and self-reported adherence to medication ($r_s = .628$; $p < .001$), but again not with adherence to lifestyle adjustments ($r_s = .875$; $p = .052$).

As for the relation between self-reported improvements and actual health outcomes, there was a significant association only between total health score and difference in FBG between baseline and assessment² ($r = - .220$; $p = .019$). We found no significant association between health score and BP or BMI, or between the other scores and the measured health outcomes.

² We calculated the difference in FBG as the value at assessment minus the value at baseline, resulting in negative values for patients with a drop in FBG. The association is therefore negative, the higher the health score, the lower (i.e. more negative) the difference in FBG (and thus the higher the drop from baseline).

RESULTS - Qualitative Analysis

I. Symptoms before joining MoPoTsyo

While most patients in high-income countries get diagnosed with diabetes type 2 before they have any symptoms; all patients interviewed indicated they had some kind of problem before joining MoPoTsyo. Most mentioned were being tired and thirsty, frequent miction, losing weight, bad wound-healing and unclear sight. As illustrated by the testimony of one of the patients:

I always urinated, I didn't sleep before I joined MoPoTsyo and I didn't know diabetes. Before I was very thin and had to go to the toilet very often. It was serious and I just wanted to sleep. I stayed in one place, I didn't know what to do. (P1: female, diabetes, insulin)

II. Finding out they had diabetes and joining MoPoTsyo

Peer educators should go around their village to inform people about diabetes and hypertension and perform urine test to see if anyone suffers from diabetes. Many patients indeed indicated that the peer came to their house to do the test. Others however, got into contact with the peer in many different ways, indicating that, by the presence of the NGO, the symptoms of diabetes got known in the community and people knew the role of the peer educator and actively looked for him/her when they wanted to be tested.

One patient for example, diagnosed herself by tasting her urine and subsequently went to the peer educator. The word diabetes in Khmer is 'sweet/sugar urine', and it is known for ages that it can be diagnosed by the observation that ants and insects rush to this type of urine, or simply by tasting it (Frank 1957).

I tasted it [my urine]. It was sweet so I went to meet the pair educator for this disease. I was worried, so I went to check my urine by this other person who had diabetes (P1: female, diabetes, insulin)

Another patient told us he was forced by his children to go to see the peer educator because they wondered he had diabetes. His children were well educated and were working in the NGO-sector so they knew about the existence of MoPoTsyo and what they did.

While I was going to the farm I fell from the bridge and my wound did not recover. It was not easy to cure and my wound got worse. My family wondered I was ill so they brought me to Calmette Hospital, but they didn't see the diabetes. After that, I got thinner and thinner. Then my children forced me to meet the peer educator because they wondered I had diabetes. When I went to MoPoTsyo the peer checked my blood sugar (P2: male, diabetes and hypertension, oral medication)

Two patients said they went to the peer because they recognized their own symptoms as possibly resulting from diabetes, one of them because his/her sister has diabetes too.

I know MoPoTsyo by phone. I called the peer educator and asked to check my blood. My sister used to have diabetes and my hands and legs were swollen. It was the same as my sister's disease (P13: male, diabetes and hypertension, new patient)

Before I joined MoPoTsyo I always went to another doctor and I spend a lot of money (...) I went to Antasom and Takeo Hospital, but the doctor never tested me for diabetes. And then I thought I might have diabetes so I went to meet the peer educator and had the blood test (...) I knew about the symptoms of diabetes such as unclear eyesight, tired and no energy; so that's why I went to see the peer educator (P4: female, diabetes, oral medication)

Interestingly, one patient was referred to the peer educator by the doctor at Ang Roka Hospital after being diagnosed. Education on chronic conditions is currently lacking in the medical curriculum in Cambodia, so most doctors do not test for diabetes and would never give patients advice on lifestyle adjustments, as illustrated by the experiences patients had with the health care system before they joined MoPoTsyo. This case shows that the existence of MoPoTsyo does not only increase the awareness of diabetes at community level but also amongst health care providers.

Before I was very tired and thirsty and I always urinated. The doctor at Ang Roka checked my sugar and said to me I have diabetes. He told me to diet, don't eat sweet and told me to meet the peer Mr. Now who lives close to me (P5: female, diabetes, insulin)

Another patient was called by the chief of the village after being diagnosed by the doctor at Ang Roka.

The doctor at Ang Roka Hospital told me I have diabetes, but he said only I had to take medicine. He did not tell me about diet and exercise. I bought medicine from Ang Roka pharmacy. It is a bit expensive, I spend 10,000 riel per week. (...) Then the chief of village called me and told me to go to the peer educator's house (P6: female, diabetes and hypertension, oral medication, no peer since 2009)

III. Encounters with the health-care system before joining MoPoTsyo

With the exception of the doctor that referred his patient to MoPoTsyo, most doctors did not tell patients they had diabetes and did not give them any advice on diet and exercise. Patients had similar experience as the patients previously questioned by Men (2007), telling that the doctor did not communicate and just gave them medicine, and that they had spend a lot of money; leading to discontinuation of treatment or healer shopping.

I fell ill so I went to the village doctor and he checked my urine. The doctor didn't tell me I had diabetes, he just injected serum or medicine (...) It didn't get better. I spend a lot of money for 4 months (\$80), only for medicine. To buy medicine, I had to go to Ang Roka pharmacy. I went there by moto-taxi, which was an extra cost. [After 4 months the peer came to test at her house] (P3: female, diabetes and hypertension, oral medication)

He [private doctor] just gave some advice to buy medicine at the private pharmacy. I went to this doctor one time per week for one year. It was too expensive so I stopped going there and started to take Khmer traditional medicine (P14: female, diabetes and hypertension, old, poor, oral medication)

One patient was seriously ill before joining MoPoTsyo – her blood sugar was 600 on admission (Van Pelt, personal communication) – and she had many wounds that wouldn't heal. The doctor at the hospital told her they had to amputate her leg but she refused and went back home, thinking she would die. Eventually she was found by the peer educator and started on insulin. It went much better but she got small abscesses from the injections³ and developed a fear of needles (Van Pelt, personal communication). She is now taking oral medicine and feels much better. MoPoTsyo pays for her medicines through the HEF because she is very poor (Van Pelt, personal communication).

I was seriously sick and went to Takeo Hospital. The doctor told me to operate my legs, but my husband disagreed to cut my leg. He told me to inject some medicine for about 30 000 riel and I told my husband to go back home and invite the monk to pray for me before I died. I am poor and had to sell everything for my illness. I spent 800 000 riel in 20 days. I even sold my cow. He [the doctor] let me go home because I told him if I died over there my family didn't have money to transport my body home. I spent 10\$ for Tuk Tuk. I went home and prayed. Then Mr Roun, the peer educator, came to my house and he tested me to find this disease. He injected insulin but now I take pills because I am very afraid of the needles because I got swollen wounds on my body (...) If it wasn't for MoPoTsyo I would have passed away (P12: female, diabetes and hypertension, insulin before now oral medication, HEF)

One patient was treated for free in a state hospital, but sent home when he got better. They told him he was recovered so he stopped using medicine. When his condition deteriorated again, he couldn't go to the clinic anymore because he was regarded to be 'cured'. After joining MoPoTsyo, the peer told him diabetes cannot be cured.

IV. Role of the peer-educator

All patients indicated that the peer educator told them about diabetes, not to eat sweet, to eat brown rice,

³ Since it is very rare to have abscesses from insulin therapy, she probably had lipohypertrophy at injection sites.

green beans and vegetables and to do exercise. Some explicitly referred to the food pyramid they had received.

I have the food pyramid of MoPoTsyo in my house, I watch it when I eat. I stick it on the wall of my room (P10: female, diabetes, hypertension and joint degeneration, oral medication)

Of the patients on medication, most said that the peer helped them to inject medicine or gave them the medicine. Only two patients mentioned that the peer accompanied them to a doctor in Ang Roka for the prescription of medication, one of which was a young woman (26yrs) on insulin.

He [peer] told me to use medicines and made an appointment for me at Ang Roka to get the medicines (P7: female, young, diabetes, insulin, no peer since 2009)

In MoPoTsyo, usually patients get diagnosed or taken in by the peer and are then send to the clinic for a consultation and the prescription of medication if necessary. The peer will accompany the patient to the hospital to act as intermediary and it seems that some patients do not really take note of the presence of the doctor. Previous qualitative research in the NGO already showed that some patients referred to the peer as 'krupeet', which is Khmer for doctor, indicating that they do not draw a clear line between the peer-educator and health professionals. It is possible that many patients do not fully understand what the peer can and cannot do, and some talked about the peer coming to their house for testing and then immediately injecting insulin, which is highly unlikely.

The peers confirmed that many patients saw them as a doctor and asked them for advice about any health problem. They would then tell the patient to go to the health center or hospital.

They believe me to be a doctor that can look after them and explained them about any problem they have with their health. I say them to go to the health center for general illness because I only know about diabetes (peer 1: male, diabetes for 3 years)

When they ask I tell them "I am not a doctor I am a peer educator, I have no medicine for you and I can only explain you about sugar". If they have other problems I tell them to go to the health center or the doctor (peer 3: male, diabetes for 2 years)

Peer educators, as providers of basic care should indeed know their boundaries, but should also adequately refer patients in case of more complicated health problems. Merely telling patients to go see a doctor is not enough, because they often do not know where to go or lack money. With more incentives and reimbursements peer-educators could become more proactive and even accompany patients to the hospital or health center where necessary, especially when they are complaining about diabetes complications. One patient told us the peer educator wrote her complaint down in her patient book but did

not give any advice, and another patient knew where to go but didn't have any money. The peer educator could have investigated whether she was eligible for compensation by the Health Equity Fund.

I still have problems with my eyes and I don't know where to go. I told the peer about my eyes and he wrote it down in the book. He did not give any advice. I am afraid of blinded eyes (P7: female, young, diabetes, insulin, no peer since 2009)

I have troubles with my eyes but if I want eye care I must go to Takeo Hospital. I cannot go because I don't have money (P10: female, diabetes, hypertension and joint degeneration, oral medication)

To explore how they saw their own role, we asked peer educators whether they felt responsible for patients who were not doing well and how they dealt with them. While they dealt with 'demotivated' patients in a similar way, they differed in their view on their own responsibility, as illustrated by the responses of two of them:

It's not my responsibility because I just advise them to use medicines. If they don't care to look after themselves that is their responsibility. I want them well but if they say they do not follow me, it's up to them. I always advise them to do well. I tell them they can do what they want because it is their right, but if they want to be in good health they can follow us (peer 1: male, diabetes for 3 years)

If their health is bad, it is my responsibility, because I control all patients (peer 2: female, diabetes for 20 years)

It is interesting to see that some peer educators take up responsibility for the health of 'their patients', while the goal of peer educating is to empower patients so they could be responsible for their own health through self-management. This phenomenon was seen as problematic by the founder of the NGO, Maurits Van Pelt, who mentioned that many older patients became entirely dependent on the peer educator instead of building up a capacity to look after themselves without the help of the peer (Van Pelt, personal communication).

In fact, patients could not imagine looking after themselves without the help of the peer. All but one said they needed the peer for getting cheaper medicine, information and follow-up of their blood sugar. It is true that few patients have a glucometer, so they need the peer to check their sugar level. The only patient saying she didn't need the peer anymore was a young woman (26yrs) on insulin who said "*I can do myself without peer. I know which medicines I need,*" but afterward she changed her mind and said she still needed him "*to bring me some medicine when I am busy.*"

Patients said they would need the peer forever to have cheaper medication. The situation of patients in ARC, where the peer had been gone for more than a year, shows that patients are unaware of the fact that they could still go to the pharmacies subcontracted by the NGO as members of MoPoTsyo, or be eligible

for the Health Equity Fund. The peer was not seen as a facilitator for accessing these benefits, but as a precondition. One patient went to buy medicine at the pharmacy in Ang Roka only when she felt sick and went to the health center in the village where they checked her blood pressure, but not her sugar.

Since the peer stopped, it has changed because I have to go buy medicine myself. Before I could go to the house of the peer educator to get medicine. Now when I feel sick I go to Ang Roka to buy medicine. It's 3000 riel. I go buy from Ang Roka but when peer educator worked, they shared medicine free for me (...) I never check blood sugar, I don't know how my sugar is now. I always go to check my blood pressure at the health centre in my village, but they don't check the sugar (P6: female, diabetes and hypertension, oral medication, no peer since 2009)

V. Change in life after joining MoPoTsyo

When asked about their current situation, responses were mixed. For some joining MoPoTsyo had changed their life profoundly and many patients said they felt much better. Some mentioned they had picked up their normal life again and had regained their ability to perform their activities of daily life, such as working in the field or cutting wood for cooking. As mentioned by one of the patients:

I feel happy because I can do my normal work again like carrying water and running around the house. I don't have any headache and unclear eyes anymore (P9: female, diabetes, only diet and exercise)

Others however, were still suffering from the symptoms of hyperglycemia due to problems they faced in trying to get their condition under control, as discussed further.

One of the most important things the peers gave the patients was knowledge. Many emphasized that, since they joined MoPoTsyo, they know how to take care of themselves. This seems very obvious, but this empowering effect of information, lies at the heart of the benefit of (peer-) education. Simply knowing what is wrong and what they can do about it gives patients the ability to self-manage their disease. Especially for patients who can control their disease only by lifestyle adjustments, since these are measures they can take up by themselves and are less limited by external circumstances such as the availability of medicines and financial constraints.

It's not like before, I have a new life. My life is very good since I joined MoPoTsyo because I know how to take care of myself by doing exercise and following the diet (P5: female, diabetes, insulin)

I can control my disease because I take medicine and follow the diet. Before I didn't know I have diabetes and I didn't diet but now I know so I carefully select all the food before I start eating (P8: male, diabetes, hypertension and overweight, oral medication)

MoPoTsyo helped me because now I know how to protect myself, when we know our sugar level we can diminish it by doing exercise or follow the diet. Now that I know that, I'm not afraid anymore and I don't worry so much. When I am worried, I diet. I can control (P11: male, diabetes, only diet and exercise)

As mentioned in the introduction, Lorig *et al.* found in their research on self-management education programs that it was not behavior change that was significantly associated with health status, but self-efficacy; pointing out the importance of merely feeling able to control your condition to improve your subjective health status. This would explain why so many patients said their lives had changed for the better after joining MoPoTsyo, although many of them still had symptoms and faced financial problems.

Another benefit, related to the previous, that was brought up by some patients was the feeling of being normal. By being able to get their disease under control, they were able to restore their previous lives.

Because I can take care of myself I can live like others again. Before I was very afraid and now I am very happy because I live like others as usual (P9: female, diabetes, only diet and exercise)

Pointing out that diabetes patients can have a normal life, was mentioned by one of the peers as a strategy to motivate patients “*and I show them that I have diabetes, but I am like the normal people (peer 3)*”

Another great benefit from joining MoPoTsyo was financial. As mentioned in the introduction, the cost of diabetes medication in Cambodia is high. A 10mL vial of insulin in Phnom Penh costs 16 USD, while none is available in the provinces. MoPoTsyo buys insulin from Insulin For Life Australia, and distributes it to subcontracted pharmacies where patients can get a 3mL vial and 5 syringes (100 unit per ml) for 11 000 Khmer Riel (2.6 USD) (Van Pelt, personal communication). The doctors working with MoPoTsyo only prescribe from a fixed list of generic medicines, which are also bought by the NGO and distributed to the subcontracted pharmacies. Patients buy them at world market reference price and very poor patients can be helped by the Health Equity Fund. Despite the added margin, which is used to recover the costs of the whole peer educator intervention, the price for diabetes medication in pharmacies contracted by MoPoTsyo is much lower than the Cambodian market prices used by the private pharmacies, as acknowledged by many patients.

I am very happy that MoPoTsyo came to help me on time, because without MoPoTsyo, I would spend a lot of money for this disease and would have to my sell land and my health would be worse (P4: female, diabetes, oral medication)

Before I sold my land for my treatment. After I joined MoPoTsyo I spend a little money and my health is better (P10: female, diabetes, hypertension and joint degeneration, oral medication)

MoPoTsyo helps me, I don't pay money for my pills and my husband also works to get some money for my health (P12: female, diabetes and hypertension, insulin before now oral medication, HEF)

I still worry, but only a little bit because I can buy medicine from MoPoTsyo which is cheaper than the private clinic (P13: male, diabetes and hypertension, new patient)

The NGO is reluctant to fund the medication and give it away for free because they depend on donor contributions, for which the continuation is unpredictable. In addition, the government does not put chronic conditions high on the agenda. If the NGO would get more funding from the government or international donors for longer timeframes it would theoretically be possible for them to financially support more patients but currently they are striving for financial sustainability. When talking about these issues, one of the peers mentioned:

HIV programs give medicines and materials for free. MoPoTsyo cannot give medicine for free because diabetes is not a transmitter disease so the government does not care so much (peer 1: male, diabetes for 3 years)

VI. Problems faced by the patients

Poverty

Since MoPoTsyo can only provide medicines at a lower cost and not for free, it can be anticipated that many patients will still face financial problems. In addition to medication, patients also have to pay for glucose strips, laboratory tests and transport to the pharmacy. Although MoPoTsyo also provides laboratory services at a lower price than in the public or private sector, which is very much appreciated by the patients, it adds another cost to the management of diabetes.

Many of the patients with financial problems were the ones that had lost a lot of money trying to find or pay for treatment before they joined MoPoTsyo. Some of them had sold all their land and had almost nothing left. Especially older women with little support from their relatives and neighbors and patients on insulin were vulnerable to financial hardship. Patients without money had to discontinue treatment, leading to a deterioration of their health status and the development of complications.

I still feel pain but sometimes I am fine, although I don't have medicine. I'm always dizzy and very exhausted and I have unclear eyes and no power. I earn a little money for eating every day. Before, MoPoTsyo helped me for insulin, I got for free. Now, I do not take medicine because I don't have any money. My children are poor so they cannot help me (P1: female, diabetes, should be on insulin)

I lack money to buy rice and to pay for transportation. I did not take medicine for 6 months because I was broke. I fainted two times. (...) My husband earns money to pay for medicine. My family looks after me and my neighbors pity me. When they have vegetables sometimes they give me (P3: female, diabetes and hypertension, oral medication)

I spend 10,000 riel [2.4 USD] per month. When I don't have money, I don't buy the medicine but when I have I buy. Often I buy it for one month to take two tablets a day, but then I have to take only one per day because I don't have much money. I also diminish from two to one per day when I am better. Sometime I have to stop taking medicine because I don't have money (P14: female, diabetes and hypertension, old, poor, oral medication)

The story of one patient, who had to sell her land to buy medicines from a private pharmacy, is illustrative of the financial problems faced by patients, how they can be pushed into poverty by the health-care system, the effects it has on adherence and their ability to control the disease. She now lives alone with her father and has no children to support her. She is often unable to buy medicines because she has no money, and she has no more land to sell. When she has no money, she discontinues treatment or breaks her pills in half.

I used to go to the hospital in Takeo but the doctor didn't tell me I had diabetes. I bought medicines at the private pharmacy in Takeo for six months and then in Ang Roka. I went there every 20 days during 6 months. It was expensive; I spent 60,000 riel [15 USD] per 20 days. I sold my land for treating my illness. Now I have only a small cow left and live with my old father. Sometimes I didn't take medicine because I didn't have money so I took Khmer medicine. I went there three time during three months but it did not improve my illness. Khmer medicine is cheap but for transport it is expensive. Then when MoPoTsyo came to my house, I knew I had diabetes. After I joined MoPoTsyo I spend a little money and my health got better. But I still do not have enough money. My family is poor but sometimes my nephew gives me some money. I cannot get money from someone else because I don't have land to sell again. When I run out of money, I don't take medicines or I reduce it from one pill to half. I have troubles with my eyes but if I want eye care I must go to Takeo Hospital. I cannot go because I don't have money (P10: female, diabetes, hypertension and joint degeneration, oral medication)

Patients were not the only ones with financial problems however, peer educators and the NGO itself also reported financial difficulties. Peer educators receive a small salary for the work they do but they all said it was insufficient to cover their costs. In theory patients should go to the peer educators' house for follow-up, but peers told us they often had to go to visit demotivated patients leading to high expenditures on gasoline for their motorbike. Peers get a bicycle from the NGO but they told many patients lived too far or it would take too much time to go with the bike, so they preferred to take the motorbike.

It's not enough.. Before I got \$40 or \$50 per month but now I get only \$10 per month. When I go to check the patients I need money for gasoline (peer 2, diabetes for 20 years)

Some patients live far away and it takes a long time to reach them and I do not have enough money for petrol (peer 3, diabetes for 2 years)

Diet and Exercise

All patients told us they followed the diet and did exercise every day, but after some discussion the problems they had with these lifestyle adjustments came up. As for the diet, the biggest problem was switching back to brown rice. Not only because it is not always easy to find, but because eating white rice has become very common since the nineties. Before the introduction of machines that husk the rice to its white polished form all Cambodians handmilled their rice, which leaves more of the protective vitamin rich film and bran. At present however, Cambodians eat large quantities of white rice – it makes up 80% of a typical meal – and patients found it difficult to change this (Van Pelt 2009). This machine polished rice has a very high glycaemic index, so patients are advised to replace it with healthier whole rice, handpolished or less polished if a machine is used. The white rice aside, most traditional Khmer dishes are tasty and healthy, using a range of different vegetables, and fish is often the principal source of protein. However, there is a tendency to add spoonfuls of sugar to many of the dishes. The intake of salt, which is even added to tropical fruit, is also high.

Patients that were able to produce whole rice and grow vegetables themselves had no problems following the diet. Some patients however, told us they didn't know how to make whole rice and where to find it. It seemed that peer educators would advise patients to eat whole rice but did not give any further explanation.

I eat brown rice every day. I buy it from others. I eat vegetable too, some I grow and some I buy. It's difficult because my house is far away from the market so I cannot eat vegetable every day, just some time (P7: female, young, diabetes, insulin, no peer since 2009)

I don't eat brown rice because I cannot find it. They [peer] don't tell where to buy, they have just told me to get it from a machine. But I don't know where the machine is (P6: female, diabetes and hypertension, oral medication, no peer since 2009)

I don't have machine to produce brown rice. And I don't know where I can buy it. He [peer-educator] didn't tell where it is. I asked him but he told me to use a Khmer machine to produce it, but nobody knows about this Khmer machines. The old generation knew but they died and young generations don't know it (P11: male, diabetes, only diet and exercise)

This inability to produce whole rice is surprising, since the overwhelming majority of MoPoTsyo members are farmers who should know how to handmill the rice they harvest themselves (Van Pelt, personal communication). This is a very cumbersome process however, so patients might prefer to ask the local miller to make less polished rice for them, but not every machine will have that function. Maybe patients simply do not want to do the effort to set aside some of their grown rice in order to handmill it

themselves. Nonetheless, as for referring patients to the health center in case of complications, we would still recommend that peer educators take up a more proactive role in making sure patients have the ability to follow-up their advice. Handmills to produce whole rice can be bought in Ang Roka for 35,000 riels (USD 8.75) and some peer-educators already use it. If possible, all peer-educators could be given such a machine to be used by them and the patients, or at least to demonstrate how to use it. If they do not have and use it themselves they shouldn't expect patients to do it either. Peer-educators carry the high burden of having to set the example.

Another problem with whole rice is that it does not have the same taste and texture as white rice. It also doesn't produce the same 'high blood sugar rush' that white rice does because of its high glycemic index. This proved especially problematic for patients cooking for an entire family, since relatives would refuse to eat whole rice. One patient said her father was unable to eat it because he did not have any more teeth and it would be too burdensome to cook two separate dishes, so she eats only white rice.

I ate brown rice before but my children complained to me that they cannot eat brown rice. Now I eat white rice, but only a little every day. I told my children it's healthy but they cannot eat it. I eat more vegetable such as waterlily etc. I have enough vegetable around my house and I can sell some also (P9: female, diabetes, only diet and exercise)

One older patient had difficulty with following the diet and taking his medication regularly because of forgetfulness:

I have some problem with myself. I'm afraid to eat something that I must not eat and I don't take medicine regularly. I eat sweet something I stop eating although I am eating. I never eat sweet but sometime I forget I eat sweet and then I remember I stop quickly (P8: male, diabetes, hypertension and overweight, oral medication)

Others admitted to eat sweet sometimes, for example at ceremonies. Many found their own way to balance the different aspects of the diet, for example by diminishing their portions of white rice instead of switching to brown rice. These changes allowed patients to follow the recommendations of the peer as best as they could, while still enjoying their meals. As stated in the introduction, eating is a social activity with a central place in human life, which could lead to a trade-off between health and well-being.

I know from the food pyramid that I should eat more vegetable and less meat. I eat sweet, but not much. I never diet all the time, when I finish eating I eat sweet for one spoon or two or I eat sweet at party or a special ceremony. I do not eat brown rice, but I diminish white rice, or eat green bean instead of brown rice (P11: male, diabetes, only diet and exercise)

As for exercise, older patients had trouble doing exercise because of general joint degeneration and some younger patients stated they did not have time to do exercise because they were too busy working.

Before I did exercise everyday but now I cannot do it anymore because I am sick. I cannot run and walk because I have pain in my legs and hands (P8: male, diabetes, hypertension and overweight, oral medication)

I never do exercise; I walk and plant my farm. I don't have much time, when I wake up I go to my farm (P7: female, young, diabetes, insulin, no peer since 2009)

Most patients however, counted working as exercise.

I do exercise every day. I do on early morning and work at my house, sometime I plough my field so I spend half a day in doing exercise (P5: female, diabetes, insulin)

I farm every day, I take the water for my vegetable and pigs, and I don't want my children to help me anymore. Before I slept late, now I wake up at 5 o'clock everyday to do exercise (P9: female, diabetes, only diet and exercise)

Talking to the peer educators shed some extra light on why some patients had difficulties with following – or did not want to follow – their recommendations. They all thought that forgetfulness was an important reason for patients not following up:

This disease makes them forget. Sometimes I explain to 10 patients and they get around 60% or 70%. Some forget because they getting old and easily forget. They just remember what is important but they cannot remember clearly (peer 1: male, diabetes for 3 years)

When I explain some cannot remember because diabetes patients often forgot. Some patients always forgot when they are feeling well (peer 3: male, diabetes for 2 years)

This last point touches upon something more than forgetfulness, i.e. the fact that some patients behave differently when they are feeling better. Each of the peer educators had problems with some patients that did not follow their advice when feeling better, as illustrated by this remark:

As peer educators we have a lot of difficulty. If patients are very worried, they take their medication carefully by themselves. But when their disease gets better they don't want to follow our advice, they don't care (peer 2: female, diabetes for 20 years)

Whether this is a bad thing, will depend on the patient's level of knowledge concerning diabetes and it's treatment. If patients do not understand that diabetes is a chronic condition and that they are still 'sick' even when they do not have any symptoms, peer educators should increase their efforts to inform them. If on the other hand, patients have adequate knowledge and use this to adjust their treatment to the limit of

control, they should be given the liberty to do so. Even if this means they don't follow up the advice of the peer. One patient told us she would diminish her medicine-intake when she was feeling better and would increase again when she got worse, in search for the optimal dose to control her blood sugar.

Besides patients that cared less when they were feeling better, peer educators also told us about patients who seemed not to care at all. As mentioned before, not all peers felt responsible for the behavior of 'their' patients, but they would all spend more time with these patients and increase their efforts to convince them of the importance of following their advice.

When they get advice from me they only follow the advice for a while, afterward they don't care. I don't know why, because in front of me when I explain they say 'yes, yes, yes', but afterward no. But I cannot go into the patient's mind. They always say yes but I cannot see what they think. I will try to explain again and again and explain the reason why they should take care of themselves and their health (peer 3: male, diabetes for 2 years)

This is important because, after initial intake, patients who are forgetful and the ones who do not care, will need the peer the most, but will also be the ones that don't go to the peers house for follow-up. Being able to visit them in their homes to try to motivate them is an important benefit that comes with peer-educating. It also consumes time and money from the peer-educators though and dedicated peers will end up having financial problems. This stands in stark contrast with how peer-education is currently viewed by donors and international agencies. In the report of the 2007 WHO consultation on peer support programs in diabetes we can read: "peers are formally recognized, but not compensated. Their role and contributions to diabetes care are acknowledged by their communities; but they are volunteers, not employees". Maurits Van Pelt is aware of the problems faced by the peers and would like to increase their salary but donors are pushing the NGO to move to 'voluntary community service' and even make this conditional to receive funding (Van Pelt, personal communication).

Curability of diabetes and worries about the future

Besides all the above mentioned problems, patients had concerns about the future, since almost all of them fully realized that diabetes cannot be cured. This is a very interesting finding since qualitative research in 2007 amongst diabetes patients in Cambodia had shown that some believed diabetes could be cured by traditional medicine (Men 2007). Both diabetes and HIV/AIDS patients were included in the 2007 research, and it was found that HIV/AIDS patients had changed their ideas about the curability of their condition in comparison to another study conducted in 2000, while diabetes patients had not. The authors concluded that this was due to the appropriate information HIV/AIDS patients had received through NGOs, while diabetic patients still received conflicting information about their disease and its treatment. The fact that patients who had joined MoPoTsyo had changed their ideas concerning traditional

medicine and the curability of diabetes after receiving adequate information from the peer educators, would support Men's conclusion that patient beliefs depend on the amount of information they have and the role NGOs can play.

Patients told us diabetes cannot be cured but "it can be delayed". One patient used the example of HIV: "no, it [diabetes] cannot be cured. It can just be delayed, like HIV (P7 female, young, diabetes, insulin, no peer since 2009). During an informal conversation, one of the patients even called diabetes "the little brother of HIV" (field notes).

Although most patients were clearly convinced that diabetes cannot be cured, some had difficulty accepting it or did not really believe what their peers said:

I think it can be cured, but some people said this disease cannot be cured but it can be delayed. The peer educator told me to take medicine forever (P5: female, diabetes, insulin)

Yes I think it can cure, but I heard from other that it cannot be cured, but that it can be delayed. In my mind I think it can be cured (P10: female, diabetes, hypertension and joint degeneration, oral medication)

Joining MoPoTsyo and realizing that diabetes cannot be cured made patients change their opinion on the use of traditional medicine. Only two patients reported still using traditional medicine, one of which was newly diagnosed and did not yet get any medication from MoPoTsyo. He said he would stop taking traditional medicine when he would receive medication from MoPoTsyo, because he did not want to mix both.

I use traditional medicine such as boiled Cambodian fruit to reduce high sugar. I've just used for one month. I take Khmer medicine because I did not get medicine from MoPoTsyo yet. I know this disease that cannot cure (...) When I will get medicine from MoPoTsyo I will stop using traditional medicine. I will use medicine from MoPoTsyo, because I don't want to use mix of these medicines (P13: male, diabetes and hypertension, new patient)

All other patients that said they previously used traditional medicine, told they had stopped after joining the NGO. Either because they found the medicine of MoPoTsyo being of better quality, lacked money to buy both or, most importantly, because they did not believe anymore in the potential of traditional medicine to cure their condition:

I use the traditional medicine for a long time but now not anymore. Medicine from MoPoTsyo is from better quality than traditional medicine (P8: male, diabetes, hypertension and overweight, oral medication)

I used a lot Khmer medicine when I got sick first time. Now I stopped using traditional medicine because diabetes cannot be cured. I took it for three years, now I stopped it. It did not help and it's expensive (P12: female, diabetes and hypertension, insulin before now oral medication, HEF)

I just took some traditional medicine to reduce hyperglycemia, but it's expensive. Traditional medicine is not good quality and it's expensive. I stopped trying to cure with traditional medicine because it cannot be cured forever (P14: female, diabetes and hypertension, old, poor, oral medication)

The downside of being fully informed and knowing diabetes is a chronic condition however, is the realization that you will have to take medicine or adjust your lifestyle for the rest of your life. Many patients were concerned about their future and their ability to buy medicines for a long time to come, especially the older ones with no income and little support from their family. Patients realized that they “will be dependent on MoPoTsyo to help us for the medicine forever” (P2: male, diabetes and hypertension, oral medication). However, knowing that MoPoTsyo provides cheaper medicine helped to cope with this prospect;

I am very afraid because it can't cure. I am worried. After peer explained to me I was still worried, but less, because I can by medicine from MoPoTsyo which is cheaper than at the private clinic. My plan is to take medicine to delay my life of diabetes (P13: male, diabetes and hypertension, new patient)

DISCUSSION

Principal findings and comparison to literature

The results of our research are promising for the setting under study. They show that peer-support for diabetes patients can lead to reasonably good outcomes in a low-resource setting. Overall, significant improvements in FBG and both systolic and diastolic blood pressure were observed in patients after being in the program for at least 2 years, with about one third of patients reaching treatment target for FBG and two thirds for BP. There were almost no changes in BMI, with half of patients having a normal BMI at both baseline and follow-up. More than two-thirds of patients reported improvement (“better” or “much better” on a visual analog scale) in terms of health, ability to control their condition and adherence to both medication and life-style adjustments; compared to before they had joined the program. Increased knowledge and self-efficacy came out as an important element in both the structured questionnaires and the in-depth interviews. Patient-reported health outcomes were significantly correlated with the actual observed drop in their FBG, but not with changes in BP or BMI.

The main problems reported by patients during in-depth interviews were lack of money to buy medicines, reluctance to change their traditional diet, difficulty to find/produce whole rice and worries about their future. These worries were partly resulting from being more informed after joining the program. A qualitative study in 2007 revealed that many diabetes patients thought their disease could be cured by traditional medicine (Men 2007). Patients in our research told us diabetes cannot be cured and most patients using traditional medicine before had discontinued after joining MoPoTsyo. They fully realised they would have diabetes until the last day of their lives and thus would need to buy medicines for a long time to come, leading to financial worries. Peer educators also reported financial problems, mostly due to gasoline-use to visit patients. Patients stories from before they had joined the program confirmed the low quality of care for diabetes patients in Cambodia’s current health care system.

Another problem that came out of the in-depth interviews was the inability of some patients to understand the role and responsibilities of the peer-educators within the overall health system. Peers were confused with doctors and were consulted for other problems than diabetes or hypertension. Referral for non diabetes-related problems and also for complications was not functioning optimal. We believe peers should play a more proactive role in this matter, acting as a liaison between patients and the health care system. To achieve this, however, peers will need more assistance and the place of the NGO in the formal health care system should be better defined.

Although the majority of patients did not reach the treatment target for glucose levels, it should be noted that any decrease in glucose levels is associated with a decreased risk for microvascular complications in patients with type 2 diabetes (UKPDS Group 1998a). It is also known to be very difficult for diabetes type 2 patients to reach treatment targets for blood glucose (Nitiyanant *et al.* 2007; Fox *et al.* 2009; Raguenaud *et al.* 2009; Kang *et al.* 2011). In addition, there is an ongoing debate on the desirability of strict glucose control (Gerstein *et al.* 2008), which sometimes comes at the expense of quality of life. Besides a potential trade-off between overall well-being and strict glucose control, there are many structural reasons why patients fail to reach treatment targets; such as financial problems, cultural problems related to the diet and an insufficient insulin availability for therapy-intensification. Finally, when looking at glucose levels over time it should be held in mind that diabetes type 2 naturally deteriorates, as demonstrated in the UK Prospective Diabetes Study (UKPDS Group 1998a).

Younger patients in our research were significantly less likely to reach the treatment target for FBG. A possible explanation is that younger patients tend to have a more aggressive form of the disease, warranting more intensive therapy. Chronic diseases in LAMICs develop at an earlier age than in HICs (Alwan 2009) and have higher death rates in the former (Strong *et al.* 2005). Younger patients also reported more difficulties with finding or producing whole rice and were often too busy to do exercise.

The high proportion of patients reaching treatment target for BP is encouraging, since this has also proved difficult in other research (Bryant 2006). Lowering BP in diabetes has been shown to reduce the incidence of diabetic complications (UKPDS Group 2008b) and the BP achieved under treatment is the main determinant of the cardiovascular and renal benefits that antihypertensive are known to have (Reboldi *et al.* 2011). The results for BMI are rather disappointing, but not very surprising. Losing weight is a difficult task for patients and the same outcomes were reported in similar studies (Raguenaud *et al.* 2009; Price *et al.* 2011). In addition, there is a cultural reluctance to lose weight in many low-resource settings because of its association with HIV/AIDS (Awah *et al.* 2008) or because being obese is seen as a sign of good health, wealth and vitality (Gill *et al.* 2008). Finally, modest weight increase is well recognized to occur with improvement in glycaemic control (UKPDS Group 1998a).

To our knowledge, there are no evaluations of peer-education programs done in similar setting to compare our results with. Interestingly though, the evaluation of a nurse-led educational program in rural Africa done by Price *et al.* (2011) yielded similar results. Blood glucose levels decreased significantly and BMI rose initially and then declined again, not significantly different from baseline. They did not measure BP and because of missed appointments only evaluated 80 patients (out of a total of 320 patients enrolled in the program). Another interesting comparison would be with the evaluation of the chronic disease clinic set up by MSF in Cambodia (Janssens *et al.* 2009; Raguenaud *et al.* 2009). The clinic was established in

the same province where we performed our research, so the patients population was similar. What differed was that they used a whole team of physicians, trained diabetes nurses and adherence counsellors to support patients instead of peer-educators. After 5 years of follow-up, blood glucose and HbA1c had dropped significantly; as well as blood pressure (the same amount as it did in our research). BMI did not change significantly. As was the case in our research, only 33.3% of patients reached treatment targets for blood glucose and about half of patients reached targets for BP. Of the 4404 patients enrolled; 2,872 (65%) were still in care at the time of the study. These comparisons suggest that peer-education has the potential to achieve similar results as education intervention delivered by trained health-professionals. Peer-education, in addition, has the benefit of being provided in the community, possibly increasing retention rates.

Strengths and weaknesses of our research

Overall our research filled a gap in the current literature, providing a quantitative and qualitative evaluation of a peer-education program in a low-resource setting, with relative long-term follow-up and measurement of clinical outcomes. A strength of the research was the length of time between baseline and follow-up assessment, spanning a period of at least 2 years for each patient. Intensive intervention programs often have a short-term benefit on glucose control, but effects tend to wear off after some years (Cooper *et al.* 2008; Bastiaens *et al.* 2009) and there is a general lack of long-term follow-up studies regarding peer-education programs in low-resource settings. In addition, measuring clinical outcomes strengthens the claim that the program is effective. Only very few studies on peer-education so far assessed changes in clinical parameters (Foster *et al.* 2007), and we found none that did so in a setting similar to ours. Improvements in quality of life, self-efficacy, knowledge, etc. are all necessary and valuable, but strengthening the evidence that peer-education leads to improvement in clinical parameters will be necessary to inform policy makers.

As for the qualitative part, including the peer-educators in the in-depth interviews provided some valuable insights which would have been missed if we had only talked to patients. Because of their own experience and because of the many patients they support, they showed great insight in the problems patients face when trying to control their condition. The number of peer-educators interviewed was low however, so more research would be helpful.

Most of the weaknesses of our research come from the design we used. Because of time- and resource constraints we could not do a prospective cohort and had to use a retrospective before-after design instead. As for all retrospective research, this means we did not have any control over the quality of our baseline data and that patient responses to the structured questionnaire could be distorted by a recall-bias.

Using self-reporting could have further prompted socially-desirable responses. Although we have tried to limit this by using peer-educators from the program in the urban slums to perform the questionnaires, these are still associated with the NGO. In addition, we used FBG instead of HbA1c to measure improvement in clinical status because the latter was not measured at baseline. This, in combination with the fact that we used a before-after design instead of a cohort, could have given a distorted view of the actual trend of blood glucose levels. It should be noted however, that both HbA1c and FBG are only surrogate markers for the outcomes of interest; long-term morbidity and mortality. HbA1c is generally accepted as a valid surrogate marker for microvascular diabetic complications, but doubts still exist about its validity for predicting macrovascular complications (Twaddell 2009). Eventually, long-term follow-up studies with measurement of hard end points would be needed.

Another important weakness is the lack of a control group. It would have been difficult however, to find a relevant group to compare with because of the lack of diabetes care in Cambodia, especially in rural areas. Showing that the program significantly improves health compared to ‘no care at all’ would not have yielded much more valuable results than a cohort. Ideally, peer-education would be compared to an existing form of care at primary health-care level to assess not only if it *works*, but if it works *better* (or at lower cost for the quality of life gained) than the care routinely available.

Related to this is the fact that probably almost any kind of intervention would have a positive effect in a context where there is no quality care available prior to the intervention, especially when measuring patient-reported improvements in health status and overall quality of life. Moreover, some patients had very high blood glucose levels when entering the program, leading to substantive differences between baseline and follow-up measurements. Longer-term follow-up will be needed to assess whether this decline in FBG will continue in the future. In addition, MoPoTsyo has been created quite recently and is the only place where patients in rural areas currently can get affordable care for diabetes, leading to a lot of enthusiasm amongst its staff and members. It would be interesting to see if this would wear-off in the future, especially when other forms of care become available at primary health care level, and caution should be made when generalizing the results to other settings, even if seemingly similar.

Finally, we were unable to do any evaluation in terms of cost-effectiveness of the program. Peer-education is theoretically a low-cost intervention, but research is needed to support this claim.

Benefits of peer-education

As discussed in the introduction, peer-education has many benefits. Firstly, it does not put additional strain on the health workforce, making it particularly valuable in low-income countries facing severe shortages of health workers. Secondly, by providing care in the community some important structural

barriers for patients are eliminated. For instance, Geng *et al.* (2010) found that lack of transportation and distance to clinic were the most common reasons for loss to follow-up in Ugandan HIV/AIDS patients. They suggested that these barriers could be removed by providing care through “alternative models such as more dispersed satellite clinics or home-based programs”. Peer-educators told us they go and visit patients in their homes when they do not show up for follow-up at the peer-educators house. This could potentially help explain the high retention rates observed in the program and would be much less feasible if care would be provided at health facilities by health professionals. Having the time and possibility to pay increased attention to patients with difficulty following treatment is very valuable in the context of chronic conditions, since patient motivation is crucial for effective self-management. Peer-educators were convinced that their home-visits to what they called ‘difficult patients’ did sometimes have positive effects on these patients’ behaviour.

Related to this is the credibility and practical knowledge peer-educators have when compared to health workers, which could further benefit their ability to help patients come to terms with both lifestyle changes and their longer term prospects. Providing care through peer-education networks could also improve the cultural acceptability of a program. Qualitative research has shown that patients in rural Cameroon regarded the treatment packages offered at clinical encounters as socially inappropriate and preferred to visit traditional healers (Awah *et al.* 2008). Adapting given treatment packages to the cultural context, as was done for example by MoPoTsyo for their food pyramid, and providing them through peer-support could potentially help overcome this cultural barrier to care.

Another benefit of providing care in the community is the local awareness it raises. This became clear during the in-depth interviews by the many ways patients initially got into contact with the NGO. Some of them recognised the symptoms of diabetes themselves and knew they could contact the peer; others were told by relatives, or even the chief of village, to go see the peer-educator. One patient got referred to MoPoTsyo by a health professional, suggesting that the existence of the NGO does not only increase the awareness of diabetes at community level but also amongst health care providers; and that providers acknowledge the role of MoPoTsyo in providing care for diabetes.

Peer-education, finally, strongly empowers patients. Not only are patients empowered at an individual level, by learning how to self-manage, they are also empowered as a group vis-à-vis the formal health care sector. Organising peer-educators and patients into a local network allows mediation of interaction with key professionals and organisations, including medical doctors, pharmacists and drug wholesalers. This is a substantive change in the relation patients normally have with these different groups and greatly increases their bargaining power. This altered position was one of the main reasons the founder of the

NGO decided to set up peer-education networks (Van Pelt, personal communication) and is illustrated by the arrangements they have made with medical professionals and the subcontracted pharmacies.

When thinking about peer-education as a policy option, the question of financial reimbursement for peer-educators warrants some reflection. As mentioned previously, WHO experts (2007) have stated about peer-educating that: “peers are formally recognized, but not compensated. Their role and contributions to diabetes care are acknowledged by their communities; but they are volunteers, not employees”. Donors are also pushing MoPoTsyo to move to ‘voluntary community service’, by defining it as a condition to receive funding (Van Pelt, personal communication). There is a tendency to focus on the financial problems faced by patients only, while it is clear from our in-depth interviews that peers will invest a lot of time and energy in visiting patients at their homes to try to motivate them to continue treatment. Here lies one of the main benefits of community-based care when compared to care provided in facilities and could potentially explain the high retention rates of the program. This kind of investments from the peers is not sustainable in the long run though and our opinion is that a principal unwillingness to provide them with some kind of reimbursement fails to value their role in providing care for diabetes patients, especially since there is none in the formal health care sector. More research is needed, but it can be already said that if peer-education networks are used by policy makers to address a gap in the health-care system they should be seen as an integral part of it. Peer-education could be implemented on a larger scale, or its role extended, but peers will need the appropriate support.

Unanswered questions and future research

As we are only starting to explore the promises of peer-education programs in low-resource settings, much still needs to be done. Firstly, we need more research to validate the effectiveness of peer-education programs. This means prospective cohorts with long-term follow up and measurement of clinical outcomes or even hard end points. Peer-education should also be compared with other forms of care through randomized controlled trials, preferably in low-resource settings. In addition, the cost-effectiveness of peer-education should be assessed.

Secondly, one of the most pressing questions is how peer-education networks should relate to the health care system. How can they best complement diabetes services where those are already available? Can they be integrated into other health services and how should this be done? It would be interesting in this regard to have more qualitative research on how health professionals see the potential role of peer-education networks and what they think the ideal amount of ‘task-shifting’ would be. This last question should also be looked at in more research, since it is not yet clear to what extent (groups of) patients can

be left to self-manage. The role of new technology - mHealth and Health Information Technology (HIT) - could be further explored in this regard.

Thirdly, the possibility of extending the role of peer-educators to cover multiple conditions should be assessed. This raises some questions though. When trying to cover multiple conditions, a point will be reached where different peer-educators will be needed in the same community, or one peer will have to support patients with different conditions. This last option could be possible if the conditions have similar treatment packages, but if not, one of the main arguments for peer-education would no longer be valid. Patients are said to be experts in managing their condition because of years of experience and are therefore able to support others. But are patients with diabetes experts in managing HIV/AIDS and its complicated medication scheme? Would people living with HIV/AIDS be able to support people with diabetes in making the necessary lifestyle changes and doing a 24hrs-urine test? Should peer educators actually "peer educate" on a disease or even a co-morbidity which they have not experienced themselves? On the other hand, would it be sensible for multiple peer-educators to work in the same community or even follow the same patient?

Conclusion: implications for policy makers

Peer support models are especially promising for resource-constrained health systems, where care for chronic condition is often non-existent or of poor quality. The results of our research indicate the potential for peer educator networks to complement professional caregivers, especially where those are scarce, expensive or less effective. In a country like Cambodia, the challenge posed by diabetes is so overwhelming and the current health system so under-resourced that peer-education is an important policy option, because it builds capacity at the level where it is most needed and immediately relevant.

It is not yet clear however, if peer-education networks are preferable to other forms of existing care. It is therefore not possible to generalise our conclusions to high-income settings where diabetes care is already provided by the formal health care system. It is theoretically conceivable that we move to a model of 'full self-management for lifelong chronic conditions' in the future and peer-education networks could potentially play an important role in this model, but this is entirely speculative. More research, comparing peer-education to other forms of care, is needed. In addition, the question remains whether peer-education should be seen as a transitional model, to be used in settings where there is no care provided until the formal health care system can take over; or as a desirable - 'end stage' - model in itself.

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Appendix I. Health policy developments in Cambodia 1996 – 2008

Year	Policy area	Policy specifics	Policy actors
1996	Health financing	The development of a <i>health financing charter</i> in 1996, legitimizing user fee payment systems [31]	Ministry of Health, Asian Development Bank, Multi lateral agencies
1996	Health planning	The development of a <i>health coverage plan</i> in 1996 [32] and updated 2002, and Guidelines for Operational Health Districts [33] based on concepts of principles of health sector planning (reorganization of services based on essential service packages and minimum population catchments).	Ministry of Health, WHO
1998	Health services management	Strengthening of <i>public-private collaborations</i> in health care services provision, particularly through models of externally contracting health services through NGOs [34]	Ministry of Health, Private sector, Non-government organizations
2002	Disease prevention and control	Strengthening of national disease control programs particularly <i>TB, malaria, HIV</i> and <i>immunization</i> , with impressive gains in coverage and decline in preventable morbidity and mortality. Global Health Initiatives commenced with the Global Fund and Global Alliance for Vaccines and Immunization.	Ministry of Health, National Disease Control Programs, The Global Fund, Global alliance for vaccines and immunization (GAVI)
2003	Health planning	The design and implementation of a <i>strategic health planning system</i> commencing from 2003, including installation of linked planning and budgeting procedures for sub-national health planners [35]	Ministry of Health, WHO
2005	Health financing	Development of <i>social health insurance strategic direction</i> , focusing initially on extension of hospital-based “health equity funds”	Ministry of Health, National and international NGOs, Bilateral and multilateral agencies
2008	Health services management	Development and trial of internal contracting models, with more comprehensive scale up proposed Health Sector Plan	Ministry of Health, The World Bank, Bilateral agencies, GAVI

Adapted from: Grundy J *et al.* (2009) Health system strengthening in Cambodia—A case study of health policy response to social transition. *Health Policy* 92, 107-115.

Appendix II. Compliance – adherence – concordance

Patient-centered care has important implications for the role of the health professional and the patient-provider relationship. In caring for chronic conditions, the physician must be prepared to accept a new medical identity and accept that he or she can only indirectly control the illness. Medical power must be shared with the patient.

Patient-centered care implies that the patient's preferences, rather than the physician's, should dictate disease management. This different view on the role of the patient has translated itself into a change in the concepts used when describing patient behaviour in following treatment prescriptions. Previously, the term 'compliance' was used, which is defined as "the extent to which the patients' behaviour coincides with medical or healthcare advice" (Sackett 1976). This concept has been criticized for reflecting a paternalistic approach to health-care professionals' interaction with patients (Lehane 2009). It also has an ideological connotation of power inequity between patient and provider. The more recent term 'adherence' is defined by WHO as "the extent to which a person's behaviour corresponds with agreed recommendations from a health care provider" (WHO 2003). The crucial difference between these concepts is that adherence requires the patient's *agreement* to the recommendations from the health care provider, while compliance is about whether the patient *follows* these recommendations. In the case of adherence, patients participate in the process of making the decision to follow the regimen (Lehane 2009). This conceptual shift reflects the new role of patients in taking care of their disease and recognizes the importance of shared-decision making, an essential aspect of patient-centered care. Shared-decision making (SDM) has been defined as "an approach in which the clinician and patient go through all phases of the decision-making process together and in which they share the preference for treatment and reach an agreement on treatment choice" (Joosten *et al.* 2008). Joosten *et al.* (2008) performed a systematic review of RCTs using SDM as intervention and their main conclusion was that SDM is particularly suitable for long-term decisions, especially in the context of a chronic illness. Eleven RCTs were included in the review and six of these reported improvements in patient satisfaction, treatment adherence, quality of life and well-being. Interestingly, the studies that reported positive outcomes involved patients making long-term decisions and/or having chronic diseases, while most of the studies that did not show significant outcomes involved single or specific decisions.

Involving the patient in decision making touches upon some philosophical issues in medicine concerning paternalism and the role of the physician in protecting the health of their patients. Physicians often see themselves as rescuers of the sick, in need of urgent help. This is a role we play in emergency settings, but

when dealing with chronic conditions the situation is different. Sharing knowledge with patients and involving them in decision making means that at some point, patients could make decisions that are not, strictly speaking, the most beneficial for their health. It is more easily said than done to support patients choices if they don't coincide with your professional opinion.

Some authors even see the concept of adherence as implying paternalism. They have suggested the term 'concordance', which has been defined as "a process of prescribing and medication taking based on partnership" (Lehane 2009) and would encompass the idea that the doctor and the patient are equals. The difference with adherence is not entirely clear however and some have replied that concordance mainly refers to the dynamics of the interaction between the health-care provider and the patient and not the actual medication-taking behaviour of the individual, which is covered by the term 'adherence' (Lehane 2009). In addition, there is an ongoing debate about the limits of shared-decision making. Some have argued that this moves away too far from the paternalistic view, neglecting the 'gate-keeping' role of health professionals in minimizing patient harm. These authors state that a certain knowledge inequality regarding treatment options and their benefits will always exist between the patient and the physician and that patients should not be given full responsibility over their treatment choice (Kelley 2005).

Despite these discussion on how much responsibility the patient should be given, all authors agree that patients and providers should be partners and that decisions should be taken together. Although there might always be a knowledge gap in terms of biomedical knowledge, it should be emphasized that the knowledge of patients and providers is complementary. Patients have another kind of knowledge, they know how it is like to live with the condition, day by day; what the difficulties are and how to overcome them. The knowledge of both patients and providers should be combined to select the best treatment option. Providers can use their biomedical knowledge to assist patients in making the right choices, in the light of their own goals and health beliefs.

Appendix III. Information sheet for the structured questionnaire

Before agreeing to participate in this research study, it is important that you listen attentively to the following explanation of the study. We are going to tell you about the purpose of the research, what we will do, the benefits for you, the possible risks and discomforts, and precautions of the program. Afterwards we will ask you if you are willing to participate.

This research is to investigate the changes you experienced in your life since you joined MoPoTsyo. We will investigate this through the use of a questionnaire. This questionnaire contains 13 questions and should take about 30 minutes.

The questionnaires will be read only by the main investigator (Natalie Eggermont), helped by a student that can translate from Khmer to English. The questionnaire will be given to approximately 140 patients and the results will be added together and presented to MoPoTsyo to help them improve their program.

All information gathered from the study will remain confidential. We will ask your patient number so we can link your answers to the questions with data MoPoTsyo gathered before, for example your blood sugar when you started with MoPoTsyo. After we have looked up this data, your patient number will be removed from the questionnaire. Your identity as a participant will not be disclosed to any unauthorized persons. Only the main researcher (Natalie Eggermont) will have access to the research materials, which will be kept in a safe place. Any references to your identity that would compromise your anonymity will be removed or disguised prior to the preparation of the research reports and publications.

You will not be at physical or psychological risk and should experience no discomfort from answering the questionnaires. However, we cannot exclude that you could have some emotional discomfort regarding certain questions although we do not expect this to happen.

There are no direct benefits by participating in this project. However, this research is expected to yield knowledge about how MoPoTsyo can improve. This will be of benefit to all the patients in the future.

Participation in this study is voluntary; refusal to participate will involve no penalty. You are free to withdraw consent and discontinue participation in this project at any time without any effects on your further treatment in the MoPoTsyo-program.

Since there are no risks of injury involved with this study, we have made no provision for monetary compensation in the event of injury resulting from the research. In the event of such injury, we will

provide assistance in locating and accessing appropriate health care services. The cost of health care services is the responsibility of the participant.

Any questions concerning the research project and/or in the case of injury due to the project, participants can call Natalie Eggermont on the following number: ... (the participants will receive the Cambodian number of Natalie, which will be made available on arrival in Cambodia)

Do you have any questions at this moment? Did you understand everything we have explained to you? If yes, are you willing to participate in this research? And do you give us permission to look into the database for your previous data?

Appendix IV. Questionnaire

MoPoTsyo evaluation questionnaire July 2010

This information was be verbally transmitted by the interviewer before obtaining informed consent.

With the following questionnaire we want to evaluate what MoPoTsyo does for you and how the program has changed your life.

This research is done by independent researchers and the questionnaire is anonymous. The people of MoPoTsyo will never see these questionnaires. It is important that you fill out this questionnaire truthfully because we need to know how the program can improve. The answers you give will in no way influence your further treatment, so if there is something you think MoPoTsyo could do better, so please tell us tell us the truth, even if it is negative.

The questions are about the change you experienced since you joined the program. Every question starts with ‘compared to before you joined the program ...’ so you don’t have to say how you feel now, but how much the situation changed compared to before. These questions are about your health, how you feel, how much money you spend, if you take your medicine regularly,... It would be best if you responded to all the questions, but if there is a question you do not want to answer you are not obliged.

The answers are always the same: you have to point on a scale how much the situation changed since you joined the program. However, if you want to say something else about the question that you think is important, you can. The peer will write it down for you under the question.

Basic patient information: *

Age..... Sex: M/F
Date diagnosed diabetes:..... Date joined program:.....
Health center:.....

** Filled in by the researcher after completion of the questionnaire, by looking into the database.*

Patient number:.....

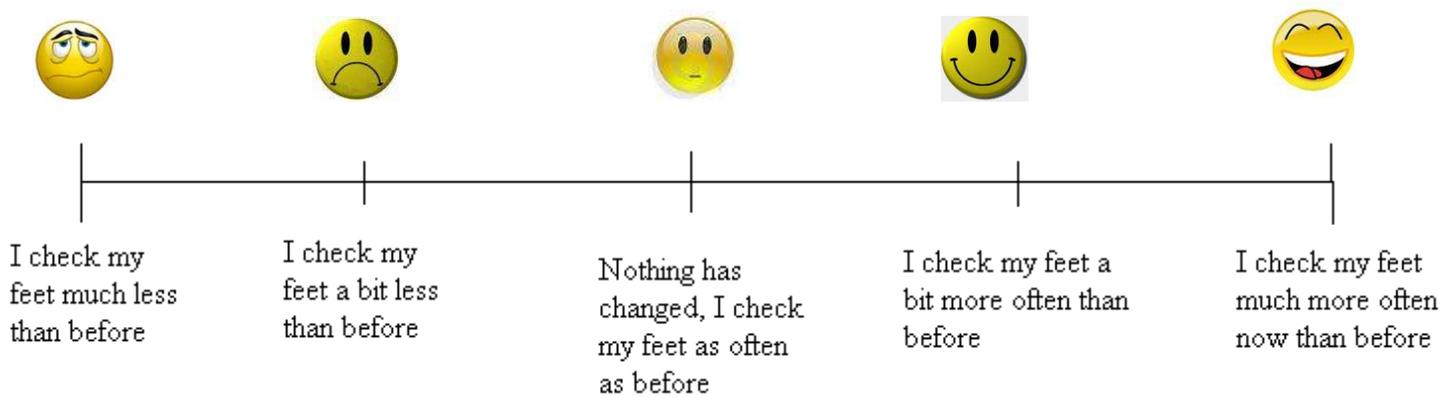
** Filled in by the interviewer, cut off after completion of basic patient information*

Example of a question + explanation of visual analog scale.

You have your own paper with the question and a scale. On this scale you have to point with your finger how much you feel the situation has changed since you have joined the program. A smiling face indicates that it is much better, a sad face indicates that it is much worse.

We will do an example together.

Compared to before you joined the program, do you check your feet more regularly or do you check them less regularly?



If you check your feet much less than before you point here (*interviewer indicates place*)

If nothing has changed, so you check your feet as much as before, point in the middle (*interviewer indicates place*)

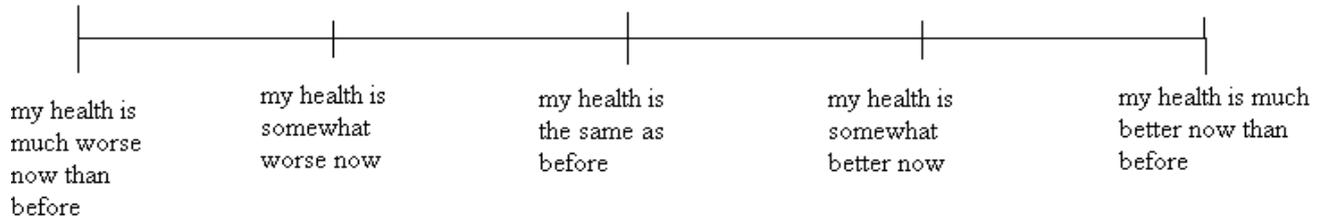
If you check your feet much more than before, point here (*interviewer indicates place*)

If it is in between, mark with your finger on the line where you feel you are. For example, if you check your feet just a bit more than before, mark here (*interviewer indicates place*).

We will now start with the questionnaire.

1* **Compared to before** you joined the program

How would you rate your health in general now?



Comment from peer:

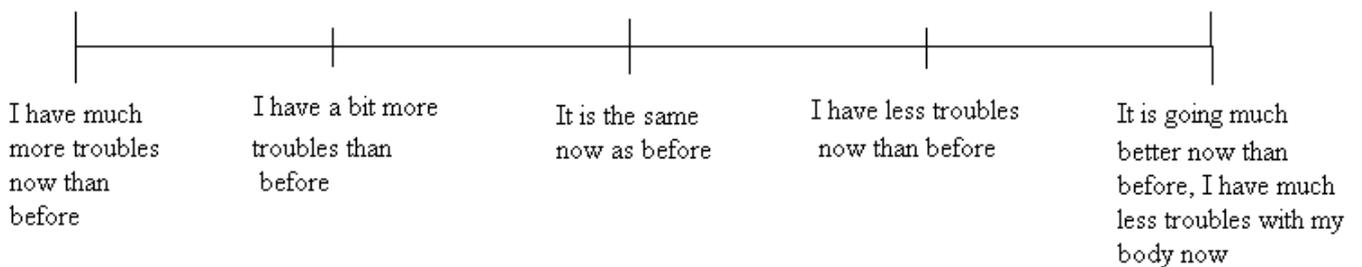
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2* **Compared to before** you joined the program

Do you have a more or less troubles on your body? (going to the toilet during the night, being very thirsty, feeling dizzy, troubles with your eyes, ...)



Comment from peer:

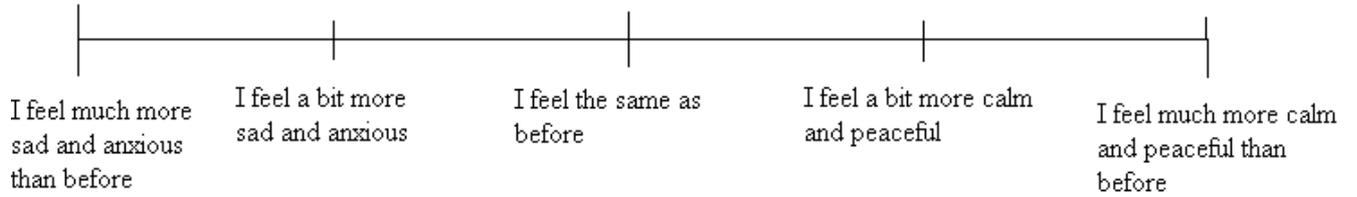
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3* Compared to before you joined the program

Do you feel more sad and anxious because you are sick or do you feel more peaceful and calm?

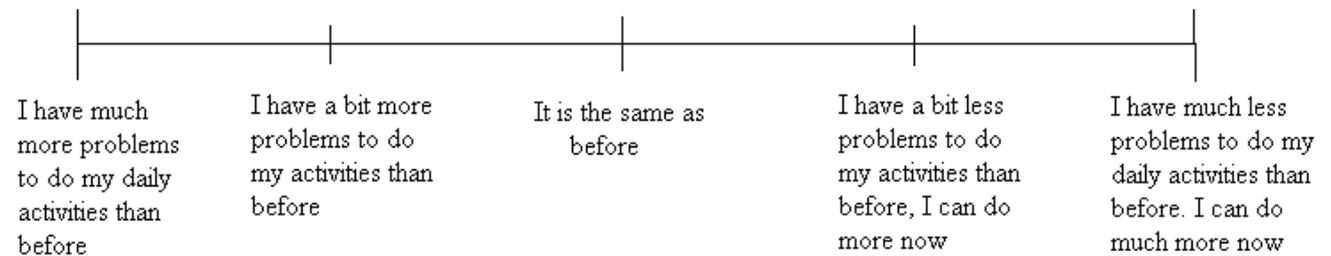


Comment from peer:

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4* Compared to before you joined the program:

Are you more limited in your daily activities because you are sick or can you do more now?

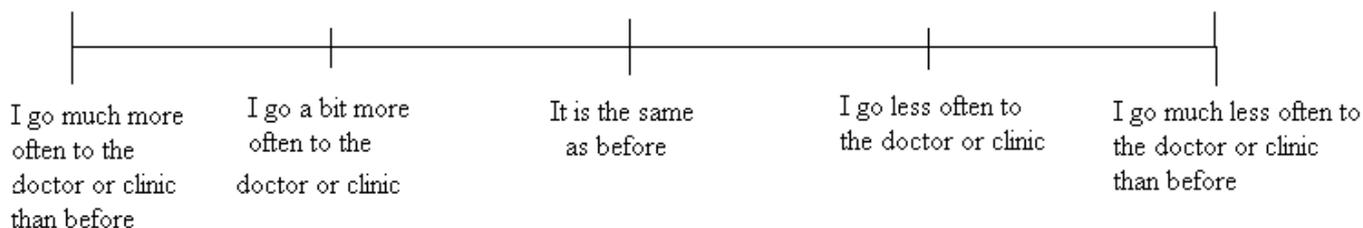


Comment from peer:

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5* Compared to before you joined the program:

Do you go more or less often to the doctor or clinic because you are very sick?



Comment from peer:

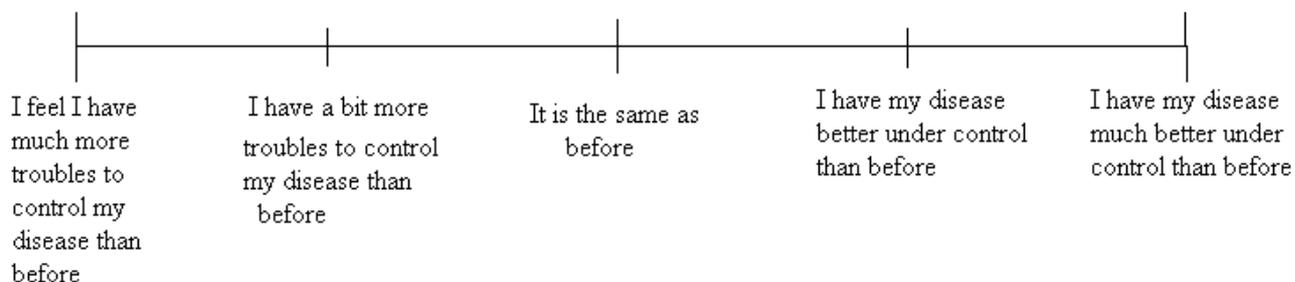
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6* Compared to before you joined the program:

Do you feel you have your disease more under control or not?



Comment from peer:

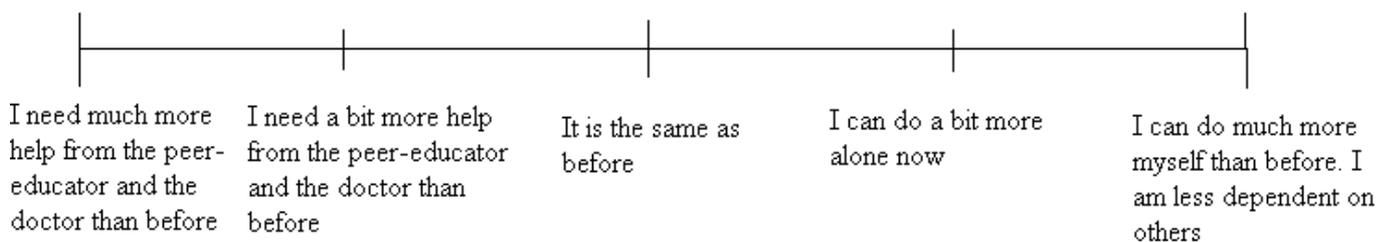
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7* Compared to before you joined the program

Do you feel you are more able to take care of yourself or are you more dependent on others?



Comment from peer:

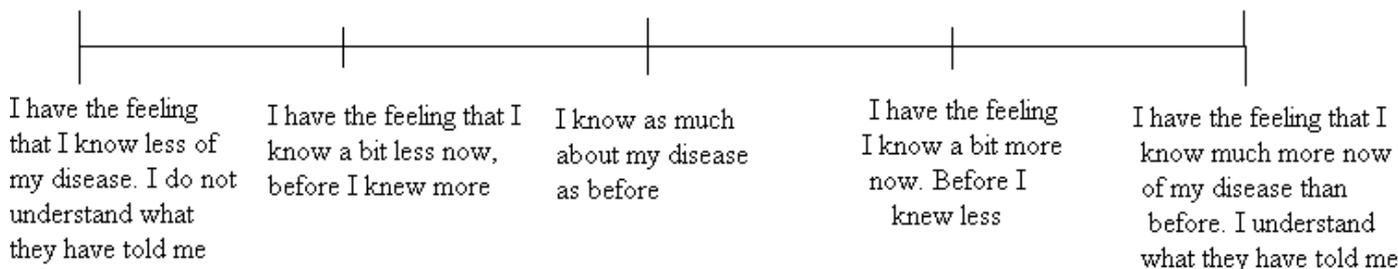
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8* Compared to before you joined the program

Do you feel you know more about your disease or do you feel you know less?



Comment from peer:

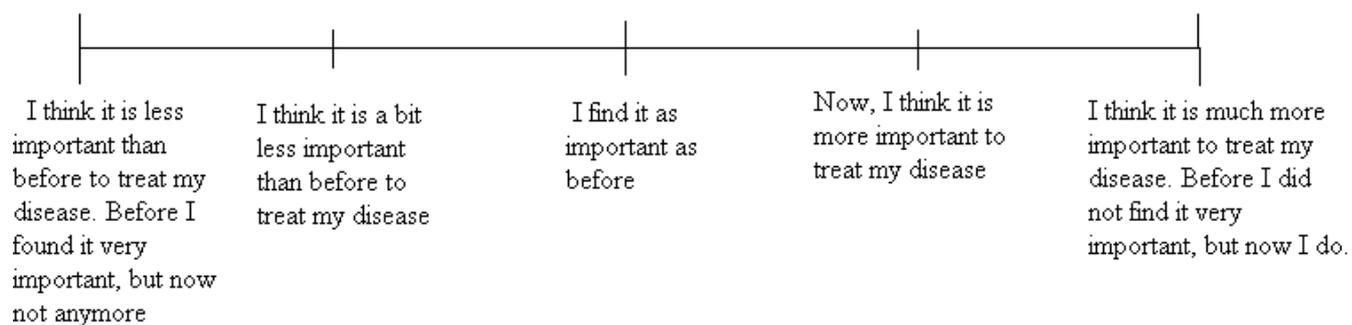
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9* Compared to before you joined the program

Do you think it is important to treat your disease?



Comment from peer:

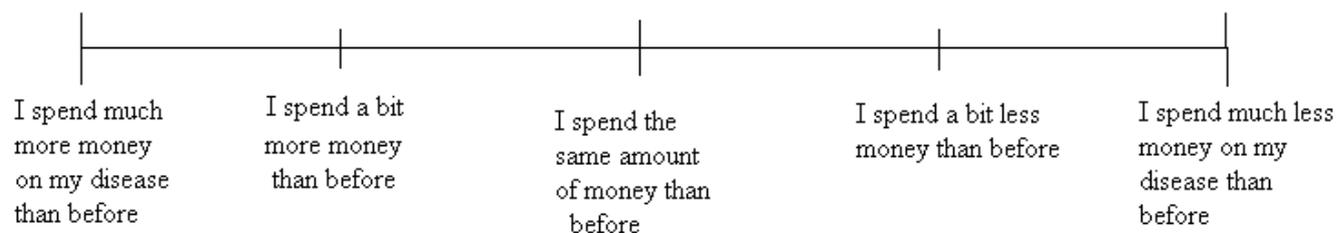
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10* Compared to before you joined the program

Do you spend a lot of money on your disease?



Comment from peer:

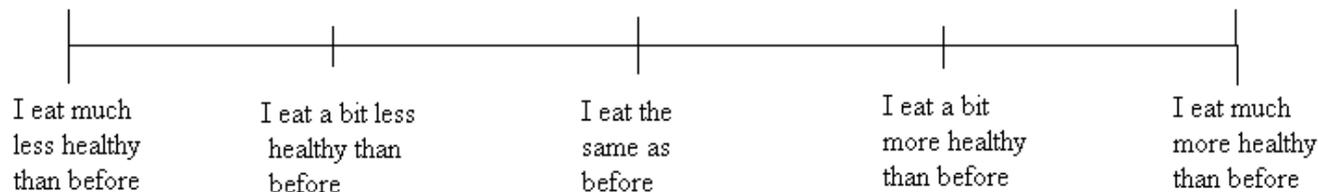
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11* Compared to before you joined the program

Do you eat more healthy or not?

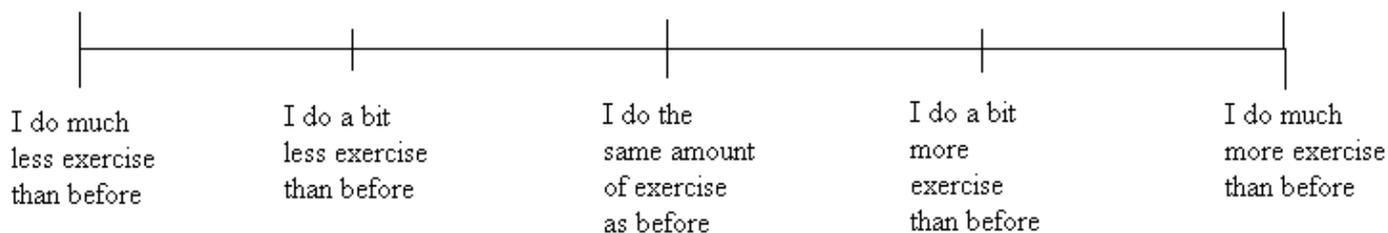


Comment from peer:

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12* Compared to before you joined the program

Do you do more exercise or less?



Comment from peer:

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Appendix V: Information sheet for the in-depth interviews

This information was be verbally transmitted by the interviewer before obtaining informed consent.

Patients:

We are going to ask you some questions about your experience of having diabetes, the difficulties you had in living with the disease and how the peer helped you with this.

This research is done by independent researchers and the interview is anonymous. An independent researcher will analyze what you have said and will, with the results of all the different interviews, formulate recommendations to MoPoTsyo so they can improve the program. Your name will not be mentioned in these recommendations, so no one except the interviewers will know which things you have said.

It is important that you answer our questions truthfully because we need to know the problems you have had and how the program can improve. The answers you give will in no way influence your further treatment, so please tell us everything that comes in your mind.

We are going to record this interview and write it down later. The tapes will be kept in a safe place and when the research is finished, they will be destroyed.

We are going to ask you questions about your illness, the difficulties you had in living with it and how the peer helped you with this. You will not be at physical or psychological risk and should experience no discomfort resulting from answering the questions. However, it is possible that you have some emotional discomfort regarding certain questions. You are free to withdraw consent and discontinue participation in this project at any time without any effects on your further treatment in the MoPoTsyo-program.

At this stage in the interview verbal consent will be asked. It will be emphasized that their participation in the study is voluntary and that refusal to participate will not influence their further treatment with MoPoTsyo.

Peers:

We are going to ask you some questions about your experience of having diabetes, how you see your role as a peer-educator, which problems the patients had and how you responded to these problems.

This research is done by independent researchers and the interview is anonymous. An independent researcher will analyze what you have said and will, with the results of all the different interviews, formulate recommendations to MoPoTsyo so they can improve the program. Your name will not be mentioned in these recommendations, so no one except the interviewers will know which things you have said.

It is important that you answer our questions truthfully because we need to know how you experience being a peer-educator and how you think the program can improve. The answers you give will in no way influence your role in the program, so please tell us everything that comes in your mind.

We are going to record this interview and write it down later. The tapes will be kept in a safe place and when the research is finished, they will be destroyed.

We are going to ask you questions about how you see your role as a peer-educator, which problems the patients had and how you responded to these problems. You will not be at physical or psychological risk and should experience no discomfort resulting from answering the questions. However, it is possible that you have some emotional discomfort regarding certain questions. You are free to withdraw consent and discontinue participation in this project at any time without any effects on your further role in the MoPoTsyo-program.

At this stage in the interview verbal consent will be asked. It will be emphasized that their participation in the study is voluntary and that refusal to participate will not influence their further treatment with MoPoTsyo.