The human perspective on

health-care reform: coping with

<u>diabetes in Kyrgyzstan</u>

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Kyrgyzstan is a small mountainous country with a predominantly agricultural economy; it gained independence with the break-up of the Soviet Union in 1991. For a significant sector of the Kyrgyzstani population, economic difficulties at national level translate into high unemployment and widespread impoverishment. Kyrgyzstan inherited an extensive but basic health-care system, with a functioning – albeit fragmented – structure for managing chronic diseases.¹ The authors of this article report on the findings of a rapid appraisal study which uses the St Vincent Declaration as a gold standard to assess the performance of diabetes care in Kyrgyzstan.

Kyrgyzstan is a landlocked country, trapped between the high mountains of the Pamirs and the Tien Shan and its larger neighbours Kazakhstan and Uzbekistan. Since independence in the early 1990s, health has been a significant issue for the new government. For people with diabetes for example,

deaths attributed to the condition have almost doubled (from 6.5 per 100 000 in 1990 to 11.3 per 100 000 in 2002), with a larger increase in Chui oblast (region). In a study of the situation, data from multiple sources were collected from the capital, Bishkek, and from Chui oblast, a mainly rural area.

The policy makers' perspective

Since 1991, the City Endocrinology Dispensary (clinic) in Bishkek has been responsible for the provision of outpatient care to local residents, as well as the development of health policy, and the implementation of diabetes services nationally. Despite its expanded responsibilities, the City Dispensary has received no additional funding. Equipment is obsolete and there is a lack of basic laboratory supplies. With some exceptions, diabetes care outside the capital is provided in regional and district hospitals that have few links with national-level institutions.

The City Dispensary is responsible for managing data on people with diabetes throughout the country and their insulin needs. In practice, however, these data are gathered by the chief endocrinologist, who calls regional colleagues by telephone and manually compiles the results.

Although a national register of people with diabetes is maintained,

it is not effectively used. The number of registered people with diabetes remained constant throughout the 1990s. This translates into a seemingly very low diabetes prevalence of 3.4 per 1000 in 2002; in 2001, of 16 295 people registered, 1693 (10%) had Type I diabetes. The level of complications is high: over 40% of people with diabetes suffer foot problems and over 30% have renal problems. While these figures for late-developing complications are considered underestimates, they are considerably higher than those in Western Europe and North America.

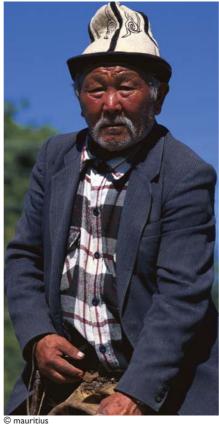
> National diabetes data are gathered manually by the chief endocrinologist through telephone calls to regional endocrinologists.

A comprehensive national diabetes programme (1999-2004) envisages the training of primary care providers (family physicians), improvements in the distribution of insulin and essential supplies, and enhanced clinical practice including education for people with diabetes, and self-management. However, despite approval by an inter-Ministerial committee, this has not been linked to designated funding.

The health professional's perspective

Insulin and diabetes supplies

According to the health professionals interviewed, the shortcomings of a fragmented, poorly functioning healthcare system that lacks physical and financial resources are exacerbated by low motivation among health carers -



a result of low salaries, long working hours, and an inadequate infrastructure. Primary care physicians reported a frequent lack of access to essential diabetes supplies. The endocrinology departments of the National Hospital and National Children's Hospital - both national referral centres for diabetes - lacked test strips and blood glucose meters, and experienced irregular supplies of insulin.

The hospitals in Kyrgyzstan are not permitted to provide insulin to people with diabetes after discharge from inpatient care - with inevitable adverse consequences. Staff report an increase in the number of people with diabetes admitted in coma (ketoacidosis) and with severe complications. The Kyrgyz Ministry of Health

purchases insulin by tender, based on the number - obtained from the City Dispensary - of registered people with diabetes. Often procured with substantial delays, these supplies are then distributed via the City Dispensary to regional facilities. Although the retention of state control over the distribution of insulin is intended to protect supplies, this has been compromised by the failure of budgets to keep pace with prices; and by logistical difficulties in ensuring that the medication actually reaches the people with diabetes.

Human resources, training and infrastructure

An inadequate capacity for the management of diabetes complications was widely reported. Health professionals at the City Dispensary were familiar with the principles of the St Vincent Declaration, which sets out internationally accepted recommendations for the detection and management of diabetes. In practice, however, they were financially and organizationally constrained from implementing its recommendations.

The decentralization process that was initiated in the late 1990s was not accompanied by sufficient training and investment in communication and infrastructure. Although in 1998 the Bishkek City Dispensary transferred responsibility to local clinics for the care of 2627 people with Type 2 diabetes, contrary to expectations, by 2001 the use of the Dispensary had increased markedly as people with diabetes

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from outside the capital returned to the city to seek what they perceived to be better quality care.²

Family physicians in rural areas were largely unaware of the presence of diabetes in the people under their care, and assumed that diabetes care was being provided by the City Dispensary. These primary care professionals reported their own inability to help anyone with a diabetes emergency; all primary care physicians reported a lack of training in the assessment of diabetes foot complications.

Family physicians in rural areas reported their own inability to help anyone with a diabetes emergency.

Furthermore, poor communications networks impede the effective functioning of the health-care system: care is provided by different specialists in various locations often not sharing information; endocrinologists reported that they were uncomfortable with the management of common diabetes complications such as foot problems; people are often transferred to general hospitals, where the specialized skills needed to manage their condition were absent.

The perspective of people with diabetes

The consistent underfunding of the Kyrgyz health-care system since independence has created a situation in which people with diabetes are required to make significant out-of-pocket contributions for the treatment

of severe complications, such as diabetes eye damage (retinopathy) or nerve damage (neuropathy). Consistent with other studies, interviewees reported that informal payments to medical staff and hospitals for essential diabetes supplies were endemic.³

Legislation which was designed to ensure free medical treatment is often disregarded outside the capital. While in hospital people with diabetes are often expected to bring their own diabetes drugs and equipment, and food.

The mainly hospital-based services for people with diabetes often involve invasive therapies. There is little use of self-management or conservative techniques. Thus minor foot ulcers are routinely referred to surgical departments where the standard treatment is an above-knee amputation – a last resort in Western Europe. Of the 27 people interviewed, only three had access to blood glucose meters and test strips in order to help manage their condition.

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Inadequate supplies

The inability to obtain consistent supplies of a prescribed type of insulin was the most frequently reported problem for people with diabetes in Kyrgyzstan. As a result, people with diabetes are continually forced to take life-threatening

risks, using products of varying strengths or duration of action. It is illegal for the state pharmacies to sell insulin; people with diabetes often buy their diabetes supplies at market stalls or from abroad.

Newly diagnosed people with diabetes in rural areas face particular problems. The study found that health facilities outside Bishkek rarely held sufficient insulin for new cases of the condition and often lacked even basic equipment to perform blood and urine tests. As a result, people often had to go without treatment for several days until supplies could be obtained. Most interviewees reported bypassing local health centres when possible.

Fear and frustration

Currently, people with diabetes are entitled to a small disability pension from the Ministry of Social Protection and Labour. However, to obtain this pension, an annual in-patient medical assessment lasting 10-12 days is required – a hang-over from Soviet days. The process involved in this assessment caused anxiety among people with diabetes due to the inflexibility of timing of admission, the expense incurred, and the potential loss of financial support.

Young people with diabetes are often educated in separate schools from their peers and excluded from routine physical activities – provoking feelings of isolation and frustration. Sadly, there were reports of children with no hope for the future who were unwilling to take insulin. Many adults reported accepting that their

children would die prematurely. Although seven of the people interviewed were attending a diabetes education programme in Bishkek, the majority reported a lack of such support from health-service agencies. Other than a basic idea of the relationship between food intake and insulin use, few of the people interviewed had any knowledge of how to manage their condition.

Over half of those interviewed complained about the late diagnoses of diabetes, inadequate management of complications, and inappropriate referrals. Of the 27 respondents, 23 reported pain in their feet and feared a possible amputation. Moreover, medical professionals were perceived as lacking in interpersonal skills and unsympathetic to the needs of people with the condition.

Messages from the study

Important efforts are being made to improve diabetes care in Kyrgyzstan. However, despite the large number of health professionals per capita and the ambitious training of family physicians, the study highlighted a significant lack of functional capacity — especially in rural areas — resulting in the ineffective management of diabetes at local level.

Investment in a number of areas appears to be imperative. There is a need to improve access to physical resources, such as glucose meters and test strips. The stable supply of insulin must be ensured — especially in rural areas. The system for procurement and distribution

of insulin should be re-evaluated. An emphasis should be placed on evidence-based practice, with a particular emphasis on self-care. Given the shortage of basic resources, the annual in-patient assessments discussed above are wasteful as well as serving no purpose. Doing away with these requires changes in the regulations regarding social protection. National guidelines on the appropriateness of interventions - such as widely used amputations - should be formulated, and staff trained in simple conservative management. Links between the different levels of the health system should be established in order to ensure continuity of care for people with diabetes.

These different requirements are interlinked. Investment in one without attention to the others is likely to fail, as demonstrated by the experience of the foot specialist who, having received expensive training, received no resources to use it.

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