Integrated health systems for chronic disease management: lessons from Type 1 diabetes in Low Income Settings

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Abstract
This thesis is a review of a series of articles looking at different aspects of diabetes management in low and middle incomes countries. From the lessons learnt this work aims to develop a model for integration of diabetes and chronic diseases.

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“Integrated health systems for chronic disease management: lessons from Type 1 diabetes in Low Income Settings”

Thesis submitted to the Faculty of Medicine of the University of Geneva

for the degree of Privat-Docent

by

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Geneva, Switzerland

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<th>Description</th>
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<tbody>
<tr>
<td>DALY</td>
<td>Disability Adjusted Life Year</td>
</tr>
<tr>
<td>DKA</td>
<td>Diabetic Ketoacidosis</td>
</tr>
<tr>
<td>GNI</td>
<td>Gross National Income</td>
</tr>
<tr>
<td>HIC</td>
<td>High Income Country</td>
</tr>
<tr>
<td>ICCCF</td>
<td>Innovative Care for Chronic Conditions Framework</td>
</tr>
<tr>
<td>LIC</td>
<td>Low Income Country</td>
</tr>
<tr>
<td>LILMIC</td>
<td>Low Income and Lower Middle Income Country</td>
</tr>
<tr>
<td>LMIC</td>
<td>Lower Middle Income Country</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development Goal</td>
</tr>
<tr>
<td>NCD</td>
<td>Noncommunicable disease</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>RAP</td>
<td>Rapid Assessment Protocol</td>
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<tr>
<td>SDG</td>
<td>Sustainable Development Goal</td>
</tr>
<tr>
<td>UHC</td>
<td>Universal Health Coverage</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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**Executive Summary**

Diabetes is a leading cause of morbidity and mortality worldwide and has been prioritised by the World Health Organization within its Global Action Plan for the Prevention and Control of Noncommunicable Diseases. Although in terms of burden Type 2 diabetes represents 95% of overall cases of diabetes, management of Type 1 diabetes in low resource settings allows for insight into chronic disease management. Chronic diseases require a variety of health system factors in order to be effectively managed by the individual and it has been argued that health systems are ill equipped to deliver this care. To address this shortcoming the World Health Organization and other experts have called for a shift in focus in the organisation of health systems including the role of the community and other stakeholders in order to adapt the delivery of care and overall environment to individuals with chronic diseases.

One approach proposed is the concept of integrated care. To date integration has focused on health system factors, such as integration in multi-disciplinary teams or between primary, secondary and tertiary care. This has not taken a larger view of the needs of people with a chronic disease. The articles included in this thesis focus on a holistic view of health systems in terms of assessing each individual component of the system as well as the interaction between different elements. This integrated view of the system is not only needed to assess barriers, but also propose and develop solutions. These elements include a Positive policy environment; Organisation of the Health System; Data Collection; Prevention; Diagnostic tools and infrastructure; Drug procurement and supply; Accessibility and affordability of medicines and care; Healthcare workers; Adherence; Patient education and empowerment; and Community involvement and diabetes associations. Case studies from Kyrgyzstan, the Philippines and Vietnam, included in this thesis, show that changes in policy need to be integrated into the local context and the reality of diabetes management. That said these wider system factors need to be integrated throughout the individual’s diagnosis, treatment and follow-up and be tailored to their needs.

In order for integration to be successful this should take place at four levels. At a global level this integration needs to be crosscutting including social, economic, environmental and
health issues. This approach should integrate health in all areas of government as well as the health sector integrating other sectors in health related decisions. National level integration is how global policy debates are integrated into national realities. Local stakeholders, such as diabetes associations, need to be included in policy discussions in order to help shape policy and its translation into health system responses. Health system level integration includes integrating the delivery of care and the community. This includes vertical integration and the role of the health system at each level of care, as well as horizontal integration in having different healthcare teams, tools and the community present at each of these echelons of service delivery. Finally at the individual level integration needs to take into account the individual with all their needs, their family situation and ensure that the health system as well as the community supports them.
1. Introduction

Diabetes is a chronic disease, defined by the World Health Organization (WHO) as a Non-communicable disease (NCD) and together with other NCDs is responsible for 52% of global deaths (1). Diabetes and other NCDs have been prioritised by the WHO in the Global Action Plan for the Prevention and Control of NCDs which has its overall aim a “25% relative reduction in premature mortality from NCDs by 2025” (2, 3). In 2010 diabetes was responsible for four million deaths in people aged 20 to 79 (4) and by 2030, diabetes will be responsible for 2.3% of global Disability Adjusted Life Years (DALY), compared to 1.3% in 2004 (5). Globally it is estimated that 381 million people aged 20-79 had diabetes in 2013 with an additional 175 million people living with diabetes but not having been diagnosed (6). Estimates for 2035 show that there will be 592 million people with diabetes, a 55% increase over the period 2013-2035. The greatest increase in diabetes will be in low and middle income countries (6).

This thesis will focus on those countries defined by the World Bank as low income (LIC) and lower middle income countries (LMIC) (7). These will be referred to as low income and lower middle-income countries (LILMIC). For the purpose of classifying different countries the World Bank uses Gross National Income (GNI) per capita. LICs are countries with a GNI per capita of US$ 1,045 or less (7). LMICs have GNI per capita of US$ 1,046 to US$ 4,125. Countries included in this grouping vary from India, Nigeria, Haiti and Bhutan. (Appendix 1) African countries represent 46.3% of the total 82 LILMICs (8). These countries represent 69.4% of global population or 3.5 billion people. Median GNI is US$ 1,350 (Range: US$ 250-US$4,060). Levels of poverty are also high in these countries with the proportion of the population living under the national poverty line ranging from 7%-75% (Median: 39%). Average health expenditure per capita is US$30 in LICs and US$82 in LMICs in comparison to US$4,586 in high income countries (HIC) (9). In 2012 in LICs life expectancy at birth for men was 60.2 year and for women 63.1 years. For LMICs this was 63.8 and 67.9, whereas in HICs this was 75.8 and 82.0.

LILMICs are facing an epidemiological transition, with increases in the prevalence of and mortality related to NCDs (10, 11). These transitions in disease patterns are linked to
globalisation, urbanisation and changes in the economic, social and demographic factors of LILMICs. NCDs coexist with communicable diseases in these contexts leading to a double burden of disease (5, 12). The 2010 Global Burden of Disease study found approximately 80% of NCD deaths now occur in low and middle income countries (13). In both South Africa (14) and Tanzania (15) the burden of chronic disease and the need for chronic care are now more important than that for acute care. Although NCDs were not included in the Millennium Development Goals (MDGs) they have now been placed on the development agenda with their inclusion in the Sustainable Development Goals (SDGs) (16, 17).

Whereas most of the focus of the WHO diabetes agenda relates to Type 2 diabetes, Type 1 diabetes is most common chronic NCD to affect children after asthma (18). Type 1 diabetes affects populations throughout the world and its incidence is increasing (19-25) especially in younger children (20, 26-28). Incidence of Type 1 diabetes varies between and within geographic regions as well as within the same country (29-34). Some have argued that these differences in incidence rates might be linked to better case detection. Estimates from the International Diabetes Federation are that 497,100 children (0-14 years age) have Type 1 diabetes and that its prevalence is increasing by 3% per year (6). In HICs it is thought that Type 1 diabetes represents between 10% and 15% of total diabetes cases, however in low and middle income countries this is probably lower (35). Estimates would suggest that total population of people with Type 1 diabetes is 5% of the overall diabetes burden (estimated at 381 million) or 19 million people (6). LILMICS have a total of 197,246 children aged 0-14 with diabetes or 40% of total cases (4). India, an LILMIC, has the second highest number of children globally with Type 1 diabetes after the United States (36).

Type 1 diabetes represents a unique example of a chronic disease requiring a variety of health system factors in order to effectively manage this condition on a daily basis (37). This condition includes the need for daily insulin, monitoring, adaptation of diet and lifestyle as well as regular health checks. Many guidelines and standards exist for the management of Type 1 diabetes (38-40). In addition the Diabetes Control and Complications Trial showed that in a study setting by providing optimal care diabetes complications could be averted (41).
Type 1 diabetes affects individuals throughout their life meaning constant adaptation to different life course factors (school versus work; paediatric versus adult care). Depending on where these individuals live the focus of diabetes management and care is different. The focus in HICs for the management of Type 1 diabetes is the prevention of both acute (hypoglycaemia, hyperglycaemia and Diabetic Ketoacidosis: DKA) and long-term (retinopathy, neuropathy and nephropathy) complications. Acute complications are linked to factors of daily management of diabetes leading to low (hypoglycaemia) or high (hyperglycaemia) blood glucose levels. These are caused by too much or too little food consumption in comparison to insulin dosage, administration of too much insulin and inadequate insulin dosage and food consumption prior to physical activity (18, 42). In addition infections can be a cause of DKA. In order to avoid hypoglycaemia or hyperglycaemia, individuals need to monitor their blood glucose, balance insulin administration with food intake and physical activity. The prevention of long-term complications is achieved by maintaining a “low” blood glucose level, needing a safe balance between avoiding hyperglycaemia in parallel to preventing hypoglycaemia (43). Diabetes management in HICs can be seen as fine-tuning of blood sugars with the use of a variety of tools such as blood glucose meters, continuous blood glucose monitoring and insulin pumps (44-52).

In LILMICs the challenges faced by individuals with Type 1 diabetes are those of survival, as currently the most common cause of mortality in children with diabetes is lack of access to insulin (53). This results in the life expectancy of a child with Type 1 diabetes in rural Mozambique being seven months in comparison to almost four years in the capital city (54). In the Democratic Republic of Congo one out of six people with Type 1 diabetes died within five years of diagnosis (55). In contrast Miller et al. (56) found that for people diagnosed with Type 1 diabetes in the 1960s and 1970s in the USA, the difference in life expectancy with that of the general population is only four to six year less. One of the main drivers of this difference is that access to insulin in many LMIC is problematic due to issues of affordability and availability (57-62). Provision of medicines is one of the six health system building blocks proposed by the WHO (63) and an inability to deliver insulin to those in need is a clear failure of health systems. Studies in six LILMICs found that the cost per vial of insulin in the public
sector varied from free in Kyrgyzstan and Nicaragua to US$ 10.9 per vial (or US$ 141.4 per year) in Mali (64, 65). Prices in the private sector were significantly higher as presented in Figure 1.

Figure 1 – Annual cost of insulin to individuals in the public and private sectors in six LILMICS adapted from Beran et al. 2016 (62); Beran and Yudkin 2010 (64); Beran et al. 2013 (65); and Beran et al. 2010 (66)

As can be seen in Figure 1, two countries, Kyrgyzstan and Nicaragua, provide insulin for free in the public sector, Vietnam provides insulin for free in the public sector for those with insurance, Mozambique and Zambia subsidise insulin and Mali has a high cost even in the public sector. The other aspect is can individuals actually access the insulin they need. Availability in facilities visited in six LILMICS was variable and ranged from 17-100% in the public sector. (Figure 2) Unavailability in the public sector meant that individuals needed to purchase their insulin in the private sector at higher costs. That said availability in the private sector in many contexts was also poor highlighting the challenge of access to this life saving medicine.
Figure 2 – Availability of insulin to individuals in the public and private sectors in six LILMICs adapted from Beran et al. 2016 (62); Beran and Yudkin 2010 (64); Beran et al. 2013 (65); and Beran et al. 2010 (66)

<table>
<thead>
<tr>
<th>Country</th>
<th>Public Availability (%)</th>
<th>Private Availability (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mali (2004)</td>
<td>17%</td>
<td>60%</td>
</tr>
<tr>
<td>Mozambique (2003)</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>Nicaragua (2007)</td>
<td>20%</td>
<td>65%</td>
</tr>
<tr>
<td>Vietnam (with HI and IL)</td>
<td>20%</td>
<td>65%</td>
</tr>
<tr>
<td>Vietnam (without HI and IL)</td>
<td>20%</td>
<td>75%</td>
</tr>
<tr>
<td>Zambia (2003)</td>
<td>35%</td>
<td>93%</td>
</tr>
<tr>
<td>Kyrgyzstan (2009)</td>
<td>0%</td>
<td>35%</td>
</tr>
<tr>
<td>Mozambique (2009)</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

HI = Health Insurance
IL = Insulin donation

Mean diabetes expenditure per person with diabetes ranged from US$ 20.89 to US$ 441.18 (Median: US$ 115.63) in LILMICs (6). (Appendix 1). Insulin is only one cost that individuals with Type 1 diabetes have. In looking at the highest cost of care for people with Type 1 diabetes insulin was only the highest cost in Mali. In Mozambique and Vietnam the highest cost was transportation whereas syringes represented the highest proportion of total costs in Nicaragua and Zambia (64). (Figure 3) These total costs represented 61%, 75%, 7%, 21% and 51% of per capita GNI in Mali, Mozambique, Nicaragua, Zambia and Vietnam representing a different financial burden on people in these countries. This is in contrast to HICs where many times these costs are covered by health systems or insurance schemes.
Other health system factors such as training of health professionals, diagnostic tools being present, and diabetes related policies are barriers to proper diabetes care in resource poor settings also contributing to this decreased life expectancy (54, 67). The example for Type 1 diabetes highlights the problems of managing chronic diseases in and that health systems require a shift from an acute to a chronic care model (5, 12, 68, 69). In order to address the challenge of NCDs and Type 1 diabetes health systems need to deliver certain aspects of care. The WHO defines a health system as all the “activities whose primary purpose is to promote, restore and maintain health.”(70), and has three main aims:

1. Increasing health of the populations they care for
2. Meeting population’s requirements
3. Protecting the population from the financial burden of illness

Health systems are not isolated from the wider social and political elements in a given context (63, 71). Therefore it is important to keep in mind the context of these countries in terms of GNI per capita, health expenditure, etc. (Appendix 1). Also different models of
health systems exist, but according to the WHO all health systems are composed of 6 building blocks (63):

1. Service delivery: healthcare provision, facilities and infrastructure that are safe and of good quality
2. Health care human resources
3. Information: Research, studies, routine surveillance systems and data collection tools for individual patients, e.g. patient files
4. Medicines, vaccines and other medical technologies, e.g. syringes, surgical equipment
5. Financing: where do the resources for the health service come from, e.g. taxation or out of pocket expenditure
6. Leadership and governance: role the health sector plays in engaging other stakeholders to address health related issues

Travis et al. (72) argue that stronger health systems are required to ensure improved health for populations. Wagner et al. (73) add that for chronic diseases health systems do not provide people the needs they have in terms of clinical care, information and psychological support. Within this context health systems for the care of Type 1 diabetes need to address both the prevention of complications and the physical and psychosocial effects of the disease on the individual (74).

The challenge is that it is argued that health systems need a “paradigm shift” from organisation around the delivery of acute care to models adapted to chronic diseases (5, 12, 68, 69). Nolte and McKee (75) contend that the largest challenge that health systems face globally is the management of chronic diseases. They add that each health system will need to find a locally adapted response to this challenge. In managing chronic conditions the health system needs to be able to provide long term care, which includes a team of healthcare workers with different skills, medicines, diagnostic tools, education and information, as well as coordinating these within and between different levels of the health system (76).
To address this challenge of management of chronic diseases in health systems Wagner et al. (77) developed the Chronic Care Model. In order to adapt this model for LILMICs the WHO further expanded this model into the Innovative Care for Chronic Conditions Framework (ICCCF) (78) by putting more emphasis on the positive policy environment and community elements. (Figure 4) The ICCCF combines three levels, the Macro level or Positive Policy Environment; the Meso level including the Community and Health System; and finally the Micro level including the three elements of community partners, healthcare team and most importantly individual with a chronic disease and their family.

**Figure 4 – WHO Innovative Care for Chronic Conditions Framework copied from World Health Organization 2002 (78)**

The ICCCF provides the different pieces of the overall puzzle in order to develop a health system capable of managing chronic diseases (79). From this framework there are certain guiding principles that are aimed at improving the delivery of care for chronic conditions. The ICCCF calls for a suitable policy environment to be established as policies outside the health system will need to be aligned to ensure proper prevention and management of chronic diseases. This is associated with one of the six building blocks of the health system, namely the Leadership the health system needs to play in ensuring “healthy policies” in a wide range of areas.
Transitioning from the delivery of acute to chronic care is a challenge for healthcare workers (80). One of the main challenges is that burden of care is placed on the individual outside of the health system and control of the healthcare provider. This requires training, having the right type (training and cadre) of health personnel present and defining appropriate roles for each type of health professional (e.g. role of nurse versus doctor) (77). There is also a shift in the role of the healthcare worker from being the expert, providing instructions and deciding for the patient, to serving as a guide providing support, advice and help for their patient as they manage their condition (81). However, the health system needs to provide the necessary environment and tools that allows the individual with the chronic condition to take on this responsibility (74, 75) with the support of the community (46, 73, 77).

One way that has been proposed to address the challenge of managing chronic conditions is through integrated care. Armitage et al. (82) found a variety of definitions for integrated care. Most of these focused on continuity of care within the health system. Integrated care is sometimes referred to as “Shared care”, “Transmural care”, “Intermediate care”, “Seamless care”, “Disease management”, “Case management”, “Continuous care”, “Integrated care pathways”, “Integrated delivery networks” or “Managed care” (83, 84). The WHO proposes two definitions for integrated care, namely:

- The “organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money.” (85)
- “The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system.” (86)

The perception of integrated care is often that it is focused on the links between health and social care for elderly individuals with chronic illness and/or disabilities (83, 84, 87, 88). Studies in the area of integration of care from HICs often focus on integration in the area of human resources, e.g. integrating nurses, specialists and non-specialists (89-96) or even complementary and alternative medicine (97) as well as how technology can be a facilitator
for integration (98-109). In a review focusing on Canada, Suter et al. (110) highlight 10 key principles for successful health systems integration, which include: a complete package of services of care; focusing on the individual; linking services to population needs; and use of multi-disciplinary teams.

In LILMICs the focus of the literature on integration can be divided into four general categories. Firstly, the literature on barriers to integration between two specific services, e.g. antenatal care and HIV/AIDS (111, 112). The next category focuses on expansion of services and integration of these into health systems and public health responses (113-117), including for example health issues such as Hepatitis C, surgery, palliative care and mental health. These articles argue for the need to address these health issues and how they might be integrated within the existing health system. Integration of communities in provision of health services forms part of the third category of available literature for LILMICs on the topic of integration (118-120). Finally, some authors propose new models of integrated care especially focusing on primary health care (121) or between different diseases (e.g. NCDs and HIV/AIDS) (122).

In looking at integrated care in Type 1 diabetes this “integration of care” often focuses on having services to integrate the transition from paediatric to adolescent and adult care (123), integration with other specialities such as eye and foot care (18) and also addressing psychosocial issues, but mainly focusing on depression (124). In thinking about integration and diabetes care there are two ways of looking at this integration:

- Horizontal integration and linking same levels of care (85), e.g. multi-disciplinary teams (18)
- Vertical integration and integrating different levels of care (85) e.g. links between primary, secondary and tertiary levels (125, 126)

Most of this literature on integration and Type 1 diabetes is from HICs with no literature identified specifically on this topic in LILMICs.
Lloyd and Wait (88) argue that the aim of integration of care for the individual is seamless care, across ages and diseases. For the carer this integration impacts coordination and cooperation with different specialities and also includes integration outside traditional settings. Finally from the policy maker’s perspective it is the recognition that there might be multiple impacts of policies and interventions. Therefore this integration can take the shape of a package of defined services for a given target population (86). For example integrated diabetes care, which provides a “one-stop shop” for all aspects of this given disease. This target population could also be defined as needing specific integrated services, e.g. health and social care (82) with the delivery of a range of services under one roof. Another important point raised by Lloyd and Wait (88) is at what level should integration happen. Is it at a policy level, the health system level, or at the level of the individual.

In the literature there are different perspectives on the issue of integration in health at these different levels. These include the global perspective on the need to integrate specific health programmes in order to avoid fragmentation of funding and vertical programmes (86). Another perspective is that of the WHO with the concept of “health in all policies” (127). This approach attempts to integrate health in all areas of government as well as the health sector integrating other sectors in health related decisions. Another global policy focus regarding integration has been defining the response through the development of Primary Health Care (PHC) (86). Since the late 1970s PHC has been seen as an essential approach in reducing health inequalities and providing care, information and services to the population (128). PHC provides the first point of entry for care, a link to higher levels of the health system or other services to improve health as well as a coordinating role with a focus on the individual (129-131). (See Appendix 2 for diagram describing the role of PHC within the overall health system). From the WHO perspective PHC includes the objective of Universal Health Coverage (UHC) (129) which aims to provide affordable, quality health-care services to all people. Three dimensions of UHC include which portion of the total population is covered, what services are part of the package of covered services of care (e.g. all care related to maternal health) and how much of the total cost is covered (132). (See Appendix 3 for the WHO model on UHC) Many LILMICs although aiming for UHC have not achieved this despite its prioritisation in a 2012 United Nations Resolution and the SDGs (16, 133, 134).
Integration is a key aspect of the ICCCF (Figure 4) (79). At the national/Macro level integration is when different decisions on policies impacting health are not compartmentalised by type or area of expertise, e.g. finance, urbanisation and trade (86). Also at the Macro level is the integration of non-state actors in policy processes. Meso/delivery of services level integration is that health services are regrouped based on the needs of individuals versus segmented by speciality or level of the health system. This includes integration within each level of the health system, coordination of services between different levels of the health system (e.g. referrals) as well as different services within the same institution (inpatient and outpatient services, pharmacy, laboratory). Within this integration of the functions of the health system is also the inclusion of the role of the community and other stakeholders outside the health system. The most important element of the ICCCF is the individual and their family as they face the burden of care on a daily basis (135). In order to allow them to play this role the health system needs to provide education and empowerment in addition to clinical care (46, 73, 77). However, as it has been described in the literature, health systems often fail to address the non-clinical needs of individuals with chronic diseases (73, 78, 136, 137). The integration of different levels of the health system is also essential as “treating patients for one condition without recognising other needs or conditions, ... undermin[es] the overall effectiveness of treatment.”(88)

The articles included in this thesis highlight previous work on health assessments in a variety of LILMICs (Mozambique and Zambia (Section 2.1), Vietnam (Section 2.6) and Kyrgyzstan (Section 2.5)) and the barriers to care in these settings. They also describe a variety of aspects that need to be taken into account when thinking about integration and health systems for diabetes care. Two reviews included look at this issue. One describes (Section 2.2) the situation in sub-Saharan Africa and proposed 11 elements needed for proper diabetes management. The other Review (Section 2.4) looks at using Type 1 diabetes as a tracer condition for management of chronic diseases as well as the need to expand beyond the health system for proper diabetes management. Another research article on a reassessment after implementation of a variety of projects (Section 2.3) highlights the need for an integrated approach to developing solutions for diabetes in LILMICs. The final
publication included (Section 2.7) is a qualitative study looking at the wide range of needs that individuals with Type 1 diabetes have and how the health system needs to adapt to this.

The WHO defines health as “total social, psychological and physical well-being.”(138) In order to achieve health for the populations they serve, health systems need to adapt their role to meet the needs of their populations. For Type 1 diabetes this care goes beyond that of the formal health system as an individual will need to manage their diabetes at home, school, work, community without the continuous assistance of a health professional. This thesis will aim to highlight lessons from Type 1 diabetes in LILMICS through integrating various health system and non-health system factors in order to improve the care for those with chronic diseases.
2. Articles

2.1. Access to care for patients with insulin-requiring diabetes in developing countries: case studies of Mozambique and Zambia


Summary
This study assessed access to diabetes care in Mozambique and Zambia using a Rapid Assessment Protocol (RAP) utilising multiple methods and data sources. Included were interviews, document reviews and observations at different levels of the health system from the Ministry of Health, health facilities, healthcare workers and individuals with diabetes. Taking a wider view the assessment also included interviews with the Ministries of Trade and Finance, the private sector (pharmacies and clinics) as well as Traditional Healers. With each of these stakeholders the aim was the understanding of the overall system of provision of care for diabetes and included the following elements:

- Organisation and delivery of diabetes care
- Resource allocation for diabetes
- National diabetes policies and programmes
- Factors related to insulin: trade issues, taxes, tendering, pricing, distribution
- Access to diagnostic tools
- Training for diabetes
- Patient factors, e.g. access to treatment, education, costs

The results of the study show that for insulin overall quantities were sufficient, but national distribution was problematic. In Mozambique in only 20% of facilities where insulin should have been present was it actually there. With regards to cost of insulin the Ministries of Health in each country purchased a 10ml 100IU vial at a price ranging from US$ 4.30 to US$ 4.60. Insulin was subsidised for individuals in both countries, with the average cost per vial being US$ 1.13 in Mozambique and US$ 2.00 in Zambia. Access to diagnostic tools was
poor with only 6% and 25% of facilities in Mozambique and Zambia respectively having the
tools to measure blood glucose. In both countries there was a lack of familiarity with insulin-
requiring diabetes, proper referral systems, care guidelines, knowledge and training. It is
interesting to note the importance of traditional healers in both settings and their role in
overall provision of care.

*What this adds to the argument of the overall thesis*

Based on its approach this study took an integrated view of diabetes care as it looked at this
from a Macro, Meso and Micro view. It did this by looking at diabetes care from the
perspective of the Ministry of Health, health facilities, health providers and individuals with
diabetes. This integrated approach went further in integrating other policy areas (Trade and
Finance), sectors (Private sector), community (diabetes association) and traditional healers.
In doing this it focused on the needs of people with diabetes in these two countries, but
looking at this from an integrated perspective.
Access to Care for Patients With Insulin-Requiring Diabetes in Developing Countries

Case studies of Mozambique and Zambia

David Beran, MSC
John S. Yudkin, MD, FRCP
Maximilian de Courten, MD, MPH

OBJECTIVE — The objective of this study was to assess the barriers to care for patients with insulin-requiring diabetes in Mozambique and Zambia.

RESEARCH DESIGN AND METHODS — We used the Rapid Assessment Protocol for Insulin Access to collect information through interviews, discussions, site visits, and document reviews. Government organizations, health facilities, care givers, and patients were asked about care for people with insulin-requiring diabetes. Between 100 and 200 interviews/discussions per country were undertaken in and around the capital city and the regional capital and in a rural area.

RESULTS — Insulin was present in both countries in sufficient quantities, although the financial burden for health services and patients means that problems with supply exist. There are problems with quantification of needs and equitable distribution of insulin. Problems with availability of syringes and testing equipment were noted, particularly in Mozambique. This lack of tools and infrastructure for diagnosis and follow-up coupled with low levels of health care worker training and lack of diagnostic reagents resulted in a substantial risk of misdiagnosis or failure to detect diabetes. The estimated prevalence of insulin-requiring diabetes differs more than 10-fold between urban and rural areas in Mozambique and 4-fold between Mozambique and Zambia, suggesting that problems in diagnosis and care result in substantial worsening of prognosis for such patients.

CONCLUSIONS — Insulin is necessary but not sufficient to improve prognosis for diabetic patients. A Rapid Assessment Protocol methodology can be used to define problems in health care delivery for diabetes. Proper care for insulin-requiring diabetes necessitates health systems able to provide trained personnel, medicines in sufficient quantity, and diagnostic and monitoring facilities.

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From the International Insulin Foundation, London, U.K.

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Abbreviations: IIF, International Insulin Foundation; RAIPA, Rapid Assessment Protocol for Insulin Access.

A table elsewhere in this issue shows conventional and Systeme International (SI) units and conversion factors for many substances.

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Type 1 diabetes has been estimated to affect ~19,000 people in the world’s poorest countries (1), but there are a lack of good data on the disease prevalence in developing countries and in particular in sub-Saharan Africa. The annual incidence of type 1 diabetes in East Africa was found to be 1.5 per 100,000 population aged 0–19 years (2) compared with 10.3 per 100,000 population in African Americans (3) and 18 per 100,000 population in the U.K. (4). However, the low prevalence of the condition may reflect poor prognosis as well as low incidence.

Type 1 diabetes is an expensive disease not only for patients but also for health systems. It has been estimated that the average annual cost of care for an East African patient with type 1 diabetes is $229, of which around two-thirds is for the purchase of insulin (5). This low prevalence and high cost mean that type 1 diabetes is likely to be low on the list of priorities for the ministries of health in sub-Saharan Africa.

Leonard Thompson, the first patient to be treated with insulin for type 1 diabetes, was given his first injection on 11 January 1922 (6). Three-quarters of a century after its discovery, insulin is still not available on an uninterrupted basis in many parts of the developing world (7–9). In consequence, the prognosis is likely to be poor for patients with type 1 diabetes in much of sub-Saharan Africa (10,11). There are, however, few detailed studies of patterns of diabetes care in these situations. We have investigated patterns of diabetes care in two African countries and related these to estimates of prevalence and prognosis.

RESEARCH DESIGN AND METHODS — The International Insulin Foundation (IIF) was established to improve the prospects for type 1 diabetic patients in the world’s poorest countries. To achieve these objectives, a clear analy-
Table 1—Questionnaires that make up the RAPIA

<table>
<thead>
<tr>
<th>Interviewees</th>
<th>Issues addressed in each RAPIA questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Macro</strong></td>
<td></td>
</tr>
<tr>
<td>Ministry of Health</td>
<td>Organization of delivery of diabetes care&lt;br/&gt;Resources available for diabetes and insulin&lt;br/&gt;National programs for diabetes and insulin&lt;br/&gt;Pricing of insulin&lt;br/&gt;Distribution of insulin&lt;br/&gt;Funding for insulin and diabetes&lt;br/&gt;Insulin tendering and purchase&lt;br/&gt;Trade issues (laws, barriers to trade)&lt;br/&gt;Trade infrastructure</td>
</tr>
<tr>
<td>Ministry of Trade</td>
<td></td>
</tr>
<tr>
<td>Ministry of Finance</td>
<td>Funding of health system&lt;br/&gt;Taxes on insulin&lt;br/&gt;Funding for insulin and diabetes&lt;br/&gt;Pricing of insulin&lt;br/&gt;Distribution of insulin</td>
</tr>
<tr>
<td>Private sector</td>
<td></td>
</tr>
<tr>
<td>National diabetes association</td>
<td>Issues with diabetes and insulin&lt;br/&gt;Insulin tendering and purchase&lt;br/&gt;Insulin distribution and storage&lt;br/&gt;Insulin pricing</td>
</tr>
<tr>
<td>Central medical store</td>
<td></td>
</tr>
<tr>
<td><strong>Meso</strong></td>
<td></td>
</tr>
<tr>
<td>Regional/district health organization</td>
<td>Issues with diabetes and insulin&lt;br/&gt;Organization of care for diabetics&lt;br/&gt;Treatment and management of diabetics&lt;br/&gt;Access to appropriate tools to diagnose and treat patients&lt;br/&gt;Infrastructure present and/or lacking for insulin provision&lt;br/&gt;Infrastructure present and/or lacking for proper diagnosis and follow-up</td>
</tr>
<tr>
<td>Hospitals, clinics, health centers, dispensaries, etc.</td>
<td></td>
</tr>
<tr>
<td>Laboratory</td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td></td>
</tr>
<tr>
<td><strong>Micro</strong></td>
<td></td>
</tr>
<tr>
<td>Health workers and traditional healers</td>
<td>Problems encountered in diagnosis and treatment of patients&lt;br/&gt;Training&lt;br/&gt;Infrastructure present and/or lacking&lt;br/&gt;Tools present and/or lacking&lt;br/&gt;Diagnosis&lt;br/&gt;Access to treatment&lt;br/&gt;Cost of treatment</td>
</tr>
<tr>
<td>Patients</td>
<td></td>
</tr>
</tbody>
</table>

The RAPIA is structured as a multi-level assessment of the different elements that influence the access to insulin and diabetes care in a given country (Table 1) and comprises between 100 and 200 interviews or discussions in each country. The framework studies the path of insulin from its arrival in the country to the point that it reaches or fails to treat the patient effectively, thus identifying how and where the system works and/or fails. The RAPIA also studies the availability of infrastructure, personnel, and resources to diagnose, treat, and care for patients with insulin-requiring diabetes.

The term “insulin-requiring diabetes” is defined as onset of diabetes at <30 years of age and a requirement for insulin within 12 months of onset. This term is used instead of the more common term “type 1 diabetes,” both because scarcity of insulin testing causes difficulties with the term “ketosis prone” and because of differences in the spectrum of insulin-requiring diabetes among African and Caucasian patients.

The RAPIA is structured as a multi-level assessment of a health system and is divided into three levels. The macro level is aimed at ministries of health, finance, and trade; national diabetes associations; educational establishments; central medical stores; and private wholesalers of medicines and medical equipment. A meso level is designed for regional and district health offices, health facilities, including pharmacies and laboratories; and district clinics. Finally, information from interviews with health care workers, traditional healers, and patients comprises the micro level. The meso and micro levels are developed specific health care interventions (15). By using many different sources of data (such as documents, interviews, and site visits) a balanced overview is obtained. Triangulating, or cross-checking between data sources, provides internal validity and reliability of the data collected.
Diabetes care in developing countries

Diabetes care in developing countries is a significant challenge due to various geographical, economic, and political factors. This section discusses the care provided in Mozambique and Zambia, highlighting the difficulties faced by patients and healthcare providers.

**Access to syringes**

Access to insulin and syringes is crucial for diabetes management. Patients in developing countries often face challenges due to the high cost of insulin and syringes, which are essential for insulin therapy.

**Insulin supply and price**

The availability and accessibility of insulin are critical for diabetes care. In Mozambique and Zambia, the insulin market is characterized by high costs and limited supply, affecting patient access and adherence.

**RESULTS**

**Insulin supply and price**

The insulin market in Mozambique and Zambia is marked by high costs and limited supply. This situation affects patient access and adherence, highlighting the need for improved insulin distribution and pricing strategies.

**Diabetic care in developing countries**

In developing countries, diabetes care is influenced by factors such as access to insulin, healthcare infrastructure, and patient education. Effective strategies are needed to ensure that diabetes care is sustainable and accessible to all.
Diabetes in patients presenting in a coma may be misdiagnosed as cerebral malaria or HIV/AIDS.

In neither country was there a system of referral pathways and treatment guidelines, so that even if diabetes was diagnosed in patients correctly, their referral and treatment may be suboptimal. This is especially true in areas remote from main hospitals.

Low levels of health care worker knowledge about diabetes lead to poor understanding of their condition by patients. Misconceptions about diet and a low level of understanding regarding insulin use leads to poor diabetes management and frequent complications. A shortage of health care workers exists in both countries. This is particularly true in rural areas, and this shortage combined with strong traditional beliefs results in many people accessing health care only through traditional healers.

The importance of traditional beliefs

Traditional healers are an integral part of the health care systems in Mozambique and Zambia. National associations exist to represent the healers, and at the ministry of health in each country a division deals with the role of traditional medicine within the health system. Many traditional healers stated that they cared for diabetic patients for a certain time and if their condition did not improve within that time frame they would then send the patients to allopathic facilities.

Many traditional healers had heard of diabetes and knew at least that the disease was characterized by excessive thirst and urination. In both countries they also stated that they would welcome closer collaboration with allopathic medical personnel and learning more about diabetes.

Estimates of prevalence and prognosis

The RAPIA enabled rough estimates of prevalence to be calculated. In both Mozambique and Zambia numbers of patients were determined based on interviews with health care workers and from patient registers. If there was more than one facility treating patients in the same area, unless patients reported visiting more than one institution, it was assumed that there was no overlap. Official government population statistics were used as the denominator. The national prevalence was calculated using the respective proportion of populations living in rural and urban areas and the capital city and applying the calculated prevalence to this population. In Mozambique the estimated prevalence of insulin-requiring diabetes was 3.5 per 100,000 population and for Zambia it was 12.0 per 100,000 population. These figures compare with estimates of type 1 diabetes prevalence by the International Diabetes Federation of 5.2 per 100,000 for Mozambique and 4.8 per 100,000 for Zambia.

From these prevalence estimates and by using an estimate of diabetes incidence of 1.5 per 100,000 per year, it is possible to estimate life expectancy for patients with insulin-requiring diabetes, both nationally and by geographical location. This life expectancy varied from 0.6 years for a child in rural Mozambique to 27 years for an adult living in the capital city in Zambia (Table 2). The prevalence and life expectancy estimates mirror differences in the quality of care, availability of diagnostic tools, and availability of insulin between and across these two countries, with prognosis in rural Mozambique being particularly poor.

CONCLUSIONS — No previous study has examined in a systematic fashion the patterns of diabetes care across countries in sub-Saharan Africa. Furthermore, studies of type 1 diabetes prevalence in sub-Saharan Africa are few (20,21) and neither a representative diabetes survey nor diabetes registry is available in the countries assessed. The RAPIA was developed to provide a situational analysis of insulin-requiring diabetes to be able to make recommendations to the national ministries of health and diabetes associations. In both Mozambique and Zambia local stakeholders were actively involved in the assessment. This resulted in the process acting as a catalyst in bringing diabetologists to the attention of the health authorities, making the RAPIA an effective tool for advocacy.

The RAPIA has suggested that management of patients with insulin-requiring diabetes in these countries is problematic, particularly outside the catchment area of the major referral hospitals. Insulin availability at a national level did not appear to be a constraint to care. Nevertheless, in Mozambique, the availability of insulin to patients, particularly outside the capital, was a major barrier. Insulin is necessary, but not sufficient, for the survival of a patient with insulin-requiring diabetes. The dearth of health care available for most insulin-requiring diabetic patients outside the capital cities, particularly in Mozambique, also included intermittent availability of supplies needed for diabetes care such as syringes, urine and blood reagent strips, and, perhaps most crucially, little experience in management of diabetes by most health care workers. The non-availability of blood or urine glucose testing facilities at the majority of health units raises the likelihood that the major contribution to the "missing patients" is failure of diagnosis at presentation.

The Mozambique study showed marked differences in diabetes care and in diabetes prevalence in the capital city and in other parts of the country. These estimates seem to be approximately two to

---

*Table 2: Comparison of prevalence and life expectancy between Mozambique and Zambia*

<table>
<thead>
<tr>
<th>Location</th>
<th>Prevalence of insulin-requiring diabetes per 100,000 population</th>
<th>Estimated life expectancy*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-14 years</td>
<td>15+ years</td>
</tr>
<tr>
<td>Mozambique</td>
<td></td>
<td></td>
</tr>
<tr>
<td>National</td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Capital</td>
<td>9.1</td>
<td>3.8</td>
</tr>
<tr>
<td>Urban</td>
<td>5.0</td>
<td>2.1</td>
</tr>
<tr>
<td>Rural</td>
<td>1.4</td>
<td>0.6</td>
</tr>
<tr>
<td>Zambia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>National</td>
<td>12.0</td>
<td>11.2</td>
</tr>
<tr>
<td>Capital</td>
<td>18.0</td>
<td>18.0</td>
</tr>
<tr>
<td>Urban</td>
<td>12.6</td>
<td>13.0</td>
</tr>
<tr>
<td>Rural</td>
<td>9.5</td>
<td>9.0</td>
</tr>
</tbody>
</table>

*Estimated life expectancy assumes incidence of insulin-requiring diabetes of 1 per 100,000 per year for 0-14 and 0.67 per 100,000 per year for 15+ ([ref. 4]) and uses the method described in the text.
three times higher for Zambia than for Mozambique, and the urban-rural varia-
tion appears substantially lower in Zambi-
a. It is improbable that the Mozambique findings represent differences in inci-
dence in different parts of the country. The size of the country and the distances
involved make it unlikely that patients would travel substantial distances for their
care. The lower numbers of diabetic
patients in other towns and rural areas are
likely to represent poorer prognosis away
from centers of excellence. The higher
priority of diabetes care in national health
care planning in Zambia may be attrib-
uted, in part, to the active advocacy and
educational role played by the Diabetes
Association of Zambia.

As stated by former U.S. President Bill
Clinton, "Until we build the human and
physical infrastructure needed to deliver
effective treatment, programs will not succeed" (22). Although he was referring
to HIV/AIDS, the same is true for diabetes.
A system with such components includ-
ing continuing supplies of drugs, diag-
nostic facilities, health worker training
and retention, and patient education is vi-
tal in the management of diabetes. Im-
provements in health care systems are,
then, a vital component of improving health and health care for patients with
many chronic conditions across sub-
Saharan Africa.

Acknowledgments — The pilot of the RAPIA
in Mozambique was made possible thanks to a
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and Medicines Unit. We also acknowledge the
support of all the other generous donors of the
IIF and the logistical and administrative sup-
port of University College London in helping
with its establishment. The IIF is a U.K. Reg-
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2003
2.2. Diabetes Care in sub-Saharan Africa


Summary

Building on the experience from Mozambique and Zambia, presented in Section 2.1, as well as additional work in Mali (139) and a review of the literature, this article highlights a variety of challenges with regards to diabetes in sub-Saharan Africa. These include the lack of data, increasing prevalence (Type 2 diabetes), low life expectancy (Type 1 diabetes), cost to individuals and health systems, the challenge of access to medicines and insulin, overall health system challenges as well as the overall development and economic situations in sub-Saharan Africa that lead to barriers to care for individuals with diabetes. This Review proposed 11 elements necessary for managing diabetes in sub-Saharan Africa, which included:

1. Organisation of the Health System – role of each level in delivery of diabetes care as well as clear referral pathways; human resources available at these levels to deliver this care (specialists versus non-specialists, nurses and other health professionals versus doctors) and their links to form multi-disciplinary teams.

2. Data Collection – routine data, patient files and registers (national, regional and facility based); studies and research.

3. Prevention – integration of primary (only for Type 2 diabetes), secondary and tertiary prevention within the role of the health system; early diagnosis and treatment; prevention of short-term and long-term complications; with this needing to be adapted to the context where these interventions are being delivered.

4. Diagnostic tools and infrastructure – Each level of the health system has the appropriate tools for diagnosis and follow-up of people with diabetes

5. Drug procurement and supply – this sub-system of the health system needs to ensure that medicines are available where and when people need them. This entails proper budgets for medicines; appropriate buying procedures; quantification of needs based
on data; efficient procurement; distribution; rational prescription and actual use of medicines.

6. Accessibility and affordability of medicines and care – how can the financial burden of diabetes be alleviated.

7. Healthcare workers – training (clinical versus soft-skills); management of long-term conditions.

8. Adherence issues – linked to medicines, but also education and empowerment with an important role of the community.

9. Patient education and empowerment – adapted to local context; not only delivered by health professionals (i.e. role of diabetes association).

10. Community involvement and diabetes associations – important role of community as a support network, source of information and education, but also for advocacy and in some cases a provider of care.

11. Positive policy environment – wider range of issues linked to diabetes; health specific policies in addition to issues that impact health, but outside of health sectors remit; link with global agendas and statements.

What this adds to the argument of the overall thesis

This Review presented different opportunities for integration. Firstly, integration in each of the 11 elements as well as across these elements. For example integration at a Policy level across different sectors impacting health; integration at a health system level between primary, secondary and tertiary care; and also integration at a patient level be it integration of management by multi-disciplinary teams or the integration of care and support provided by the health system and diabetes association.

The other aspect of integration is across sectors and types of organisations, bringing in NGOs, diabetes associations, the private sector and other community groups. This is both at a national level, but also at a global level in order to raise awareness about diabetes management both nationally and globally and also to develop solutions. For example one approach proposed is the concept of “twinning” between diabetes associations in HICs and those in LILMICs. This could be viewed as “integration” of existing knowledge and experience
from other settings for the benefit of sub-Saharan Africa. This incorporation of existing knowledge could also be from HIV/AIDS programmes that have shown significant success in sub-Saharan Africa. It is important to note that the 11 elements presented were also found to be relevant in further research in Europe (140), Asia (141) and Latin America (142).
Diabetes care in sub-Saharan Africa

David Beren, John S Yudkin

The increasing numbers of people with type 2 diabetes is a worldwide concern. It presents an added challenge in sub-Saharan Africa, where diabetes must compete for resources with communicable diseases. A scarcity of financial resources and appropriate staff mean that many people with type 2 diabetes have complications and that those with type 1 diabetes have an extremely short life-expectancy, whether or not they have been diagnosed with the disorder. We review the current evidence on diabetes care in sub-Saharan Africa and propose an 11-point action plan to address this problem in the region.

Introduction

Many incidence data1,2 and an assumed life expectancy of 5 years, and produce a figure of 35 000 people with type 1 diabetes.11 Estimates suggest that for type 1 diabetes in children, the prevalence in North America and the West Indies is 0.062%, compared with 0.029% in Africa.12 The incidence of type 1 diabetes is increasing in many parts of the world, especially in low prevalence countries and in younger children.10 Improved care is also likely to improve prognosis of these patients, with an additional effect on prevalence.

The number of people with type 2 diabetes worldwide was estimated at 171 million in 2000 and is predicted to rise to 366 million in 2030.13 In a review of diabetes in Africa by Sohngwi and colleagues,14 the prevalence of diabetes ranged from 1% in rural areas to between 3% and 6% in urban areas. In a population of Indian origin in sub-Saharan Africa the prevalence was between 12% and 13%. Prevalence rates in other African settings range from an apparent absence of diabetes in Togo to rates of 10-46% in northern Sudan. Gallen15 and colleagues16 estimated that in 2000, 7 146 000 people in sub-Saharan Africa had diabetes, with a projected increase to 18 645 000 in 2030. These projections do not take into account the effect of urbanisation3 and ageing,5 with UN estimates that by 2025 54-1% of Africans will live in urban areas. These numbers, however, do not account for the rates of obesity which have been increasing strikingly across much of urban Africa.17

As the prevalence of diabetes continues to rise, the parallel increase in complications will strain health-care resources.12 Mbanza and Sohngwi14 collected data for prevalence of complications, and showed that retinopathy affects 16–55% of people with diabetes, with some 21–25% of people with newly diagnosed type 2 diabetes presenting with retinopathy. These investigators estimated that 13–20% of type 1 diabetes patients in sub-Saharan Africa have overt nephropathy, which is responsible for 50% of all-cause mortality in these patients. Other studies have shown peripheral neuropathy in 10–46% of patients. In Tanzania, treatment of diabetic complications represented 30–86% of total outpatient costs in the main hospital in the capital city with yearly spending per head of US$138, some 19 times more than per head government expenditure on health at average exchange rate.18

Much of the discourse on access to antiretroviral treatment in resource-poor countries has concentrated on the effects on prices of patents and the trade-related aspects of intellectual property. Such considerations do
Recent developments have made it possible to diagnose and treat lymphoma earlier, leading to improved outcomes. However, the high costs of treatment remain a significant barrier for many patients. In the United States, the median annual cost of treatment for lymphoma is estimated to be $50,000, with the total cost for a lifetime of treatment ranging from $200,000 to $1 million. These costs can be significantly lower in regions with well-established healthcare systems and economies of scale in the pharmaceutical industry. In developing countries, access to effective treatment is often limited due to a combination of economic constraints and infrastructural challenges.

Despite these challenges, there are opportunities for improvement. The World Health Organization (WHO) and other international organizations have developed guidelines and policies aimed at improving access to cancer care. The integration of cancer care into primary healthcare systems and the scaling up of cancer services are key strategies to address this issue.

---

**Table: Insulin availability and cost in International Diabetes Federation surveys 2004, 2005, and 2006**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Number of African countries surveyed</th>
<th>Availability of insulin (% of time)</th>
<th>Cost of 50 ml (100 vial) (US$), by type of insulin, mean (median, range)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>25-39% 50-75% 100%</td>
<td>Overall Animal Human</td>
</tr>
<tr>
<td>2004 Diab and colleagues</td>
<td>7</td>
<td>28% 58% 14%</td>
<td>(5-2-13) N/A N/A</td>
</tr>
<tr>
<td>2005 International Diabetes Federation</td>
<td>9</td>
<td>22% 75% 0%</td>
<td>N/A N/A 8.6 18.21</td>
</tr>
<tr>
<td>2005 International Diabetes Federation 'Task Force'</td>
<td>10</td>
<td>30% 65% 10%</td>
<td>12.0 (0, 10-30) 12.2 (8, 3-26) 17.1 (15, 5-40) 14.0 (13, 3-34) private</td>
</tr>
</tbody>
</table>

Notes: Data not available. *Insulin concentration not specified. 
1Quoted in article as average, including non-governmental organizations.
such as the African Diabetes Declaration, calling on
governments, NGOs, and other stakeholders to ensure
adequate and affordable medications, earlier detection,
and optimum care.

In the wake of the adverse publicity arising from
South Africa's court action on intellectual property and
pharmaceuticals,\textsuperscript{18} the drug industry has responded
with several initiatives to exemplify their social
responsibility. As an example, Novo Nordisk has
established an equity pricing initiative, offering insulin
to public-health systems in the 50 poorest countries at
prices not exceeding 20% of the average price in North
America, Europe, and Japan.\textsuperscript{9} With the adoption of
this scheme, the price of insulin in the public sector in
Mozambique has dropped by about 50%.\textsuperscript{8} However, the
equity pricing scheme has not had a substantial effect
on insulin availability for several reasons, including
inadequate information being available to eligible
countries, the exclusion of many poor and populous
countries—such as Nigeria and India—from the list of
least developed countries, and the exclusion from the
scheme of Insulin supplied to the private sector, from
which patients buy their supplies during the frequent
periods when insulin is unavailable in government
health units. Novo Nordisk has also established the
World Diabetes Foundation to provide grants to support
prevention and treatment of diabetes in developing
countries. Tanzania presents an example of a successful
national diabetes programme in sub-Saharan Africa,
where collaboration between the Tanzanian Diabetes
Association and Ministry of Health has established a
network of diabetes clinics throughout the country,
along with health-worker training, guidelines, and
patient education material.\textsuperscript{10}

WHO, in collaboration with Health Action Inter-
national, has recently published a report\textsuperscript{17} in which
pioglitazone (a sulphonylurea), used for the treatment
of type 2 diabetes, was shown to cost the equivalent of
about 8 days' wages for 1 month of treatment. Insulin
was not considered in this survey. The WHO essential
drugs list includes short-acting and intermediate-acting
insulin formulations,\textsuperscript{11} and most countries, have
created national drugs lists which have also included
insulin.

In parallel with these global initiatives, the work of
two NGOs (International Insulin Foundation and Santé
Diabète Mali) has contributed substantially to improving
knowledge of diabetes in sub-Saharan Africa. The
International Insulin Foundation aims to help resource-
poor countries to develop sustainable programmes of
insulin access and diabetes care. A rapid assessment
protocol for insulin access has been developed to
investigate barriers to insulin access, by studying the
path of insulin from its arrival in the country to its
reaching the person with diabetes.\textsuperscript{12} The foundation also
looks at systems of care to provide information on the
health system's capability for provision of diabetes care.

\begin{center}
\begin{tabular}{|c|}
\hline
\textbf{Panel: Key areas to be addressed if diabetes is to be tackled in sub-Saharan Africa, as identified by International Insulin Foundation} \\
\hline
- Organisation of the health system \\
- Prevention \\
- Data collection \\
- Diagnostic tools and infrastructure \\
- Drug procurement and supply \\
- Accessibility and affordability of medicines and care \\
- Training and availability of health-care workers \\
- Adherence issues \\
- Patient education and empowerment \\
- Community involvement and diabetes associations \\
- Positive policy environment \\
\hline
\end{tabular}
\end{center}

The rapid assessment protocol for insulin access has
been used in Mozambique, Zambia,\textsuperscript{13} and Mali, where reom-
mendations have been prioritised by national partners and diabetes programmes implemented. In Mali, Santé Diabète Mali a French NGO, works on
several aspects of diabetes, including implementation of
the reom-mendations from the rapid assessment protocol for insulin access and training of medical staff. Its regular newsletter, available in French and English, provides a variety of resources for nutritional and other
aspects of management of diabetes in a resource-poor
setting.\textsuperscript{14}

\textbf{Solutions}

The International Insulin Foundation has suggested
11 key areas that need to be addressed if diabetes is to be
tackled in sub-Saharan Africa (panel).\textsuperscript{15}

\textbf{Health system organisation, data collection, and
diabetes prevention}

Health systems in sub-Saharan Africa are currently
organised for the treatment of acute rather than chronic
conditions.\textsuperscript{16} These systems face an immense challenge
to tackle HIV/AIDS, tuberculosis, malaria, diarrhoeal
disease, and respiratory infections.\textsuperscript{17} Chronic disorders,
such as diabetes and hypertension share with
HIV/AIDS and tuberculosis several common factors,
including the need for diagnostic tools, trained
personnel able to initiate and adapt treatment of a
life-long condition, a referral system for management
of complex regimens of complications, and the need
for an effective system for regular supply of medicines
throughout the country. Prevention of diabetes is
needed not only to avert much of the suffering for
people with the disorder, but also to prevent increased
use and costs engendered by complications. For type 2
diabetes, primary prevention will need political
courage, because the advancing tide of globalisation
and its effect on both urban migration and the obesity
epidemic needs to be confronted.\textsuperscript{18}
Systematic recording, analysis, and dissemination of data for mortality, morbidity, and risk factors, are the key to effective care planning. Patient registers can be used to organise patient and population data both for health-care planning and to improve care. Such registers have been undeveloped in many African countries but WHO regional office for Africa is encouraging the expansion of local databases of disease burden, risk factors and principal determinants of non-communicable diseases. Standardised registers kept at each facility can be regrouped on a district, regional, and national level, while also providing a basis for audit. Other measures are available to assist governments in assessing the chronic disease burden and effectiveness of health systems, including WHO’s stepwise approach and the rapid assessment protocol for insulin access.

Diagnostic aids and drugs
The cost to the health system and the patient of testing for diabetes might be an important constraint to care. In Mozambique, only 18% of health facilities have the ability to measure blood glucose concentration and even fewer (8%) test for urinary ketones, implying that people with type 1 diabetes who present in ketoads are likely to die without diagnosis. Each level of the health system needs a means of measuring blood glucose concentrations, something which needs staff training, but which would also be helped by standardisation of the types of instruments and testing strips used.

Continuous availability of medicines plays an essential part in the provision of health care for chronic conditions. As discussed, WHO’s essential drug list includes oral hypoglycaemic agents and both short-acting and intermediate-acting insulin formulations. Reliable health and supply systems, sustainable financing, affordable pricing, and rational use are necessary for proper access to medicines, with improved tendering or pooled procurement used to minimise cost. Evidence from in-country studies show that improvement is needed in quantification, procurement systems, and distribution to prevent unnecessary waste, with improved training for prescribers and dispensers. What is notable, however, is that despite the availability of generic insulin on the world market, the market power of the major suppliers, and particularly of Novo Nordisk remains a major influence on insulin procurement in sub-Saharan Africa. The International Union Against Tuberculosis and Lung Disease has introduced an asthma drug facility to make good quality essential drugs for asthma affordable for low-income countries, modelled on a similar concept for the supply of antituberculosis drugs. This is an excellent model, which would substantially improve access to insulin and which, in a situation where WHO’s concerns lie with drugs for conditions with major effects on global disease burden, one which the International Diabetes Federation and its insulin taskforce might consider.

Diabetes and other chronic diseases place a large financial burden on people with these disorders and their families in many countries, often leading the household into poverty. Medicines for diabetes care should be accessible at public facilities free of charge, or at subsidised price where feasible. Clearly defined and applied exemption criteria, or other means of financing care for patients, exist in few countries and are necessary for consultation fees, laboratory tests, and medicines, as well as professional fees for diagnosis and disease, and employment. These criteria need to be easily verifiable and should not cause treatment delays.

Health-care workers
Health-care workers need to coordinate treatment, educate patients in self-care, and have an active role in prevention. Understanding of diabetes management is generally poor among health-care workers, especially those in rural areas in Africa. Training programmes, such as those in Tanzania or Mali, need to be rolled out to improve knowledge, with appropriately developed materials as guidelines and protocols. An initiative by the International Diabetes Federation in Africa is developing guidelines for health-care workers and education material for patients that will be suitable for widespread use. Pharmacists, laboratory technicians, and other ancillary staff also need appropriate training.

The major problem with diabetes planning is the dearth of senior specialists in diabetes care, and the resultant scarcity of specialist training in the region, with most of the specialists having been trained abroad.

Patient adherence, education, and empowerment
Many factors, such as health service organisation and accessibility of care, will affect adherence, but studies have shown that cost of treatment is the main barrier to adherence in chronic disease. Patient education material needs to be available and accessible in terms of language and culture, especially for children and illiterate patients. People need not only knowledge and skills, but also motivation to improve the quality of their lives.

Patient education should focus on prevention as well as treatment, with materials that are culturally appropriate and adapted to populations with poor reading skills since nearly half the population in this region is classed as illiterate.

Community involvement and diabetes associations
Illness is expensive in terms of costs of care, and also causes loss of family income. In many societies, illness of one person can affect the whole community, type of disease, and employment. These criteria need to be
Integrated into the formal system of care and trained in appropriate referral to the formal health sector. As is evident from the Tanzanian example, diabetes associations can play a vital part in improving patterns of care. These organisations can help with care and also provide advocacy on issues such as the growing disease burden, costs, and availability of treatment. When diabetes associations provide care, for reasons of geo-political equity and sustainability the care should complement and fully integrate with the formal health sector. World Diabetes Day provides a yearly opportunity for diabetes associations to raise public awareness about diabetes.

Positive policy environment
Many countries in sub-Saharan Africa do not have a policy framework for non-communicable diseases and diabetes. Such a framework should incorporate prevention, organisation of care, import duties on medicines and supplies, subsidies for medicines and care, education, disease monitoring, and allocation of appropriate resources. Multilateral donors need to recognise the growing burden of non-communicable diseases, including diabetes, in developing countries. An expanded Millennium Development Goal for non-communicable diseases has been proposed. High level political commitment is needed to address issues, such as food availability, cash crops, and urbanisation, which will have a major role in determining the success or failure of prevention and care.

Conclusion
The Nigerian President Olusegun Obasanjo has said, “We cannot afford to say, ‘we must tackle other diseases first—HIV/AIDS, malaria, tuberculosis—then we will deal with chronic diseases’.” Health care in sub-Saharan Africa faces many challenges, including a high burden of communicable disease and a scarcity of financial and human resources. Diabetes and other chronic conditions present an additional challenge. But these also present an opportunity—the challenge of developing functioning health systems to deliver continuing integrated care. In this respect, the challenge of non-communicable diseases is not so different from that of HIV/AIDS. By strengthening health systems, the aim should be to ensure that they can cope with type 1 diabetes as well as with communicable disease.

Several issues remain, which together conspire against raising the profile of diabetes management on the global agenda. Firstly, WHO’s non-communicable disease division gives little attention to problems of managing patients with clinical disease. Secondly, where the WHO essential drugs and medicines division considers access to medicines or prequalification to assure quality, emphasis is on the major contributors to burden of disease, with less attention to drugs such as insulin, for which the need is absolute but the numbers small. Finally, the International Diabetes Federation is an association of national Diabetes Associations, rather than an international organisation with staff and projects. We suggest that a development office as part of the secretariat could achieve substantial progress in improving care for people with diabetes in the least developed countries, with the costs of sustaining such an initiative being relatively modest. In the absence of a procurement and quality assurance scheme for insulin being made available through the essential drugs and medicines division of WHO, such a task needs to fall to an NGO, as for drugs for asthma and should also be considered by the International Diabetes Federation.

In 1990, a missionary doctor wrote in his notes on diseases he saw in Africa “diabetes is very uncommon and very fatal” 105 years later, type 1 diabetes in Africa is still uncommon and fatal, whereas type 2 diabetes is arising in epidemic proportions. The efforts needed to improve the outcomes for both types of diabetes are similar to those for HIV/AIDS—trained health-care workers, a functioning health-care system, guidelines, continuing availability of drugs and monitoring reagents, and a functioning referral system. The campaign for World Diabetes Day in 2006 is Diabetes Care for Everyone. While new technologies have improved the spectrum of insulin profiles and delivery systems in developed countries, outcomes from diabetes in developing countries are similar to those before the discovery of insulin. The battle to stem the rising tide of type 2 diabetes is being lost, with the disorder having gone from affecting mainly the developed world to one that will dominate the health facilities of resource poor countries, especially in urban areas. Action is needed to ensure that diabetes does not erase all the advances in health since 1921 when Banting and Best discovered insulin.

Conflict of interest statement
We declare that we have no conflict of interest.

Acknowledgments
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References
2.3. Results of improvements in diabetes care in Mozambique: a reassessment 6 years later using the Rapid Assessment Protocol for Insulin Access


**Summary**

This research is a reassessment of the situation in 2009 in Mozambique following an initial assessment carried out in 2003 and referred to in Section 2.1. Following the initial assessment in 2003 a variety of activities were developed focusing on improving the different elements presented in Section 2.2. Results included the development of a national NCD Plan, healthcare worker training, development of the diabetes association, patient education, activities around World Diabetes Day and an increase in availability of diagnostic tools and insulin.

**What this adds to the argument of the overall thesis**

From this paper what is clear is that an integrated approach is needed in improving diabetes care and that all 11 elements (presented in Section 2.2) need to be addressed in parallel in order to have overall changes in diabetes management. For example to improve the health system healthcare worker training is needed in addition to increasing the availability of medicines and diagnostic tools. Again this paper highlighted that the 11 points are interlinked and a holistic view of the system is needed to change the way diabetes care is delivered. The holistic nature is also highlighted by the way the assessment again took an overall system approach, rather than just focusing on improvements in one area, e.g. increase in numbers of health professionals trained in diabetes and availability of insulin. This study also shows the importance of integrating research into policy and programming.

As mentioned in Section 2.2 another area of integration proposed is the concept of using experience from HICs to help address challenges in settings such as Mozambique. The project in Mozambique was in part supported by Diabetes UK (diabetes association based in
the UK) and some of the tools used in the UK were adapted to the Mozambican context. The study visit to the UK for the person responsible for NCDs and diabetes at the Ministry of Health included a variety of actors to present the 11 elements from a UK/HIC perspective. In parallel this visit and other activities enabled an increase in awareness and ways forward for diabetes management in LILMICs.
Special Report

The Diabetes UK Mozambique Twinning Programme. Results of improvements in diabetes care in Mozambique: a reassessment 6 years later using the Rapid Assessment Protocol for Insulin Access

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Abstract

Objective To assess improvements in diabetes care in Mozambique between 2003 and 2009 following the implementation of the Diabetes UK Twinning Programme.

Methods As in 2003, a Rapid Assessment Protocol was implemented from August to September 2009 in order to assess the improvements in diabetes care and impact of the Diabetes UK Twinning Programme. One hundred and eighty-four interviews were carried out at different levels of the health system in different areas of Mozambique.

Results The Diabetes UK Twinning Programme in Mozambique allowed the development of the first comprehensive non-communicable disease plan in sub-Saharan Africa. The other main improvements include a strengthening of the diabetes association with an 8-fold increase in membership, 265 health workers trained in diabetes care in all provinces, the development of patient education materials inspired by some Diabetes UK tools and the expansion of public awareness, particularly from events associated with World Diabetes Day.

Conclusions Much progress has been made in Mozambique with regard to diabetes and non-communicable diseases. Besides the direct impact of specific activities supported by Diabetes UK, this project allowed for ‘collateral’ benefits in the overall provision of diabetes care. As diabetes and non-communicable diseases have a low profile on the global health agenda, twinning partnerships based on rigorous needs assessment have the capacity to make significant improvements in diabetes care at a relatively low level of investment. Moreover, this study suggests that the tool used might be of value in assessing progress in health system strengthening as well as in conducting the initial needs assessment.


Keywords developing countries, diabetes, Mozambique, non-communicable disease

Abbreviations AMODIA, Mozambican Diabetes Association; IDF, International Diabetes Federation; IIF, International Insulin Foundation; MISAU, Mozambique Ministry of Health; RAPPA, Rapid Assessment Protocol for Insulin Access

Introduction

Non-communicable diseases represent the leading cause of death worldwide, mainly impacting developing countries [1].

Included in this non-communicable disease burden are 285 million people worldwide with diabetes, mainly in low- and middle-income countries [2]. It is predicted that sub-Saharan Africa will see an increase of 98.1% in the prevalence of diabetes over the period 2010–2030, the largest increase of any region [2]. Healthcare systems in sub-Saharan Africa are poorly equipped to manage diabetes and other non-communicable diseases [3]. The requirements for managing diabetes include regular availability of drugs, laboratory facilities, data
collection tools and a trained healthcare team and patients [4,5].

In addition, the cost and availability of diabetes-related medicines and supplies are a major barrier in sub-Saharan Africa [6-8]. The Rapid Assessment Protocol for Insulin Access (RAPIA) was developed by the International Insulin Foundation (IIF) to assess the barriers to diabetes care in order to provide practical recommendations to improve the management of diabetes [9]. This protocol has been implemented in Mozambique (2003), Zambia (2003), Mali (2004), Nicaragua (2007), Vietnam (2008) and Kyrgyzstan (2009), with a similar assessment in the Philippines (2008) using a modified RAPIA [10-16].

Barriers to care which were identified were not limited to the availability of insulin, but included issues of monitoring and health worker expertise in diabetes. In each instance, RAPIA findings were reported back to the Ministry of Health, the Diabetes Association and the country office of the WHO and, in most cases, this was followed with the development of projects to address the gaps identified.

Twining partnerships between diabetes associations in industrialized countries with those in resource-poor countries were proposed by the International Diabetes Federation (IDF) and, between 2006 and 2009, such a partnership was initiated between Diabetes UK and the Diabetes Association (AMODIA) and Ministry of Health (MISAU) in Mozambique [17].

In this paper, we present the findings of a repeat RAPIA, 6 years after the initial assessment, and following a 3-year partnership between Diabetes UK, AMODIA and MISAU. The findings suggest that a clear analysis of the situation followed by a twining partnership has the capacity to make significant improvements in diabetes care at a relatively low level of investment.

Methods

Mozambique is located on the south-eastern coast of Africa and borders Tanzania to the north, Malawi, Zambia and Zimbabwe to the west and South Africa and Swaziland to the south. The country is divided into 11 provinces, three geographical areas (North, Central and South) and 144 districts. The estimated population is 22 million with 44.3% aged from 0 to 14 years, 52.8% from 14–64 years and 2.9% 65 years and above. Life expectancy at birth is 41.2 years as a result of a high prevalence of HIV/AIDS (an estimate of 16.1% in 2007) [18].

Mozambique’s gross domestic product (GDP) per capita at purchasing power parity (PPP) is estimated to be $900 [18]. On the United Nation’s Development Programme’s Human Development Index, Mozambique is ranked 175 out of 179 countries [19].

WHO estimates show that in 2006 Mozambique spent a total of $56 per person at purchasing power parity on health care, equal to 4.7% of the gross domestic product [20]. Health services in Mozambique are provided at the primary level by health posts (652) and health centres (433), by rural hospitals (27) and district hospitals (8) at the secondary level, general (5) and provincial hospitals (7) at the tertiary level and at the quaternary level by central hospitals (3). Overall, this represents one health unit per 15 000 inhabitants, but with 60% of the population having no access to these [21].

In Mozambique, data from a population-based study in 2005 found a prevalence of diabetes in the population aged 25-64 years of 3.8% [22] and it is estimated that there are 300 prevalent cases of Type 1 diabetes in children aged from 0 to 14 years [23]. Our estimates found a total of 674 people with Type 1 diabetes (339 in the group of 0-14 years old and 335 aged ≥15 years).

Mozambique was the first country where the RAPIA was implemented in 2003 [11,24]. Following this, recommendations were prioritized by MISAU and AMODIA. These were:

(i) improve AMODIA;
(ii) implement Chronic Disease Law providing 80% subsidy on medicines for all chronic diseases, including diabetes;
(iii) improve data collection;
(iv) increase training;
(v) improve communication between Central Medical Store (the centre for all public service drug provision and distribution) and periphery;
(vi) increase awareness of diabetes in the general public;
(vii) improve access to diagnostic tools;
(viii) develop care guidelines;
(ix) increase number of diabetes consultations.

In order to achieve this, the IIF provided technical support and the World Diabetes Foundation provided in-country funding for a variety of projects. In 2006, a team from Diabetes UK joined the authors in Mozambique to assess the feasibility of a twining project between Diabetes UK and Mozambique. The proposal was accepted by the Diabetes UK Executive Board, and the Programme was initiated in January 2007 with the following objectives:

(i) developing a Training of Trainers programme initiated by MISAU;
(ii) training of specialists in diabetes care;
(iii) developing patient education materials;
(iv) organizing World Diabetes Day events;
(v) providing advocacy and policy support to MISAU;
(vi) developing a core group of people involved in diabetes;
(vii) development of AMODIA to become a national diabetes association;
(viii) initiating long-term research programmes in health services and clinical aspects of diabetes.

The influence of the Programme was assessed by repeating the RAPIA in August-September 2009, with the Project Coordinator (DB) and team of five local interviewers conducting a total of 184 interviews (detailed in Table 1) in the three original areas where the RAPIA had been implemented in 2003—Maputo, Beira and Lichinga—as well as in Gaza Province in southern Mozambique. The RAPIA interviews were identical between the two assessments, with the topics covered as documented in Benar
et al. [9] (Table 1). Because the information collected was largely qualitative and semi-quantitative, no formal statistical comparison between the two RAPlAs was performed. With regard to access to medicines, the initial implementation of the RAPlA only looked at the issue of insulin supply and cost. However, for this repeat assessment, oral medicines for diabetes were also included.

**Results**

The changes between 2003 and 2009 are presented using the framework of the Diabetes Foundation Report on implementing national diabetes programmes in sub-Saharan Africa and its 11 elements seen as key to a "positive diabetes environment" [4].

**Positive policy environment**

The biggest change between 2003 and 2009 is that diabetes is now on MISAU’s agenda and that non-communicable diseases are viewed as a public health problem in Mozambique. Shortly after the RAPlA in 2003, the Non-Communicable Disease Department within MISAU became functional. A National Strategic Plan for Non-Communicable Diseases was developed with the support of WHO, the IIP and Diabetes UK and received Ministerial approval in October 2008. Non-communicable diseases now also have a specific budget within MISAU. Through World Diabetes Day activities, other departments within MISAU, including School Health and Nutrition, have been involved in diabetes and non-communicable disease prevention. At a provincial level, all provinces now have non-communicable disease focal points nominated, where they have as their role implementation of the national plan.

**Organization of the health system**

In 2003, Maputo Central Hospital was the only facility that provided comprehensive diabetes care. Two general hospitals in the vicinity of Maputo had the basic tools for diagnosis, but lacked both trained staff and insulin, so referred their patients to the Central Hospital. No diabetes care was provided at health centres. In 2009, Maputo Central Hospital was still the main referral facility for people with diabetes, with a clinic additionally provided by AMODIA, but general hospitals and even health centres were by this time providing diabetes care. The situation in Beira between 2003 and 2009 had also improved. In 2003 diabetes care was provided mainly by an expatriate doctor. This was still the case in 2009, but with the additional involvement of Mozambican doctors trained in diabetes care. Lichinga has seen the most obvious changes. In 2003 there was no specialized care for people with diabetes, meaning that patients needed to travel long distances to receive adequate care. Care in Lichinga is now provided at the Provincial Hospital and City Health Centre. Despite these improvements, patient pathways remain complicated and care is still dependent on where people live, with Maputo providing the best care available.

**Data collection**

Patient files and registers were present in 2003, but in most cases they were difficult to use for the purpose of gathering data due to their completeness. The use of these tools has improved greatly. Statistics on non-communicable diseases are now collected at different levels of the health system. The original RAPlA and a population-based study of non-communicable disease risk factors, using the WHO Stepwise methodology, added to the data available on diabetes in Mozambique [25].

**Prevention**

Availability of materials, patient education and any awareness-raising activities were absent in 2003. World Diabetes Day activities have been organized since 2004 and have involved the provision of information about diabetes and nutritional education; facilities for measuring body mass index, capillary glucose and blood pressure; supervised physical activity sessions; and widespread media coverage on radio, television and in the press. In 2009, these events were organized in five regions of Mozambique and 'healthy lifestyle' events are part of the non-communicable disease plans. Altogether, 11 of these events were...
organized in 2009, reaching approximately 20,000 people.
Patient and community education sessions are now given by
AMODIA in Maputo and by healthcare workers.

The remaining weakness is the availability of specialized tools
for the early detection and management of diabetes-related
complications.

Diagnostic tools and infrastructure

In 2003, according to the healthcare workers interviewed,
problems with the diagnosis of diabetes were mainly as a result of
a lack of tools such as glucometers and urine test strips and
healthcare workers lacking the knowledge of the clinical signs of
diabetes. Besides the improvements in availability of glucose
measuring instruments, there has been an overall improvement in
the presence of tools such as sphygmomanometers, weighing
scales and measuring tapes. Details of the improvement of
availability of tools and clinical knowledge on the management
are detailed in Table 2.

Drug procurement and supply

The time taken to prepare tenders, receive medicines and then
distribute them throughout Mozambique decreased from 1 year

Table 2 Comparison of key indicators from RAPIA 2003 and 2009 in 2009 standardized prices

<table>
<thead>
<tr>
<th>Indicator</th>
<th>2003</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insulin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSISAU expenditure on insulin for 18 months</td>
<td>$706.5</td>
<td>$271.8</td>
</tr>
<tr>
<td>Average tender price per vial of insulin (18 months)</td>
<td>$8.03</td>
<td>$4.50</td>
</tr>
<tr>
<td>Total quantity of insulin (10ml 100 IU vials) purchased (18 months)</td>
<td>113,800</td>
<td>60,400</td>
</tr>
<tr>
<td>Insulin expenditure as a percentage of total spending on medicines by MSISAU</td>
<td>1.77%</td>
<td>0.64%</td>
</tr>
<tr>
<td>Proportion of total amount of insulin in Maputo</td>
<td>77%</td>
<td>46%</td>
</tr>
<tr>
<td>Time for tender (maximum)</td>
<td>12 months</td>
<td>9 months</td>
</tr>
<tr>
<td>Margin of mark-up by private pharmacy</td>
<td>76%</td>
<td>59%</td>
</tr>
<tr>
<td>Insulin always present at percentage of hospitals</td>
<td>20%</td>
<td>100%</td>
</tr>
<tr>
<td>Average price per vial of insulin to public pharmacies</td>
<td>$6.42</td>
<td>$5.50</td>
</tr>
<tr>
<td>Average price per vial of insulin to patient (private)</td>
<td>$10.40</td>
<td>$12.39</td>
</tr>
<tr>
<td>Average price per vial of insulin to patient (public)</td>
<td>$1.32</td>
<td>$0.20</td>
</tr>
<tr>
<td>Syringes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Price of syringes public sector</td>
<td>$0.05</td>
<td>$0.20</td>
</tr>
<tr>
<td>Price of syringes private sector</td>
<td>$0.23</td>
<td>$0.34</td>
</tr>
<tr>
<td>Presence of diagnostic tools</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood glucose machine</td>
<td>21%</td>
<td>87%</td>
</tr>
<tr>
<td>Consumables available for the blood glucose machine</td>
<td>6%</td>
<td>27%</td>
</tr>
<tr>
<td>Urine testing strips</td>
<td>18%</td>
<td>73%</td>
</tr>
<tr>
<td>Ketone strips</td>
<td>8%</td>
<td>73%</td>
</tr>
<tr>
<td>Healthcare workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of healthcare workers who have received training in diabetes (2003 basic, 2009 specialized)</td>
<td>52%</td>
<td>65%</td>
</tr>
</tbody>
</table>

*Life expectancy was calculated by taking data from registers in facilities where people with Type 1 diabetes would be seen and assumed to represent prevalence. In Beira, this was the only one facility (Central Hospital) for both 2003 and 2009. In Lichinga, this was the Provincial Hospital in 2003 and the Provincial Hospital and City Health Centre in 2009. As the healthcare workers responsible for diabetes were the same at both facilities in 2009, they were able to give the overall number. In 2003, for Maputo, the data came from the Central Hospital; in 2009 these data came from the diabetes association. The IDF incidence rate for sub-Saharan Africa, of 0.9 cases per 100,000 population per year, was used (23). With these two elements, life expectancy was calculated by dividing the prevalence collected from registers by this incidence rate.

**Because numbers of people with ‘Type 1 diabetes’ in 2003 was based on definition on basis of insulin treatment and, in 2009, on basis of insulin-requiring diabetes, reliable estimates of life expectancy in this age group was not possible.

IDF; International Diabetes Federation; MSISAU, Mozambique Ministry of Health; RAPIA, Rapid Assessment Protocol for Insulin Access.
to 9 months between 2003 and 2009. In the 18 months studied during the period 2002 to 2003, 115 800 vials of insulin (100 IU) were purchased at a total cost of $706 549.56 at an average cost of $6.03 per vial at 2009 prices. Over the 18 months studied from 2008 to 2009, 60 400 vials were purchased at a total cost of $278 800.00 (average cost of $4.60 per vial) (Table 2). This shows a clear decrease in the price and quantity of insulin purchased. Based on the interviews, this decrease in price was based on improved tendering practices and Mozambique benefiting from a differential pricing initiative from one of the main insulin manufacturers. With regard to the decrease in quantity, this was as a result of better planning at all levels of the health system, thus avoiding the over-purchase of insulin that had been seen in 2003.

The total expenditure for 18 months (2008–2009) on oral medicines (metformin and glibenclamide) for diabetes and insulin was equal to $3 083 800, equivalent to approximately 5.1–6.2% of total expenditure on medicines (the total expenditure on medicines was $30–46m in 2008). For insulin, this represented 0.45–0.54%, down from 1.73–2.01% of the total costs in 2003. Distribution of insulin from the central level to the periphery also improved with the total amount of insulin present in the capital city (representing approximately 11% of the total population), dropping from 77% in 2003 to 46% in 2009.

Accessibility and affordability of medicines and care

In 2003, it was found that Mozambique’s Law on Chronic Disease, which allowed people with a chronic condition to receive their medication at an 80% discount, was not always implemented and people were paying more than the subsidized rate. Following the recommendations of IIF, and work by MISAU, this law was fully implemented in 2006 and, in 2007, the Minister of Health decreed a $0.20 prescription fee for all medicines, impacting the affordability of insulin and other medications for people with diabetes.

Access to medicines has improved overall. In 2003, only 20% of hospitals visited had insulin, while in 2009 all hospitals visited had insulin (Table 2). Problems with regard to the availability of syringes in the public sector were present in 2003 and will persist. In 2003, the price range, at 2009 prices, for syringes was $0.05–0.23 per syringe in the private sector. In 2009, it was found that this range had increased from $0.08 to $1.13 per single-use syringe (Table 2).

Healthcare workers

Training materials have been developed based on IDF Africa manuals adapted to the Mozambican context. Courses initiated by MISAU were facilitated by a qualified local faculty with the support of external funding from Diabetes UK and the World Diabetes Foundation. By the end of 2009, a total of 265 healthcare workers from different levels of the health system, and in all Provinces, had participated in this training.

In 2003, 52% of healthcare workers interviewed said they had received some training in diabetes and this was linked to a general lack of awareness of diabetes. Data from the interviews with health workers in 2009 show that 65% had received special training in diabetes (Table 2). In addition, two doctors from Mozambique participated in a specialized course in diabetes education organized by IDF Africa. A senior physician was sent for training in South Africa in endocrinology and research methodology. In 2003, a lack of knowledge in diabetes was identified in medical students and this has been addressed with a special training course for postgraduate medical students.

Adherence issues

There were three factors impacting adherence in 2003: access to insulin and medicines, knowledge of diabetes (including diet) and continuity of care. Access to medicines was the main concern for people interviewed in 2003. In 2009, the main issue identified by people with diabetes was following or being able to afford a proper ‘diabetic’ diet (48%).

Knowledge of diabetes, its chronic nature and the need for ongoing care has improved since 2003. However, the use of traditional medicine, and the discontinuation of treatment when people feel well, are still problems.

Patient education and empowerment

In 2003, most clinics had no information to hand out to patients or any visual aids. Since then, specific materials have been developed using examples of materials from many countries and associations, including Diabetes UK. Members of AMODIA have been trained in how to teach their colleagues and this has also been included in healthcare worker training.

Community involvement and diabetes associations

In 2003, AMODIA Maputo had only 124 active members and was the only branch of the association nationwide. The main role of AMODIA at this time was delivery of care. AMODIA Maputo now has over 2600 members and has shifted its role from care provider to support network in Maputo. Since 2003, two new branches of AMODIA have been established, in Beira and Quelimane. The link developed with external partners such as the IDF, the World Diabetes Foundation and Diabetes UK has helped raise the profile of AMODIA and it is now viewed by MISAU as a partner for improving diabetes care and health promotion.

Other results

Other impacts of this project have been that one of the authors (CSM) was invited to the UK for a study visit to look at diabetes care in the UK, to meet policymakers, staff and volunteers working for Diabetes UK and to speak at the Annual Professional Conference of Diabetes UK in 2008. Awareness on the issue of
diabetes and non-communicable diseases in Mozambique, in sub-Saharan Africa and resource-poor countries has been increased through publications, and at presentations and posters at various national, regional and international meetings resulting from this work.

Discussion
This assessment shows that, since 2003, much progress has been made in Mozambique with regard to diabetes and non-communicable diseases. The progress made in Mozambique in addressing the growing challenge of diabetes and non-communicable diseases should be applauded, as these developments need to be put into the context of a health system where the attention remains linked to communicable diseases and only $9.00 spent per person per year on health care by the government.

A few factors were highlighted as having enabled such positive developments to take place in Mozambique. These included:

(i) creation of the Non-Communicable Disease Department within the Ministry of Health;
(ii) commitment of decision makers;
(i) non-communicable diseases were included in two key government documents, Mozambique’s ‘Plano de Ação para a Redução da Pobreza Absoluta’ II (PARPA; poverty reduction plan) [21] and MISAU’s ‘Plano Económico e Social’ (economic and social plan) [26];
(iii) site visits to different facilities and provinces by two authors (CSM and DB) with practical recommendations;
(iv) increase in data on diabetes;
(i) burden of non-communicable disease risk factors using the WHO STEPwise approach;
1. overall vision and numbers;
2. media attention;
(ii) RAPPA (2003);
1. situation of the health system;
2. impact on the public of extremely low life expectancy for children with Type 1 diabetes under 15 years of age;
3. highlighting of an unknown situation regarding the state of diabetes care.

Besides the direct impact of Diabetes UK’s support to training courses, development of educational material, World Diabetes Day activities and the development of the National Strategy on Non-Communicable Diseases, the twinning project has had other ‘collateral’ benefits, such as improved access to insulin and diagnostic tools. These, of course, had an impact on the prognosis of people with Type 1 diabetes, especially children, with an estimated increase in life expectancy from 1.6 to 2.9 years after disease onset from 2003 to 2009. This is probably attributable to three factors: (i) improved availability of insulin, (ii) improved availability of diagnostic tools and (iii) increased training of healthcare workers, which has led to increased awareness of Type 1 diabetes (see Table 2). We believe that any such estimate for adults with Type 1 diabetes was hazardous because differences in these numbers may have been more likely to result from improved awareness of the needs for insulin treatment in patients with Type 2 diabetes.

With the total external financial support provided by Diabetes UK and the World Diabetes Foundation being less than £400 000, the authors consider that this programme provides value for money. The model used in this work comprised an initial situation analysis, with understanding of the local situation and needs, thus allowing local priorities to be identified. In this way, the objectives of Diabetes UK could be linked to these priorities, this being followed by implementation and a reassessment to gauge success and to develop new recommendations in order to continue building on these initial results.

As discussed by Kessner et al. [27] and Nolte et al. [28], diabetes can be used as a tracer for the effectiveness of health systems. Therefore, the lessons learnt from this work can be applied to other non-communicable diseases and also chronic communicable diseases.

Despite the large and increasing burden of non-communicable diseases, the resources allocated to these conditions are 15 times less than for communicable diseases, such as HIV/AIDS, tuberculosis and malaria [1]. Improving care for people with diabetes and other non-communicable diseases in a resource-poor country is a daunting prospect that, as yet, has not been addressed by the traditional bilateral and multilateral donors or by the large funds and foundations involved in health. The UK Government has advocated the benefits of links and twinning schemes in the strengthening of health systems in resource-poor countries [29]. This study shows a concrete example of how twinning can be used to address the issue of non-communicable diseases in a resource setting with a relatively low level of investment.

Competing interests
Nothing to declare.

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References
2.4. Health systems and the management of chronic diseases: lessons from Type 1 diabetes


**Summary**

This Review provides a theoretical perspective on the management of chronic diseases and the role of health systems. It argues that based on work by Kessner et al. (143) and Nolte et al. (144) Type 1 diabetes is an “interesting” tracer disease to analyse health systems and their capacity for management of chronic diseases. Kessner et al. (143) proposed that tracer conditions need to meet the following six criteria and in looking at Type 1 diabetes this Review presented how these criteria are met:

1. Tracer disease has a quantifiable impact on the individual and treatment and care for this disease should impact outcomes
   a. In Type 1 diabetes care has a clear impact on outcomes and given the absolute need for insulin individuals with Type 1 diabetes will die without this medicine being provided by the health system
2. Tracer disease is well defined and easily diagnosed
   a. Type 1 diabetes is clearly defined clinically with specific diagnostic criteria
3. Tracer disease has a known prevalence and this should be significant enough to allow for data collection on disease and outcomes
   a. Prevalence of Type 1 diabetes varies between populations, but it is present around the world
4. Progression of the tracer disease should be altered with use of health services
   a. For Type 1 diabetes disease progression and complications are linked to health service use
5. Management of tracer disease should be well defined for at least one of the following: prevention; diagnosis; treatment; or rehabilitation
   a. For Type 1 diabetes diagnosis and treatment are well defined
6. Epidemiology and non-medical aspects should be understood
a. Epidemiology is known in many settings and varies between different populations. Non-medical aspects are also described to a certain extent.

However, looking more a the last element of “non-medical” aspects proposed by Kessner et al. (143) the wider needs of people with Type 1 diabetes are not clearly understood and health systems need to focus more on what Bury (145) defined as a “biographical disruption”. This is when a person develops a chronic disease and they need to adapt their daily lives to this new situation. It is not only this personal change, but also how others now view these individuals.

*What this adds to the argument of the overall thesis*

From this Review the key concepts linked to this thesis are the need to focus on the individual. For this a variety of health system factors need to be integrated, and using Type 1 diabetes as a tracer can measure these as well as wider personal factors. Health systems and technological advances have revolutionised the management of Type 1 diabetes from the discovery of insulin in 1921 in HICs, but these innovations have not necessarily led to improved diabetes management especially in LILMICs. One reason for this that this review highlights is that the majority of the time the individual spends managing their diabetes is outside the formal health system and this needs to be addressed and integrated within the health system.
**REVIEW**

Health systems and the management of chronic diseases: lessons from Type 1 diabetes

David Beran*

- Type 1 diabetes is a useful tracer condition in looking at chronic diseases in health systems.
- The management of chronic diseases is one of the largest challenges that health systems throughout the world face.
- Health systems are currently organized for acute care and not chronic conditions.
- Diabetes care requires an integrated approach, with the person with diabetes, the family and community being involved in care as most of the time diabetes is managed outside of the health system.
- Currently, health systems fail to meet the needs of people with chronic diseases as they do not address nonclinical aspects appropriately.
- Care for chronic diseases needs to be tailored to each individual.

**SUMMARY**  
Type 1 diabetes is a good example of a chronic noncommunicable disease and some have even suggested that it may be used as a ‘tracer’ condition. Chronic noncommunicable diseases are the leading challenge that health systems throughout the world currently face and a shift is needed at different levels of the health system to manage these conditions effectively. However, Type 1 diabetes like most chronic noncommunicable diseases is managed outside the health system, and therefore a larger perspective than purely medical care is needed. This is also required as any chronic disease changes the individual’s perspective and their needs in managing their condition on a daily basis. The purpose of this review is to present a health systems’ perspective on the management of diabetes and chronic conditions. In presenting this perspective, the review aims to highlight that although the individual is included in the Innovative Care for Chronic Conditions Framework, current literature fails to address the individual’s experience and how the health system only plays a small role in their overall care.

The management of Type 1 diabetes requires an integrated approach, with the person with diabetes, the family and community being involved in care, which is common to all chronic noncommunicable diseases (NCWDs) [3,4]. Chronic diseases (CDs) are defined as diseases that have a long duration, generally progress slowly and do not have a cure [2,4]. Some CDs are communicable, such as AIDS and tuberculosis (TB). Noncommunicable diseases (NCDs) are those diseases that cannot be transmitted from person to person [1,3]. NCWDs are the leading cause of...
worldwide mortality with the main causes being cardiovascular disease, cancer, chronic lung disease and diabetes [4]. In 2005, all CDs accounted for 72% of the total global burden of disease in the population aged 30 years and older [4]. In the USA, it is estimated that 100 million people have at least one CD and managing these diseases accounts for 75% of national health expenditure [5].

Approximately 80% of deaths from CDs now occur in low- and middle-income countries [5]. Death rates in these countries, in contrast to high-income settings, are highest in middle-aged people who are the most economically active segment of the population [6]. These countries are now facing the double burden of disease with an increasing number of people suffering from non-communicable diseases such as AIDS, TB and malaria [7, 8]. In Tanzania, Setel et al. regrouped diseases, whether they were acute or chronic, to reflect their care needs [6]. It was found that 86% of disability-adjusted life years (DALYs) were attributable to CDs. Another study from South Africa found that the need for chronic care has increased more than the need for acute care [6].

Many health systems are not currently organized for the long-term care of individuals, but rather acute care [9, 10]. The management of CDs requires a more integrated health system than that needed for one-off acute care with regular availability of drugs, laboratory facilities, data collection tools, a trained healthcare team and educated and empowered patients [11, 12]. Type 1 diabetes is an interesting example of a CNCD in that it requires strict management of different aspects of life (medicines, diet and so on) as well as being managed for the most part outside the formal health system.

**Type 1 diabetes as a ‘tracer condition’**

Kessner et al. were the first to use the concept of tracers with regards to health systems [12]. They used this concept in a similar way as radioactive tracers are used by healthcare workers to see how different organs work. They then applied this idea to health systems, with certain conditions being used as tracers on how a health system worked. They stated that tracers needed to be distinct and identifiable health problems and were required to show how particular parts of the health system work together to provide healthcare. Tracers measure both the processes and outcomes of care.

They established six criteria for tracers. In order of importance these are:

- The condition used as a tracer should have a measurable impact on the patient and treatment of this condition should also influence outcomes;
- A tracer condition should be well defined and easily diagnosed;
- The prevalence of the diseases should be significant enough to allow for adequate data collection;
- The progression of the disease should vary with varying use of the health system;
- Medical/clinical management of the condition should be well defined in at least one of the following areas: prevention, diagnosis, treatment or rehabilitation;
- Non-medical aspects of the condition should be known as well as the epidemiology.

The suitability of Type 1 diabetes with regards to these six criteria is detailed in Table 1.
Health systems & the management of chronic diseases: lessons from Type 1 diabetes

**REVIEW**

A health system as defined by the WHO is all “activities whose primary purpose is to promote, restore and maintain health” [110]. This definition includes not only the formal health services, but also traditional healers and all use of medicines. Health systems have three main objectives according to the WHO [110]:

- Improving the health of the populations they serve;
- Responding to people’s expectations;
- Providing financial protection against the costs of ill-health.

Stronger health systems are needed to achieve better health for populations [36]. For people with CNCDs, the aim of the health system is to prevent complications and the negative physical and psychosocial impact the disease may have on the individual [2]. As CDs are now the leading cause of death in the world, health systems need a ‘paradigm shift’ from an acute to a chronic care model [1, 17, 101, 111]. Nolte and McKee state that the management of CDs is one of the largest challenges that health systems throughout the world currently face and that each system needs to find a locally adapted solution [39]. The management of all CDs has common factors mainly linked to the fact that care needs to be provided over a long period of time, which requires the input from a multidisciplinary team of healthcare workers, access to medicines and diagnostic tools, patient empowerment and the coordination of different elements of the health system [39]. The key principles for the management of CDs are [29, 101]:

- The development of a treatment partnership between healthcare worker and patient to support self-management;
- Focus on the individual’s main concerns;
- Use of the ‘5 As’: assess, advise, agree, assist and arrange;
- Promotion of patient self-management;
- Organization of healthcare delivery and proactive follow-up;
- Involvement of ‘expert patients’, peer educators and support staff;
- Linkage between the patient and the community;
- Utilization of written information, such as, registers, treatment plans and so on, and written information for the patients to use for monitoring, reminders and so on;
- Use of a clinical team;
- Assurance of continuity of care.

Despite medical advances in the clinical treatment of most CDs, the benefits have not impacted the outcomes for people with these conditions sometimes because they are not

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### Table 1. The suitability of Type 1 diabetes as a ‘tracer’ condition.

<table>
<thead>
<tr>
<th>Criteria for ‘tracer’ condition based on Kessner et al. [12]</th>
<th>Factor related to Type 1 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition should have a measurable impact on the patient</td>
<td>Type 1 diabetes has a clear impact on the individual</td>
</tr>
<tr>
<td>Treatment of this condition should also influence outcomes</td>
<td>Without insulin the person will die</td>
</tr>
<tr>
<td>Well defined and easily diagnosed condition</td>
<td>Any failure within the health system in managing Type 1 diabetes will immediately have an impact on the individual</td>
</tr>
<tr>
<td>Prevalence of the diseases should be significant enough to allow for adequate data collection</td>
<td>Type 1 diabetes is clearly defined clinically with specific diagnostic criteria</td>
</tr>
<tr>
<td>Progression of the disease should vary with varying use of the health system</td>
<td>This is the case in some populations, but not all. However, each population no matter where should have at least some people with Type 1 diabetes</td>
</tr>
<tr>
<td>Medical/clinical management of the condition should be well defined in at least one of the following areas:</td>
<td>Progression and development of complications is directly linked to use of the health system</td>
</tr>
<tr>
<td>• Prevention</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>• Diagnosis</td>
<td>Treatment</td>
</tr>
<tr>
<td>• Treatment</td>
<td>Type 1 diabetes qualifies in the following areas:</td>
</tr>
<tr>
<td>• Rehabilitation</td>
<td>Non-medical aspects of the condition should be known as well as the epidemiology</td>
</tr>
<tr>
<td>Non-medical aspects of the condition should be known as well as the epidemiology</td>
<td>These are known and clearly described in the literature. Epidemiology in most settings is known. In others where it is unknown, predictions exist as Type 1 diabetes is present to varying degrees in all populations</td>
</tr>
</tbody>
</table>

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adapted[19,20]. This so-called ‘quality gap’ is due to the [21]:

- Increased burden of CDs leading to higher demand for health services;
- Complex nature of the scientific and technological advances that have taken place and the ability to adapt these to clinical practice;
- Poor organization of the system, which is unable to adapt to these changes.

Health systems do not work in isolation of the other sociopolitical elements of a given country, and therefore different models of health systems exist [22,110,112–114]. Functions of health systems are: procurement and supply of medicines, disposables and equipment; healthcare workers in sufficient numbers and with the right skills for the given population and disease burden, sustainable financing and healthcare costs that do not overburden the poor and have a financial, budgetary and regulatory framework [112,113].

In trying to achieve these aims, health systems need to provide six key elements [112]:

- Service delivery: presence of safe and quality healthcare and facilities and infrastructure;
- Healthcare workforce;
- Information: research, surveillance systems and so on;
- Medical products, vaccines and technologies;
- Financing;
- Leadership and governance: sometimes called ‘stewardship’, is the role that the government plays in engaging other national actors that impact health [22,110].

Another key element of a health system is responsiveness, with the health system needing to respond to the expectations people have. The needs of people with CDs “should be promptly attended to, without long delays in waiting for diagnosis and treatment – not only for better health outcomes but also to respect the value of people’s time and to reduce their anxiety” [110].

In order to address this, Wagner et al. developed the Chronic Care Model (CCM) [24], which was further expanded by the WHO into the Innovative Care for Chronic Conditions Framework (ICCCF) [103]. The elements this model describes for the effective management of CDs are [30]:

- Use of plans and protocols;
- Reorganization of the delivery of care to focus on patient needs, such as:
  - More time spent with patient;
  - Different resources, such as education and health professionals, such as dieticians, made available;
  - Integrated follow-up.
- Need to focus on informational needs and the need for behavior change of patients;
- Access to other specialties when needed;
- Use of information systems.

The WHO framework in Figure 1, shows the inputs necessary to move health systems away from an acute model to one that can address the issue of CDs.

The model above describes the necessary elements that need to be present in order to provide patients with the best level of care for their CD, be it Type 1 diabetes or HIV/AIDS. Included in this model are three levels [103].

Micro: the patient interaction – this includes patients and their families, a motivated healthcare team and informed communities. These three elements work together to ensure care for the individual in the health system, but most importantly at home and in the community [23]. Lewis and Dixon [24] and Bodenheimer et al. [5] have described this as ‘three overlapping galaxies’ needed to effectively deliver chronic care. The individual needs to care for themselves by adhering to medicines and lifestyle. Healthcare workers need to provide care and take a multidisciplinary approach to care. Society needs to create healthy environments and remove social and cultural barriers to individual lifestyle choices. However, as detailed by Vallis [25] barriers exist at these three levels.

Meso: healthcare organization and community – this element includes healthcare workers’ skills, the mix of health personnel cadres present, patient follow-up, information systems and tools for patient self-management and self-care. In addition to the health system, the community plays a complementary role to the health system providing support, addressing stigma, resources and additional services.

Macro: policy level – this level addresses leadership and advocacy influencing decision-makers on addressing the challenge of CDs. A
A cross-cutting view of policies is also necessary in that policies affecting people with CDs do not only fall within the area of health. This also needs to be linked to legislation and how this is developed. These policies and legislation also need to ensure proper resource allocation (human and financial) to address NCDs. In addition, policy makers need to be active in developing partnerships to address the challenges of CDs.

This model highlights that for the shift from acute to chronic care, health systems need to adopt the following eight key steps in developing a health system capable of managing CNCDs.

- **Support a paradigm shift**
  Health systems in low- and middle-income countries are now facing a ‘double burden’ of disease, due to changes in epidemiology and aging populations. In parallel, some high-income countries have failed to address CDs appropriately. The paradigm shift needs to take health systems that are currently organized around acute care and design them to manage CDs. In order to tackle these CDs, health system strengthening is necessary in order to ensure continued monitoring of the patient and a continuum of testing, medicines and care.

- **Manage the political environment**
  In order for an effective health system to be put into place that can manage CDs, a suitable policy environment needs to be in place. This environment encompasses the individual with a CD, their family, healthcare providers and the community as a whole. This policy environment is responsible for legislation, leadership, policy integration, partnerships, financing and the allocation of human resources.

- **Build integrated healthcare**
  For appropriate management of CNCDs an integrated health system needs to be in place. Each level of the health system has a role to play in care, and thus certain material and human resources need to be present. Also a certain level of organization and coordination between different levels of the health system and different sectors within the same institution (inpatient and outpatient services, pharmacy, laboratory and so on) need to be in place for patient management and referral. Guidelines need to be developed.
and used as well as data to ensure efficient and effective care [19,20,115].

- Align sectoral policies for health
For effective management of CDs, other policies need to be aligned with those impacting on health. One such example of addressing the multisectoral approach to create a favorable policy environment for people with diabetes was trying to remove any taxes on materials used by people with diabetes [115]. Another example of this is described by Ham – one of the requirements for the successful management of CDs in a health system is universal coverage and that care should be free at the point of use ensuring that cost is not a barrier to care [26].

- Use healthcare professionals more effectively
The transition from acute to chronic care poses a challenge to healthcare professionals [27]. One of the challenges with this is that the onus of care is placed on the individual. Using healthcare workers effectively ensures that the patient benefits from a higher level of care. Issues of training, rational use and availability of appropriate healthcare workers is needed [37]. The health system needs to be better organized overall as well as on a facility level basis with teams of healthcare workers involved in care [18,19,115]. There is a lack of time and also division of roles that different healthcare workers can play in addressing the different needs a person with a CD has [3]. In managing CDs, Greenhalgh describes how the healthcare worker’s role switches from being an expert and instructing and deciding for their patient, to being a guide in supporting, advising and helping their patient manage their condition [21].

- Center care on the patient & family
The health system may provide the majority of aspects that a person with a CD requires, however, the burden of care falls on the individual and their family as the majority of the time spent managing a CD is taken outside of the health system [24]. Issues around patient education and empowerment need to be addressed [18,19,115]. Patients need to be informed and take an active role in their care so that the interactions they have with healthcare workers are more ‘productive’ [38]. This places a large onus on education of both the individual and their family. The health system, therefore, needs to not only provide medical care, but also the means to improve the individual’s knowledge and self-management skills with people with CDs and their families required “to play a fully informed role in their care” [24].

- Support patients in their communities
The issue of coping with a CD versus managing it is seen as important and peer support plays a vital role in helping with this [23]. It is therefore necessary for the community to mobilize resources to meet the needs of people with CDs [18,19,115]. The main community involvement in diabetes care, for example, is through diabetes associations. Involvement of other community members such as local government officials, community leaders, village chiefs or elders, as well as traditional healers, is important [2,29].

- Emphasize prevention
Primary, secondary and tertiary prevention of CNCDs is necessary. Ham states that this is a key element to managing CDs in a health system [26]. As CNCDs cannot be cured the health system has to focus on trying to improve outcomes and quality of life (QoL) [28]. However, the responsibility of care is on the individual, and therefore the healthcare worker and health system need to provide the necessary environment and tools that allow the individual to do this [1,24].

Chronic diseases & health systems: the need to focus on the individual’s perspective
The individual in managing their diabetes, for example, will only have 2 h with the health system and the remaining 8758 h managing their diabetes at home and in their communities [30]. From the individual’s perspective there is a change in all aspects of the individual’s lifestyle, adoption of self-management skills, including taking medicines, the need for family involvement and developing coping mechanisms [18,20,31]. In addition, the person has a ‘disease without an illness’ in that the person clinically has a CD, but does not necessarily feel unwell [12,32].

Currently health systems fail to meet the needs of people with CDs as they do not address non-clinical aspects such as education and psychological support [25,29,103]. In addition, healthcare workers often do not address the capacity of the individual to function with their condition and fail to provide all the necessary information and support for psychosocial factors, leading to poor
self-management [36]. This is due to healthcare workers not having enough time, inadequate follow-up and guidelines either lacking or not being properly used [29].

CDs are described by Bury as a ‘biographical disruption’, where the life of the person and things that they normally take for granted are changed [36]. CDs impact life at home and work, as well as time spent caring for the condition and the socioeconomic costs of the condition [36]. This change in ‘biography’ is described in Figure 2. With an acute condition the change in routine is for a few days, weeks or even months, but once recovered the individual returns to ‘normal’. With a CD the definition of ‘normal’ changes as the person needs to adapt their life to manage this disease. In addition, the person may face a certain amount of stigma because of their condition [36].

The other aspect of the change due to a CD is the view that the person now has of themselves and the views of others. People come to view themselves and be viewed as ‘diabetics’ or ‘asthmatics’ and so on [37,38]. They may see themselves or be viewed as unwell even though their condition may not cause them any problem [29]. Despite these labels most CDs are invisible to others and the change is only with the way the individual adapts their lifestyle [39]. This is a change in what people perceive as normal and also an increased awareness of their body and what is wrong [36]. Williams states that in addition to lifestyle changes, pain, suffering and death become a reality for people with a CD and their families [29]. This is an added challenge, especially in children, as CDs and death are usually distant or something that happens to older people [40]. Therefore CDs do not only impact the physical health of people, but also their mental state [41].

Children with CDs have many similarities in their life experiences and challenges. Stein and Jessop quote Pless and Pinkerton in that what impacts children and their families more than the disease itself is its chronic nature [41]. Psychosocial aspects are important and healthcare workers need to focus on the individual needs of each child. Williams, in work with adults, also describes different stages that the person diagnosed with a CD goes through [29]. The first stage is ‘what is going on here’, which leads to an increased attention to things that are happening as a result of the disease. The second aspect discussed is the questioning that follows the onset of a CD. The ‘why me’, ‘why now’, ‘what have I done’. As health professionals cannot provide an explanation to these questions, people with a CD develop their own answers and reasoning for onset of the disease. The last aspect discussed is the ‘mobilization of resources’ once the person comes to terms with their situation. These can be social, financial, medical and so on. This aspect as discussed by Bury is described as coping as the ‘cognitive process’ that enables people with a CD to ‘tolerate’ or ‘put up’ with the condition they have [36]. Coping is the first stage in a process that leads the individual to adapt their attitudes and way of managing their condition [36]. The last aspect that brings together these other concepts is ‘style’. In a sense this is how people package their coping and strategy in the way they behave and interact with society [46].

Following the coping phase the next stage is normalization where the CD becomes normal and part of how the person behaves in order to minimize the impact of the condition on their day-to-day life [36]. Finally, the strategy focuses on the actions individuals take and what they do with their condition and the attitudes that they develop. Strategies may be altered and adapted in their interaction and social interactions.

Kay et al. argue that there are really two dimensions when looking at chronic care of an individual, the care dimension and the psychosocial dimension [116]. Box 1 describes the elements of these two dimensions. This table highlights the variety of needs that are required from the health system for the individual to manage their CD and how some of them fall outside the remit of what is traditionally viewed as the health system. Also some of these needs are tangible, in that the health system can provide these. Whereas others
could be viewed as needing a process to implement them, or some such as ‘religion and belief’ could even be viewed as intangible. This is a challenge as healthcare workers only focus on the symptoms of the CD versus the integral person with their condition – that is, the psychosocial dimension [20].

CD management needs to be tailored to the individual including both the care and psychosocial dimensions. Goals need to be set, but for the healthcare workers these are clinical, such as better blood glucose readings, whereas for the individual these are personal, being able to go to a party and eat what they want, partake in physical activity and so on [2]. The terms self-care or self-management are key in the management of CDs as the responsibility of day-to-day care is placed on the individual. Self-care is defined as activities that individuals, families and communities carry out in order to improve health, prevent diseases, limit illness and restore health. Self-care is based on ‘lay experience and daily living with a given condition’ and includes such aspects as self-diagnosis, self-management, self-medication and self-monitoring [11].

The term self-management was first used to describe the active participation of people with a given condition in their treatment [2]. Self-management addresses both the direct physical aspects of the condition that the person suffers, but also the psychological impact the disease may have. This is seen as a collaborative process between the healthcare worker and patient. Self-management in an ideal world is the individual with a CD being able to take the clinical information they have been given and use their experience to adjust the way they care for themselves [2]. This can be influenced by family and friends, but ultimately self-management leads to goals to be established and the individual using the resources available to them to self-manage their condition. It is important to note that self-management is not just taking medicines, but also adapting to and adapting one’s environment to best suit the care of the condition.

Management of chronic diseases: the importance of the individual’s needs

In looking at the literature linked to improving health systems for CDs no studies discuss the needs of people with a given condition in improving health systems and very few address the situation outside the developed world. The literature focuses mainly on:

- Theoretical models [3,17,32-34,42-46].
- Descriptions of initiatives in specific countries [347-354].
- How the CCM has been implemented for specific diseases [59-61].
- The role of different levels of the health system, especially primary care, in the management of CDs [5,64-66].
- The role of nurses [67,68].

As stated by Kralik et al. the literature on the management of CDs is focused on the healthcare workers’ perspective or outcomes [69]. The outcomes described in the literature are either clinical [64,70-72] or organizational [73-80]. One study by Glasgow et al. looked at patients’ self-reporting if the care received was in line with the CCM [30]. However, a clear gap in the literature exists in identifying the needs people with a specific CD have and linking this to the organization of care. Ham in a review of the use of the CCM, highlights this gap and states that what is required is to focus the development of health
Health systems & the management of chronic diseases: lessons from Type 1 diabetes

REVIEW

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From the individual’s perspective being diagnosed with a CD means a complete change in the way they lead their lives. The perspective that they have of themselves and the way they are viewed by society changes. People with CDs require both their medical and social needs to be dealt with by the health system.

The literature linked to improving health systems for CDs fails to address the needs of people with a given condition in improving health systems and very few address the situation outside the developed world. The focus is mainly on the theoretical aspect of implementing the CCM or ICCCF or describing the implementation of this model in specific settings or for specific diseases. If outcomes were measured these were either clinical or organizational. Few studies try to identify ways of enhancing aspects of self-efficacy, management and care.

One could argue that in comparison to other CDs Type 1 diabetes is unique in that any failure in the health system or the individual’s self-efficacy, management or care will lead to an immediate impact and that people with Type 1 diabetes know exactly how a specific health action will have an impact on their outcomes. However, very little is known about the management of Type 1 diabetes outside the health system.

Future perspective

As CDs continue to increase throughout the world innovative solutions will need to be found to address these conditions. As health systems are not designed for this long-term care in parallel to people managing these conditions at home, school, work and so on, these environments will need to be included in what we view as part of the health system. Health system research will need to investigate the needs of people managing their CD in these settings and health professionals will have to adapt to this new paradigm where their role in disease management will be less active and need to be adapted to the individual. This tailoring of care will be necessary as each individual is unique, and living in different situations, for example, a young school child versus a professional, and this means that the approach of health professionals and the health system itself will need to change. In addition, the role of the community and other potential providers of medical care or support will need to be investigated, developed and adapted to each setting.
One key element in this is providing education, again tailored to the individual, but also ensuring that the individual is empowered. Empowerment is defined by the knowledge, skills, attitudes and self-awareness that people need to have in order to change their own behavior. For this, people with CDs need to know that a specific health action will have an impact on their outcomes. These outcomes may not only be clinical, for example, improved blood glucose management for someone with diabetes, but also social in that the individual is now able to ‘adapt’ their diabetes to any activity they want.

In delivering this new model, research will play a key role. The importance of combining clinical, health system and individual research will also be key to ensuring adequate management of these conditions. Clinical research will be needed to develop treatments and their delivery. Health system research will be necessary to optimize the organization of this delivery and finally research into the individual and their needs will be necessary to ensure that the treatment and the way it is delivered is in line with what is expected and does not create any clinical or social barrier that may impede proper treatment and adherence.

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Papers of special note have been highlighted as:

# of considerable interest
11 Must read for anyone interested in the issue of chronic diseases that presents both a theoretical perspective and practical example of how health systems need to cope with the burden of chronic diseases.
14 Interesting approach to health systems research using a tracer condition methodology.
16 Practical use of Kesner et al.’s work on tracer conditions. Also highlights the challenges of diabetes management in some low- and middle-income countries.
Extremely interesting article that not only highlights issues surrounding chronic diseases, but also how evidence can be translated into action.


For those who want to learn to get and get a different perspective on health and illness than purely a biomedical one.


Truly unique article that presents the changes in the individual with a chronic condition in a theoretical way, but allows for this to be applied directly to practical cases.


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2.5. Diabetes in Kyrgyzstan: changes between 2002 and 2009


Summary

This research paper is included to provide a “case study” of a given LILMIC, Kyrgyzstan, with regards to the health system for diabetes. This article compared two studies looking at the health system’s capacity to manage diabetes carried out in 2002 and 2009 using RAP as a tool for assessment. Kyrgyzstan has been recognised as a good example of an LILMIC in terms of health system reforms especially in the area of maternal and child health. Also in contrast to other LILMICS, Kyrgyzstan has a high burden of NCDs versus the more “traditional” disease burden of so called developing nations.

The comparison of the of the studies in 2002 and 2009 highlighted the following positive developments:

- Increased importance of diabetes associations
- Establishment of a diabetes law enabling people with diabetes to access a list of required tools for their management
- Increased access to insulin and provision of insulin for free within the health system
- Increased presence of diagnostic tools at different levels of the health system

However, many factors had not changed over this period, such as:

- Healthcare workers and their knowledge of diabetes
- Organisation of the health system for diabetes care
  - Still focused on tertiary care
  - Seen as specialist disease
  - Need for people to go to Bishkek (capital city) for care
- Lack of reliable data
What this adds to the argument of the overall thesis

This study highlights a few interesting elements when examined from the angle of integration. Firstly, a positive development in terms of the increased role of the diabetes associations in Kyrgyzstan shows how these types of organisations can be integrated and used for the overall benefit of the health system and policies. Although a positive development the diabetes law was not integrated into practice due to the actual financial cost of providing all the elements of care the law includes. Although insulin access increased, it did so at a significant cost to the health system. The Kyrgyz health system instead of buying only human insulin also bought analogue insulin. Had the government only bought human insulin it would have had an additional US$ 700,000 for potentially other diabetes related activities or even increasing its purchase of metformin (an oral treatment for Type 2 diabetes), which was not bought in sufficient quantities. Although some argue that analogue insulin is “better” than human insulin this example brings to light the need to integrate both the patient and health system view in managing diabetes. From an individual perspective it might be better to provide analogue insulin, however this has a financial cost to the whole system limiting its ability to provide other aspects of diabetes care or even other health services in general.

Three other lessons from this study are the need to integrate PHC in the management of diabetes; that although the donor agenda in an LILMIC like Kyrgyzstan has enabled reforms and improvements in other areas of health it has not been successful in addressing diabetes and other NCDs; and finally this study actually enabled the integration of research into policy through its approach and by continuously including local stakeholders in the research process and restitution of results.
Diabetes in Kyrgyzstan: changes between 2002 and 2009

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ABSTRACT

Health system reform in Kyrgyzstan is seen as a relative success story in central Asia. Initially, most attention focused on structural changes, and it is only since 2006 that the delivery of care and the experience of health service users have risen on the agenda. One exception from the earlier period was a rapid appraisal of the management of diabetes, undertaken in 2002. Using that study as a baseline, we describe the findings of a new evaluation of diabetes management, undertaken in 2009, using the Rapid Assessment Protocol for Insulin Access, now implemented in seven countries. Access to care has improved through the creation of the Family Medical Centres and the deployment of endocrinologists to them. Another improvement is the access to insulin and related medicines, although assessment of the procurement system reveals that the government is getting very poor value for money. Looking ahead, there are grounds for optimism that the passage of the law on diabetes may progressively have a greater impact. Although the law is not yet fully implemented, it has enabled the diabetes associations to defend the rights of their members. This increased capacity is credited with some improvements in diabetes care. Copyright © 2012 John Wiley & Sons, Ltd.

KEY WORDS: diabetes; health systems; health system management; chronic diseases; health system assessments

INTRODUCTION

The newly independent states that emerged from the Soviet Union in 1991 faced the challenge of reforming their health systems to adapt to their new political and

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financial reality (Kutzin et al., 2010b). Kyrgyzstan, one of the poorest of the ex-Soviet republics, was confronted with particular challenges. A mountainous country with few natural resources, it faced rapid economic collapse as the Soviet trading system fell apart. It inherited a health system that was inefficient and unsustainable (Melemanaliev et al., 2005), and in 1996, the Ministry of Health, with assistance from several bilateral donors and the World Health Organisation (WHO), launched an ambitious National Health Care Reform Programme, ‘Manas’, which offered a blueprint for health system development. In 2006, this programme was succeeded by the ‘Manas Taalimi’, which maintained the continuity of reform and strategic directions. The programme was implemented within the framework of the first sector-wide approach programme in the former Soviet Union and thus provided a mechanism to coordinate multiple stakeholders around shared priorities and measurable indicators (Ministry of Health of the Kyrgyz Republic, 2006; Mirzoev et al., 2010). These reforms had four objectives (Ministry of Health of the Kyrgyz Republic, 2006; Ministry of Health, 2009):

(i) improved health system effectiveness through development of family practice and restructuring the hospital sector,

(ii) improved access to essential services and achievement of universal coverage including mandatory health insurance and more efficient resource allocation mechanisms,

(iii) improved efficiency and quality of care, to be achieved by improved resource allocation mechanisms and provider payments based on outcomes, and

(iv) improved flexibility, with greater autonomy of health facilities and reduction of the inherited extensive hospital stock.

The implementation of these radical health system reforms is considered to have been relatively successful, despite challenging economic and political circumstances (Ministry of Health, 2011), in contrast to its central Asian neighbours (Rechel et al., 2011) and many other low and middle income countries (Balabanova et al., 2011). Kyrgyzstan has sought to enhance financial protection, with a state-guaranteed basic benefits package guaranteeing basic health care for all and a reduction of the once ubiquitous informal payments, especially for medicines (Falkingham et al., 2010; Ministry of Health, 2011). The two successive programmes sought to transform primary health care, with retrained family practitioners working in group practices and using newly developed clinical protocols to treat common chronic conditions (including diabetes). An Essential Drug List, with matching financing, and a focus on generic medicines sought to reduce costs (WHO/DFID Manas Health Policy Analysis Project, 2005a, 2005b). Other activities included rationalisation of hospital provision (with a 42% fall in capacity) and creation of a functioning single-payer system that aggregated previously diverse funding streams and tackled longstanding geographical inequities.

There is some evidence that these changes have made a difference to processes of patient care (Ministry of Health, 2009; Ministry of Health, 2011). Services are reported to be more accessible (WHO/DFID Manas Health Policy Analysis Project, 2005a; Falkingham et al., 2010). The quality of treatment provided in primary care facilities is reported to have improved, with fewer hospital referrals (WHO/DFID
Manas Health Policy Analysis Project, 2005a; Hardison et al., 2007). Savings have been made from closing hospitals and the funds diverted to the budget for medicines (Kutzin et al., 2010a).

So far, however, most research has focused on structural changes. It is less clear if the experience of health service users have changed, if at all. One survey reported greater utilisation of essential services, geographically and across socio-economic groups (Falkingham et al., 2010). Other patient surveys of responsiveness also report clear improvements, with patients rating family practices highly on quality (Jakab and Kutzin, 2009). Nevertheless, evidence on patient experience remains scarce.

One way of identifying changes involves using a tracer methodology, in which a condition with certain characteristics is used to understand how the health system impacts on those at the front line, whether as providers or receivers of care (Kessner et al., 1973; Nolte et al., 2006). Such a condition needs to be sufficiently common, with those who have it easy to identify, and requires involvement of different types of health providers over long periods. Examples from low and middle income countries include maternal care, tuberculosis and diabetes, whereas work in progress in high income countries includes the pathway followed by those with certain cancers. The focus of this approach is on the experience of patients and the obstacles and enabling factors they face when accessing the health system at different points in time and for different services (clinical or non-clinical such as nutrition support). Consistent with the WHO’s goals, a health system that can provide patients with consistently effective care, is responsive to their multiple needs and values and does not pose financial burden on their households can be viewed as successful (WHO, 2000).

An early example examined the health system response to diabetes in Kyrgyzstan in 2002 (Hopkinson et al., 2004) using an analytical framework comprising inputs required for effective and responsive care. It found weaknesses in all of them, whether physical (regularity of supply of insulin and testing equipment), human (education of patients and health workers), knowledge (lack of guidelines on treatment regimens and management of complications) or social (support for patients to lead normal lives). The system was fragmented and dysfunctional; patients experienced very poor outcomes and health professionals were demotivated by their inability to provide appropriate care. Although the study focused on diabetes, in keeping with the tracer concept, it exposed weaknesses that affected the delivery of care to those with many other chronic disorders. The study also highlighted the need to look beyond the health system and to labour market legislation and social security arrangements, all of which needed attention if patient experiences and outcomes were to be addressed.

The perceived success of the subsequent reforms in Kyrgyzstan, catalogued previously, justifies looking at what has changed. In 2009, Kyrgyzstan was one of five countries worldwide selected by the Rockefeller Foundation as an example of Good Health at Low Cost, whereby improved health and access to essential care can be achieved with limited resources (Balabanova et al., 2011). Since the 2002 study, experience in using diabetes as a tracer condition has accumulated (Balabanova et al., 2009), leading to the development of a formal protocol, the Rapid Assessment Protocol for Insulin Access (RAPIA), developed by the International Insulin Foundation. This...
tool has now been used in Mali, Mozambique, Nicaragua, the Philippines, Vietnam and Zambia (IIF, 2004c; IIF, 2004b; IIF, 2004a; Beran et al., 2005; Beran et al., 2007; Beran et al., 2009; Higuchi 2009). This paper describes the findings obtained when using this instrument in 2009 (Abdrayimova and Beran, 2009), comparing them with the situation in 2002.

METHODS

The RAPIA instrument is designed to capture the different factors that influence the access to care for people with diabetes (Beran et al., 2006). It draws on the principles employed in Rapid Assessment Protocols, which have been used extensively to assess responses for communicable diseases, including malaria, tuberculosis and, especially, sexually transmitted diseases (Manderson and Aaby, 1992; Scrimshaw and Hurtado, 1997; Rhodes et al., 1999; WHO, 2002). Quantitative and qualitative data are collected from a range of sources, seeking to understand clinical pathways and the availability and use of resources, both from the perspective of the users and the front line providers. It also seeks to understand how the health system integrates with other sectors necessary for people with diabetes to function effectively (Atun et al., 2010).

The analysis was conducted at three levels: (i) the macro level (national government, major companies, the National Diabetes Association, Central Medical Store and educators); (ii) meso level (regional authorities and administrators in ‘health facilities’); and (iii) micro level (health workers and people with diabetes).

Semi-structured interviews were used to follow the pathway from the purchase and importing of insulin and related products until they reach the patient. The interviews also sought to map the ways in which policies and programmes that are designed and endorsed at the national level are then adapted and implemented by regional and provincial structures and how these translate into practices in health facilities. This recognises that there is often a gap between policies and implementation and that unintended consequences may arise. Information from interviews is supplemented with site visits and observations as well as a detailed documentary analysis of relevant material. The now standard study instrument was adapted to the Kyrgyz context and field tested. All national level interviews were carried out by the two lead authors, in Russian or English, following piloting of the interview guide to ensure consistency of meaning. At regional and district level, interviews were conducted in Russian or Kyrgyz by locally recruited and trained staff, with experience in health services research.

The research was carried out in the capital, Bishkek, Issyk-Kul Oblast (region) (a northern region, and in three of its rayons (districts)) and Osh Oblast (a southern region, and in three of its rayons). The regions were selected by local stakeholders as representative of different geographical and socio-economic situations. A total of 192 interviews were conducted (Table 1). The study covered all levels of care relevant to the management of diabetes. In Bishkek, this included all secondary and tertiary facilities (Republican Hospital, City Hospital, City Endocrinology Dispensary) and two primary care facilities (Family Medical Centres (FMCs)). Similarly, in
DIABETES IN KYRGYZSTAN BETWEEN 2002 AND 2009

Table 1. Detail of number of interviews of the Rapid Assessment Protocol for Insulin Access in Kyrgyzstan

<table>
<thead>
<tr>
<th></th>
<th>Macro</th>
<th>Meso</th>
<th>Micro</th>
<th>Total</th>
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<tbody>
<tr>
<td>Bishkek</td>
<td>10</td>
<td>15</td>
<td>58</td>
<td>83</td>
</tr>
<tr>
<td>Issyk-Kul</td>
<td>12</td>
<td>35</td>
<td>47</td>
<td>62</td>
</tr>
<tr>
<td>Osh</td>
<td>15</td>
<td>47</td>
<td>62</td>
<td>62</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>42</td>
<td>140</td>
<td>192</td>
</tr>
</tbody>
</table>

Issyk-Kul and Osh regions, the regional hospital and the regional FMC were included, whereas in each district, the district hospital and district FMC were included. In each facility, the director, health workers involved in diabetes care, family doctors, nurses, the laboratory and pharmacy were interviewed. Patients were interviewed at the facility or, where this was not possible, at their home.

The study was conducted jointly by the International Insulin Foundation based in London and the Health Policy Analysis Centre based in Kyrgyzstan with financial support from the International Diabetes Federation. The study received ethical approval from University College London (Project 0025/001) and local authorisation from the Ministry of Health. All respondents received information about the purpose and aims of the research. Verbal consent was obtained prior to interview with all interviewees.

After a brief summary of the epidemiology of diabetes in Kyrgyzstan, the findings are structured according to the WHO’s health system building blocks (WHO, 2007b), except that here, financing is combined with medical products as those aspects specific to diabetes largely relate to medicines and monitoring equipment.

RESULTS

The epidemiology of diabetes in Kyrgyzstan

Like many low income countries, Kyrgyzstan is facing an increasing prevalence of diabetes. The International Diabetes Federation estimates from its models that it will increase from 4.3% in 2007 to 5.8% in 2025 among those aged from 20 to 79 years (a 34% increase). (IDF, 2006) This may be conservative, as data from the Ministry of Health already record a 26.9% increase in the number of cases between 2002 and 2008. However, a relatively small proportion of those estimated to have diabetes are known to the authorities. In 2008, 0.9% of the population aged 20–79 years (28 893 people) were registered as having diabetes, with around 8% of them (2238) requiring insulin. Although the estimated burden of diabetes is still lower than that in other countries of the former Soviet Union, there are concerns about the ability of the health system to cope. Mortality from diabetes has doubled since the transition (increasing from 6.2/100 000 in 1990 to 12.2 in 2009), much more than in the rest of the region (WHO, 2011). Using data on registered cases, we found that the prevalence of type 1 diabetes among children was 8.4 times as high in the capital
than in the distant Batken region in 2007; this was believed to represent migration by families facing difficulties accessing care in remote areas and also, possibly, differential survival.

**Leadership and governance**

The Ministry of Health is responsible for developing health policy in Kyrgyzstan. A national diabetes plan had been agreed by nine ministries in 1998, but it had no legal status, there was no accompanying funding and, in 2002, it still seemed largely aspirational. At that time, formal legal entitlements for people with diabetes were based on generic laws, such as those on health, disability and employment. In 2006, a specific law on diabetes was enacted, entitling people with diabetes to certain benefits (Kyrgyz Republic, 2006), including free treatment (insulin, oral medicines and glucometers). The law also envisages training healthcare workers in diabetes education and counselling, evidence-based treatment and support for healthy lifestyles, while incorporating broader social objectives such as more equitable access to prevention and care, equal educational and employment opportunities and disability benefits. Two aims of the health system component of this law are raising awareness through health promotion in primary health facilities by involving the community and provision of diabetes care at all levels of the health system. In practice, however, it has only been implemented partially, and the only substantive result was that insulin was being purchased centrally and distributed by the Ministry of Health, but other measures, such as free provision of glucometers and health system strengthening measures, have not happened. Two non-governmental associations work on diabetes, the Diabetes Association of Kyrgyzstan (DAK) and the Kyrgyz Diabetes Federation (KDF), both based in Bishkek. They provide patient education, training of healthcare workers, support for patients and their families and advocate for better care. The DAK is a group of healthcare workers and patients, whereas the KDF comprises mainly parents of children with diabetes.

**Human resources**

Family general practitioners, who in other countries might be expected to undertake much routine management of diabetes, lacked the expertise, with some reporting that they were ‘scared’, especially if insulin was involved. Only 43% of the family general practitioners interviewed treated people with diabetes. Some limited training has been provided for doctors, including one course run by the DAK run jointly with the Association of Internal Medicine and attended by 40 doctors in Bishkek. It focused on insulin, use of different oral medicines, the nature of diabetes and chronic and acute complications. Other courses, run by pharmaceutical companies, were viewed as being of little practical value. Some doctors in Bishkek believed that the focus on generic skills in family medicine training paid insufficient attention to technical expertise in areas such as diabetes that was not being compensated for by the creation of more specialists. They believed that this led to frequent delay in diagnosis.

The primary responsibility for managing diabetes thus resides with endocrinologists, a description applied to 43 physicians in Kyrgyzstan, a doubling since 2002.
However, not all have specialist training, and none had specific training in paediatric endocrinology. Unlike the situation in 2002 when endocrinologists were employed solely in specialist facilities in the capital, some are now deployed to regional facilities and are typically employed jointly by FMCs and district and regional hospitals. Their role is primarily to serve as a focal point for the management of diabetes and other endocrine disorders, but they also act as the primary carers for patients not requiring insulin (in those districts where an endocrinologist is in post). In 2002, all patients with diabetes would have had to travel to specialist facilities in the capital. This is no longer the case except for children with type 1 diabetes or people with diabetes-related complications, who must still travel to Bishkek. There, outpatient care is provided at the City Endocrinology Dispensary, with in-patient care at City Hospital #1. Specialist care is also available at the Department of Endocrinology in the Republican (National) Hospital, and at the Cardiology Institute. As in 2002, children with diabetes in northern Kyrgyzstan must also travel to Bishkek, whereas those in the south can now receive care from a small paediatric endocrinology unit in Osh.

Nurses in Kyrgyzstan play no role in diabetes management, reflecting their generally low status as ‘assistants to doctors’. A few in specialised facilities have received advanced clinical training, but this does not include diabetes. Furthermore, such training was seen as of limited value as they were unable to apply their new skills when returning to the wards.

Service delivery

In 2002, patients with diabetes were admitted each year for ‘assessment’. The practice persists; although previously it took place only in the Republican Hospital in Bishkek, it is now also done in Regional Hospital (except for children, who must go to Bishkek). It comprises laboratory tests (urine and blood glucose), ophthalmological examination, neurology examination and consultation with an endocrinologist. These investigations, which could be carried out in a few hours at most, typically involve a 10-day in-patient stay. This approach was designed to address the known failings of the system and allowed specialists to review progress and adjust the treatment plan. However, it reinforces facility-based treatment, encourages the medicalisation of diabetes management and does nothing to build capacity in primary care.

There is also a very high rate of admission of patients with diabetes for poorly defined problems. In one hospital, people with diabetes accounted for 16.7% of all bed days in 2008. One rayon hospital director noted ‘we always have people with diabetes’.

Information

This includes management information, information for patients and guidelines for health professionals. Access to management data for people working within the health system was a problem in 2002, and it remains the same currently. Patients retain their own records that they take to each facility they visit. Activity data are collected by facilities and transmitted upwards to the health ministry, although data on individuals attending different facilities are not linked. The central register,
described in 2002, is still maintained but is still viewed as inaccurate by local stakeholders. An almost complete lack of computers at health facilities means that data are collected manually, with the potential for errors and omissions. There is no linkage with death certification, so it is likely that numbers are inflated as it includes some people who have died. Data from the register are used to prepare an annual ‘Report on prevalence on Endocrine Pathologies’, which is used to inform the procurement of insulin, but otherwise, data are not used for policy and programme development.

The 2002 study described a virtual absence of educational information for people with diabetes. There are now active efforts to address this problem. Educational centres have now been established at the City Endocrinology Dispensary, the Department of Endocrinology at the National Children’s Hospital and the National Hospital by the DAK and the KDF. However, patient education remains the responsibility of doctors, who have little training in patient education and who are reported often to be too busy to deliver sessions. Some patient education materials are provided by the pharmaceutical industry, but these are typically only in Russian, although many people from outside of Bishkek read only Kyrgyz. These materials also have little relevance to the dietary and socio-economic situation in Kyrgyzstan. A continuing problem, identified in 2002, is that the traditional Kyrgyz diet is high in fat and carbohydrate, and it is difficult to obtain the food recommended in international guidelines.

Education for children was found to be much better than for adults as they can attend sessions at the ‘Diabetes School’ at the National Paediatric Hospital and the Osh Regional Children’s Hospital. Sessions include the child and his or her family and take place at the time of diagnosis.

It is now increasingly recognised that many aspects of medical care in the Soviet system lacked any evidential basis, exemplified by the widespread use of therapies involving lights, magnets and lasers and also many ineffective medications. Although these practices remain common in many parts of the former Soviet Union, there has been a major effort in Kyrgyzstan to develop and implement clinical guidelines based on international evidence; considerable success is reported in maternal and child health for example. In the area of diabetes, the guidelines are based closely on those of the American Diabetes Association and the European Association for the Study of Diabetes (Nathan et al., 2008). Unfortunately, these require investigations that are unavailable in the public sector in Kyrgyzstan, such as the use of HbA1c to monitor control, and include many drugs still on patent and so very expensive. In 2009, these guidelines still existed only on paper.

Medical products and technology

The 2002 study reported major problems with insulin supplies, with a particular challenge being access to an uninterrupted supply of insulin of the appropriate strength and duration of action. The new law on diabetes, which provides free treatment for people with diabetes (Kyrgyz Republic, 2006), does seem to have been associated with some improvements on the ground. There was an adequate supply of insulin in all nine districts visited except one, where none was available.
There are, however, persisting weaknesses in the system of procuring medicines. The Kyrgyz Essential Medicines List contains several expensive proprietary drugs that are not on the corresponding WHO list (WHO, 2007a). There are significant missed opportunities for cost saving. Although 71% of insulin purchased in 2009 met WHO guidelines (Table 2), this accounted for only 43% of total expenditure, implying that the remaining 29%, largely comprising analogue insulin or insulin in penfills, consumed 57% of the insulin budget. Following WHO guidance would have reduced annual costs by $740,000 or around 40% of the total in 2009.

The main problem in 2009 with insulin was not the overall amount but its distribution in the country. Health workers reported that facilities received not what they ordered but what was available. Thus, penfill insulin was often used with a regular syringe, and people often had to switch insulin regimens. There were also problems of stock control within facilities, reflecting concern about ‘running out’ of insulin as resupply took place only every 3 months.

Affordability of medicines should not, in theory, be a problem as drugs for diabetes are purchased centrally and provided free of charge. However, this only applies to those on the Essential Medicines List. The Ministry purchases glibenclamide, glimepiride, metformin and repaglinide (Table 3), a surprising choice as repaglinide is on neither the WHO nor the national lists (Table 4) and could be replaced by metformin. Although metformin was the most commonly prescribed oral diabetic drug, the amount purchased by the Ministry of Health is inadequate, estimated to cover 1% of national requirements in 2009. The number of metformin tablets bought in 2009 was 180,048. With the dose being two tablets per day, this would only be enough for 247 people of the 26,555 non-insulin-dependent people with diabetes (1%). Health facilities purchased additional metformin, but this still left a significant shortfall that had to be purchased from private pharmacies by patients. The pharmacies promote, and patients seem to prefer, the more expensive branded version, suggesting significant supplier-induced demand. Thus, many people with diabetes face a substantial financial burden. The problem is exacerbated by weak procurement; the Ministry of Health purchases glibenclamide and metformin at, respectively, 5.4 and 10.3 times the international market prices (Management Sciences for Health 2008). Its purchases of repaglinide include both branded and generic versions, with the former nine times the price of the latter, and glimepiride from two manufacturers differed in price by a factor of 14 (Table 3).

Although affordability of insulin was generally no longer a problem, in contrast to the situation in 2002, there was limited availability of syringes in the public sector. Seventy-five per cent of facilities visited had none, so most people purchased them from private pharmacies. Those that were available were of poor quality, rarely designed for insulin administration and having inappropriate markings. Needles for penfills were readily available, but there were problems in obtaining the pens. For these reasons, many people bought syringes in the private sector, at an average cost of Som 5.00 (€0.12; range Som 2.00–Som 7.00, €0.05–€0.16). These are single use syringes, so a person injecting insulin twice per day should use about 60 syringes per month for a total cost of €7.20. In practice, patients reported reusing them, as is common globally.
Table 2. Analysis of insulin purchases in 2009

<table>
<thead>
<tr>
<th>Insulin</th>
<th>Total units (100 IU/10 ml vial equivalent)</th>
<th>Percentage of total volume</th>
<th>Cost per 100 IU/10 ml vial equivalent ($)</th>
<th>Total cost ($)</th>
<th>Percentage of total cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting WHO criteria</td>
<td>160 000</td>
<td>71%</td>
<td>5.12</td>
<td>818 400</td>
<td>43</td>
</tr>
<tr>
<td>Not meeting WHO criteria</td>
<td>64 150</td>
<td>29%</td>
<td>16.65</td>
<td>1 068 184</td>
<td>57</td>
</tr>
<tr>
<td>Total</td>
<td>224 150</td>
<td></td>
<td></td>
<td>1 886 584</td>
<td></td>
</tr>
<tr>
<td>All insulin purchased using WHO criteria</td>
<td>224 150</td>
<td></td>
<td></td>
<td>1 147 648</td>
<td></td>
</tr>
<tr>
<td>Potential saving by purchasing using WHO</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>criteria</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

WHO, World Health Organisation.
Table 3. 2009 oral medicine purchases by the Ministry of Health

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Presentation (mg)</th>
<th>Unit price ($)</th>
<th>Quantity (tablets)</th>
<th>Total price ($)</th>
<th>Percentage of total expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repaglinide (branded)</td>
<td>2</td>
<td>2.73</td>
<td>120,000</td>
<td>327,272.73</td>
<td>50</td>
</tr>
<tr>
<td>Repaglinide (generic)</td>
<td>2</td>
<td>0.30</td>
<td>120,000</td>
<td>36,000.00</td>
<td>6</td>
</tr>
<tr>
<td>Glimipiride (generic)</td>
<td>5</td>
<td>0.30</td>
<td>45,000</td>
<td>13,500.00</td>
<td>2</td>
</tr>
<tr>
<td>Glimepiride (generic)</td>
<td>5</td>
<td>4.29</td>
<td>45,000</td>
<td>192,857.14</td>
<td>30</td>
</tr>
<tr>
<td>Metformin (generic)</td>
<td>850</td>
<td>0.08</td>
<td>90,000</td>
<td>6,750.00</td>
<td>1</td>
</tr>
<tr>
<td>Metformin (generic)</td>
<td>850</td>
<td>0.07</td>
<td>90,048</td>
<td>60,300.00</td>
<td>1</td>
</tr>
<tr>
<td>Glibenclamide (generic)</td>
<td>5</td>
<td>0.02</td>
<td>2,400,000</td>
<td>40,000.00</td>
<td>6</td>
</tr>
<tr>
<td>Glibenclamide (generic)</td>
<td>5</td>
<td>0.01</td>
<td>2,400,000</td>
<td>29,000.00</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>651,409.87</td>
<td></td>
</tr>
</tbody>
</table>
Table 4. Comparison between World Health Organisation and Kyrgyz Essential Medicine Lists

<table>
<thead>
<tr>
<th></th>
<th>World Health Organisation 2007</th>
<th>Kyrgyzstan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insulin</td>
<td>Soluble and intermediate acting Vials</td>
<td>No specification of formulations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>40 and 100 IU in vial and cartridge presentations</td>
</tr>
<tr>
<td>Glibenclamide</td>
<td>2.5 and 5 mg tablets</td>
<td>1.75, 2.5, 3.5 and 5 mg tablets</td>
</tr>
<tr>
<td>Metformin</td>
<td>500 mg tablets</td>
<td>250, 500 and 850 mg tablets</td>
</tr>
<tr>
<td>Gliclazide</td>
<td>Not included</td>
<td>30, 40 and 80 mg tablets</td>
</tr>
<tr>
<td>Rosiglitazone</td>
<td>Not included</td>
<td>2, 4 and 8 mg tablets</td>
</tr>
<tr>
<td>Glimepiride</td>
<td>Not included</td>
<td>1, 2, 3, 4 and 6 mg tablets</td>
</tr>
</tbody>
</table>

The 2002 study found a severe lack of testing equipment, affecting both patients and physicians. This constrained the ability of those with diabetes to manage their condition, requiring them to attend health facilities for routine monitoring and increasing the cost of seeking care.

By 2009, all facilities visited had equipment for monitoring blood glucose. As in the earlier study, only some were also able to perform urinalysis (Table 5). No public facility could undertake HbA1c testing, which was only available privately at a cost of Som 200 ($4.62).

Most testing was undertaken using spectrophotometers. This was the preferred method as reagents were generally available and maintenance was straightforward (although some laboratories had problems). Glucometers were rarely used because of the lack of test strips (in many cases, the machines were obsolete, and the strips are no longer manufactured). Others simply lacked batteries. There were also shortages of instruments needed to diagnose diabetic complications, such as ophthalmoscopes, even in the Republican Hospital. Physicians attributed the inconsistent availability of diagnostic equipment to shortage of funds. Any improvements since the 2002 study were at best marginal.

In 2002, few patients had access to any means of home glucose testing as both glucometers and strips were prohibitively expensive. By 2009, donations of glucometers through diabetes associations had increased availability, but obtaining affordable strips remained difficult.

People with diabetes were asked to estimate the overall cost of drugs, syringes and needles and monitoring equipment. On average, this came to Som 1429 ($32.97) per month, which, when summed over a year, is equivalent to 43% of the per capita GDP of Kyrgyzstan.

DISCUSSION

Although Kyrgyzstan is viewed widely as a relative success in implementing health system reforms (WHO/DFID Manas Health Policy Analysis Project, 2005a; Kutzin et al., 2009; Kutzin et al., 2010b; Balabanova et al., 2011), at least in terms of putting in place evidence-based policies and reforming the structures to deliver them, as well as in improving key health indicators such as maternal mortality (33% fall...
<table>
<thead>
<tr>
<th></th>
<th>Glucometer</th>
<th>Strips for glucometer</th>
<th>Biochemistry to measure blood glucose</th>
<th>Spectrophotometer to measure blood glucose</th>
<th>Urine strips</th>
<th>Ketone strips</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability at facility visited (%)</td>
<td>67</td>
<td>38</td>
<td>33</td>
<td>95</td>
<td>71</td>
<td>38</td>
</tr>
</tbody>
</table>

Table 5. Availability of diagnostic equipment at facilities visited.
between 1995 and 2004) and infant mortality (26% fall from 1995 to 2004, a likely underestimate of the true scale of achievement as the definition of a live birth changed during this time) (Ministry of Health of the Kyrgyz Republic, 2006), it is clear that, 7 years on from the original study, relatively little has changed for the ordinary person with diabetes.

One difference has been the creation of the FMCs and the deployment of endocrinologists to them, a measure that seems to have improved access to care, at least for those not requiring insulin. However, they are able to do somewhat less than what would be expected of a family physician in many western countries. Despite a substantial investment in retraining family physicians, they are still unable to manage diabetes, a matter of considerable concern given the expected growth of non-communicable diseases (NCD) in general in the coming years.

Another improvement is the access to insulin and related medicines, although the assessment of the procurement system reveals that the government is getting very poor value for money. This may reflect the fact that the pharmaceutical industry is among the most liberalised industries in the country (Balabanova and Coker, 2008; Balabanova et al., 2011). It seems likely that it could afford to meet the needs of those currently spending large sums in private pharmacies if it could address this issue. The problem is compounded by lack of price controls leading to excessive retail mark-ups.

Less significant changes include improved data collection, although those data are still not used effectively. Issues related to evidence-based medical practice, equitable use of public sector resources, and patient education and empowerment remain to be tackled.

Looking ahead, there are grounds for optimism that the passage of the law on diabetes may have a progressively greater impact given earlier successes with laws on fortification of flour with iron and promotion of milk substitutes (Ibraimova et al., 2011). Although the law is not yet fully implemented, it has enabled the diabetes associations to defend the rights of their members. This increased level of advocacy and education are credited with some improvements in diabetes care.

The contrast between the headline successes in those health indicators included in the Millennium Development Goals and the picture painted by this study is reinforced by the observation that there has been no decline in cardiovascular deaths in Kyrgyzstan in the past 5 years (Ibraimova et al., 2011). This would be consistent with previously voiced concerns that the exclusion of NCDs from the Millennium Development Goals may have lowered the priority they are given by both donor and recipient governments (Rechel et al., 2005), an issue that has gained prominence following the recent United Nations High Level meeting on NCDs (Beaglehole et al., 2011). However, previous experience in successfully tackling the challenge of diabetes in another resource-poor setting through a Twinning Project between Diabetes UK and Mozambique could be a way of building on these results to effectively improve the care of people with diabetes (Yudkin et al., 2009; Beran et al., 2010).

CONCLUSION

The development of focal points for diabetes care at FMCs was the main health system factor that led to some improvements in diabetes care and is a clear result
of health system reforms. The main change between 2002 and 2009 was the improvement in access to insulin, but poor purchasing practices and irrational use are wasting vital resources. Two non-health reform factors have also played an important role in improving diabetes care: the significant role played by the diabetes associations in their support, education and voice for people with diabetes, and the passing of the diabetes law. These advances plus the presentation of the results of the 2009 study to local stakeholders in 2010 could be argued to have influenced the inclusion of diabetes as part of the existing cardiovascular disease programme, thereby expanding the area of NCDs within Kyrgyzstan’s next health programme, ‘Den sooluk’.

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The authors declare no conflicts of interest.

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2.6. Delivering diabetes care in the Philippines and Vietnam: Policy and Practice issues


*Summary*

This article highlights the findings from two parallel surveys in the Philippines and Vietnam. These two countries are aiming to achieve UHC as well as decentralise services. These studies found a variety of factors impacting care based on the 11 points presented in Section 2.2. Positive aspects were the high availability of diagnostic tools especially in Vietnam, availability of medicines, care and services in large urban areas in both countries. Negative aspects included the affordability of medicines, poor access to care outside of large urban areas, meaning people had to travel long distances, and a lack of patient education.

*What this adds to the argument of the overall thesis*

From this work one element of integration is to look at both availability and affordability of medicines and services. This was highlighted in the previous Sections (Section 2.1, 2.3 and 2.5), but this study truly highlights this factor in that availability of medicines was not problematic, but in many cases these were only obtainable at high costs. Care also was available in these countries, but one could argue that affordability was poor in that people had to travel and this had high travel costs to access this. This highlights the failure to integrate diabetes care in the policy of decentralisation that these countries have embarked on. In order to have successful decentralisation of care all 11 elements previously discussed need to also be decentralised. With regards to insurance schemes and UHC these also need to include diabetes and a variety of factors in order to ensure proper uptake of these schemes and their applicability to diabetes care. This is linked to the overall lesson from this study in terms of integration namely that of specific health policies with one specific condition that is still viewed as a “specialist” disease and not widely on the national and global agendas.
Delivering Diabetes Care in the Philippines and Vietnam: Policy and Practice Issues

David Beran, MSc and Michiyo Higuchi, MD, DrPH

Abstract

The aim of this study is the comparison of 2 studies looking at the barriers to access of diabetes care and medicines in the Philippines and Vietnam. These studies used the Rapid Assessment Protocol for Insulin Access. Diabetes care is provided in specialized facilities and appropriate referral systems are lacking. In Vietnam, no problems were reported with regard to diagnostic tools, whereas this was a concern in the public sector in the Philippines. Both countries had high prices for medicines in comparison to international standards. Availability of medicines was better in Vietnam than in the Philippines, especially with regard to insulin. This affected adherence as did a lack of patient education. As countries aim to provide health care to the majority of their populations through universal coverage, the challenge of diabetes cannot be neglected. Trying to achieve universal coverage in parallel to decentralization, national and local governments need adapted guidance for this.

Keywords
access, decentralization, diabetes, health systems, insurance, Philippines, Vietnam

Introduction

“Diabetes is a major threat to global public health that is rapidly getting worse,” and Asia will see the largest absolute increase from 66 993 000 to 99 401 000 estimated individuals with diabetes between 2007 and 2025. Diabetes and other chronic conditions have now replaced communicable diseases as the most common causes of morbidity and mortality, with Asian countries having witnessed this “epidemiological transition” in a very short period of time. This change in the burden of disease affects the functioning of health systems in moving from acute to chronic care. In 2008, it was reported that the shift of the leading causes of morbidity from communicable to noncommunicable diseases (NCDs) occurred in Vietnam. In the Philippines, NCDs account for

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6 of the top 10 causes of mortality. This shift in burden is also linked to problems in delivery of care, with a study including the Philippines and Vietnam finding that more than half of the people with diabetes receiving care were not well controlled.

To address this change in disease burden and also identify the barriers to chronic care, a clear assessment of the health system is needed. It has been suggested that diabetes can be used as a tracer condition for the proper functioning of health systems and its ability to manage chronic conditions, and therefore it was decided to assess the barriers to access to diabetes medicines and care in the Philippines and Vietnam.

The International Diabetes Federation estimates that the prevalence of diabetes in adults in the 20 to 79 age group for Vietnam is 2.5% and in the Philippines 6.5%. Local studies have shown prevalence rates of 2.7% and 4.4% in urban areas in Vietnam, and the second National Diabetes Survey in the Philippines in 2002 found diabetes prevalence rates in the 20 to 65 age group to be 5.3% in the capital city and 4.8% in urban and rural areas. Besides this disease burden, diabetes is also a financial burden with cost estimates in 2007 for the Philippines and Vietnam being US$775 million and US$320 million, respectively. It is estimated that these figures will increase to US$2.3 billion and US$1.1 billion for each country by 2025.

The Philippines and Vietnam are aiming to achieve universal health insurance coverage and have decentralized the management of health to lower levels of the country’s administrative structure. The Philippines is ranked 102 and Vietnam is ranked 114 out of 182 on the UNDP’s Human Development Index. They have similar domestic population size with approximately 86 million people. Gross national income per capita (in US dollars) is equal to US$3430 in the Philippines and US$2310 in Vietnam. The Philippines (male 68, female 71) has a lower life expectancy than Vietnam (male 72, female 75). Of total government expenditure, 6.4% was spent on health in the Philippines and 6.8% in Vietnam, with out of pocket health expenditure being higher in Vietnam, 86.1%, versus 80.3% in the Philippines of total expenditure on health.

The objective of the article is to analyze the results of 2 studies carried out in the Philippines and Vietnam looking at the barriers to access to diabetes care and medicines and suggest recommendations that may be applicable to other countries in Southeast Asia facing similar challenges.

Methods

The Rapid Assessment Protocol for Insulin Access (RAPIA) was developed by the International Insulin Foundation and is structured as a multilevel assessment of the different elements that influence the access to diabetes care (see Table 1). The RAPIA draws on the principles of rapid assessment protocols, which have been used extensively to assess services for communicable diseases, including malaria, tuberculosis, and sexually transmitted diseases, for the purpose of developing interventions. This methodology does not statistically analyze the health system by using representative samples but has as its aim to assess in a short time the situation with regard to diabetes care in a given country in order to provide different stakeholders recommendations for action.

The RAPIA is divided into 3 components. The first is the macro level, which is aimed at the ministerial levels, private sector, national diabetes association, central medical store, and educators. The meso level targets provincial health officials, “health care settings” (hospitals, clinics, health centers, etc), and pharmacies/dispensaries. Finally, in the micro level carers (health care workers and traditional healers) and people with diabetes are interviewed. The meso and micro levels are implemented in different areas chosen by local stakeholders to be representative of different geographical and socioeconomic situations within the country.

The questionnaires developed and the questions included in them follow each level of the path from the beginning with the purchase and importation of insulin and medicines to the country until these reach or fail to reach the patient. In parallel, the path of care is assessed. The questionnaires


Table 1. Levels of the RAPIA<sup>25</sup>

<table>
<thead>
<tr>
<th>Level</th>
<th>Issues Addressed in RAPIA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Macro</strong></td>
<td></td>
</tr>
<tr>
<td>Ministry of Trade</td>
<td>Trade issues (laws, barriers to trade)</td>
</tr>
<tr>
<td></td>
<td>Trade infrastructure</td>
</tr>
<tr>
<td>Ministry of Finance</td>
<td>Funding of health system</td>
</tr>
<tr>
<td></td>
<td>Taxes on diabetes medicines</td>
</tr>
<tr>
<td>Ministry of Health</td>
<td>Funding of health system</td>
</tr>
<tr>
<td></td>
<td>Organization of delivery of diabetes care and education</td>
</tr>
<tr>
<td></td>
<td>Resources available for diabetes</td>
</tr>
<tr>
<td></td>
<td>National programs for diabetes</td>
</tr>
<tr>
<td></td>
<td>Pricing of insulin and medicines</td>
</tr>
<tr>
<td></td>
<td>Distribution of insulin and medicines</td>
</tr>
<tr>
<td></td>
<td>Funding for insulin and diabetes and education</td>
</tr>
<tr>
<td></td>
<td>Tendering and purchase of insulin and medicines</td>
</tr>
<tr>
<td>Private sector</td>
<td>Pricing of insulin and medicines</td>
</tr>
<tr>
<td></td>
<td>Distribution of insulin and medicines</td>
</tr>
<tr>
<td>National diabetes association</td>
<td>Issues with diabetes and insulin</td>
</tr>
<tr>
<td>Central medical store</td>
<td>Tendering and purchase of insulin and medicines</td>
</tr>
<tr>
<td></td>
<td>Distribution and storage of insulin and medicines</td>
</tr>
<tr>
<td></td>
<td>Pricing of insulin and medicines</td>
</tr>
<tr>
<td>Educators</td>
<td>Training of health care professionals with regard to diabetes</td>
</tr>
<tr>
<td>Meso</td>
<td></td>
</tr>
<tr>
<td>Regional health organization</td>
<td>Issues with diabetes in specific area</td>
</tr>
<tr>
<td>Hospitals, clinics, health centers, dispensaries, and so on</td>
<td>Organization of care for patients with diabetes</td>
</tr>
<tr>
<td></td>
<td>Treatment and management of patients with diabetes</td>
</tr>
<tr>
<td>Regional medical store</td>
<td>Infrastructure present and/or lacking for diabetes care</td>
</tr>
<tr>
<td>Laboratory</td>
<td>Access to appropriate tools for diagnosis and treatment</td>
</tr>
<tr>
<td></td>
<td>Diagnosis of patients</td>
</tr>
<tr>
<td>Pharmacy/dispensary</td>
<td>Distribution and storage of insulin and medicines</td>
</tr>
<tr>
<td></td>
<td>Pricing of insulin and medicines</td>
</tr>
<tr>
<td><strong>Micro</strong></td>
<td></td>
</tr>
<tr>
<td>Health workers</td>
<td>Problems encountered in treatment of patients</td>
</tr>
<tr>
<td></td>
<td>Training for diabetes care</td>
</tr>
<tr>
<td></td>
<td>Infrastructure present and/or lacking for diabetes care</td>
</tr>
<tr>
<td>Traditional healers</td>
<td>Tools present and/or lacking (including education)</td>
</tr>
<tr>
<td>People with diabetes</td>
<td>Problems encountered in treatment of patients</td>
</tr>
<tr>
<td></td>
<td>Treatment of patients with diabetes</td>
</tr>
<tr>
<td></td>
<td>Access to treatment and education</td>
</tr>
<tr>
<td></td>
<td>Cost of treatment</td>
</tr>
</tbody>
</table>


Serve as a guide and can be adapted to the country investigated. The information is gathered through the different questionnaires (qualitative and quantitative data), site visits, document reviews, and discussions.
Table 2. Number of Interviews Carried Out for the Studies in Vietnam and the Philippines

<table>
<thead>
<tr>
<th>Country</th>
<th>Area</th>
<th>Macro</th>
<th>Meso</th>
<th>Micro</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philippines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vietnam</td>
<td>Hanoi and North</td>
<td>4</td>
<td>56</td>
<td>299</td>
<td>359</td>
</tr>
<tr>
<td></td>
<td>Ho Chi Minh City and South</td>
<td>6</td>
<td>45</td>
<td>50</td>
<td>101</td>
</tr>
<tr>
<td></td>
<td>Total Vietnam</td>
<td>10</td>
<td>76</td>
<td>104</td>
<td>190</td>
</tr>
</tbody>
</table>

Two studies were separately conducted around the same time in 2008. Local teams trained on how to use the tool carried out interviews. Both teams informed on and collaborated with each other. The Vietnam team, lead by DB, visited 4 areas and carried out 190 interviews. The Philippine team, lead by MH, visited 5 areas and carried out 359 interviews (see Table 2). Both teams approached respondents from different health administration levels (province, district, municipalities, and community) and different sectors (public and private). It was the main reason for the different sample sizes in these studies that more diabetes patients were interviewed in the Philippines to address diversity of patient choices in the country. Different facilities were visited to assess diabetes care with the main facilities viewed as a “center of excellence” for diabetes being surveyed as well as other main facilities. In addition, other facilities were surveyed with the research targeting the lowest-level facility where one would expect diabetes care to be delivered. For people with diabetes, interviews were either carried out on the day of the visit or interviewers returned the day when diabetes consultations were held.

Results

Provision of Diabetes Care

Diabetes care is mainly provided by hospitals with specialized care available at the provincial level in both countries. Most care for diabetes in Vietnam was provided in large urban areas where physicians working in tertiary referral facilities often saw patients for routine consultations. Due to a lack of knowledge of health care workers at lower levels of the health system, care for type 1 diabetes in the Philippines and Vietnam was only provided in a limited number of facilities in main cities. Endocrinology and diabetology are relatively new specialties in Vietnam and therefore there are few doctors considered specialists in this field. In the Philippines, specialty training for endocrinology exists and a private nonprofit institute offers different courses in diabetes.

At the main tertiary facilities in Hanoi and Ho Chi Minh City, all staff have received specialized training in different aspects of diabetes care. At these facilities, nurses play a more active role in care and patient education because of this training. In the Philippines, specialists were concentrated in the provincial capital and usually run private clinics, but also offer some consultations in the public sector.

At provincial and general hospitals in Vietnam some doctors will have had some training in diabetes either from abroad or from specialists from Hanoi or Ho Chi Minh City. In Vietnam, the aim is to devolve diabetes care to the district level, but the main barrier to this policy is lack of trained health care workers. The Philippines has addressed this problem by having professional associations provide both health professionals and lay members with training courses for diabetes educators. Nutritionists and dieticians also play a role in diabetes management, whereas these specialties were lacking in Vietnam.

Guidance exists from the Ministry of Health in Vietnam as to which types of tests should be available to patients at different levels of the health system. There are licensing criteria in the
Table 3. Price per Tablet Based on Public Sector Tenders and Brand Premium in Vietnam\textsuperscript{21}

<table>
<thead>
<tr>
<th>Medicine and Strength</th>
<th>Price in US$</th>
<th>Brand Premium</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Gilbenclamide 5 mg</td>
<td>0.03</td>
<td>0.02</td>
</tr>
<tr>
<td>Glimpiride 2 mg</td>
<td>0.21</td>
<td>0.04</td>
</tr>
<tr>
<td>Glimpiride 4 mg</td>
<td>0.29</td>
<td>0.15</td>
</tr>
<tr>
<td>Metformin 500 mg</td>
<td>0.08</td>
<td>0.02</td>
</tr>
<tr>
<td>Metformin 850 mg</td>
<td>0.14</td>
<td>0.03</td>
</tr>
<tr>
<td>Metformin 1000 mg</td>
<td>0.16</td>
<td>0.08</td>
</tr>
<tr>
<td>Rosiglitazone 2 mg and Metformin 500 mg</td>
<td>0.50</td>
<td>0.22</td>
</tr>
<tr>
<td>Gliclazide 30 mg</td>
<td>0.12</td>
<td>0.04</td>
</tr>
<tr>
<td>Gliclazide 80 mg</td>
<td>0.12</td>
<td>0.04</td>
</tr>
<tr>
<td>Metformin 500 mg and Gilbenclamide 2.5 mg</td>
<td>0.18</td>
<td>0.08</td>
</tr>
<tr>
<td>Metformin 500 mg and Gilbenclamide 5 mg</td>
<td>0.44</td>
<td>0.09</td>
</tr>
<tr>
<td>Rosiglitazone 4 mg</td>
<td>0.96</td>
<td>0.96</td>
</tr>
</tbody>
</table>

\( a \) Only generic versions. \\
\( b \) Only branded versions.

Philippines that include guidance on laboratory equipment. No issues with supplies of reagents or equipment were reported in Vietnam, unlike in the public sector in the Philippines where this was a problem.

Purchase and Supply of Diabetes Medicines

The Ministry of Health in Vietnam prepares guidance prices for different medicines, which are used by each facility to prepare their individual tenders. Some of these prices were up to 6 times higher than those available on the international market. The purchasing of branded medicines versus generics had an impact on expenditure of facilities in Vietnam and ultimately on the individual and/or the insurance system. This information is detailed in Table 3. In the Philippines, prices for common diabetes medicines were found to be substantially higher than international benchmark prices as shown in Table 4.

Unlike in Vietnam, medicines for public facilities in the Philippines are procured through the public bidding process at each local government unit based on an annual procurement plan. The Philippine International Trading Corporation, a government-owned and controlled corporation, is responsible for “parallel medicines importation.” These medicines are sold to public hospitals and community medicines outlets at generally lower prices. This is part of the strategies led by the Department of Health to try to reduce medicines price.

In both countries, Gilbenclamide and Metformin were available in the majority of hospital pharmacies visited. In Vietnam, other oral medications and insulin were also readily available in the public and private sectors, but this was not the case in the public sector in the Philippines. In pediatric facilities, insulin was not readily available in the public sector in Vietnam and was only available at the main public hospital and in some private hospitals in each province visited in the Philippines.

Insulin and oral medicines for diabetes are subject to 5% import duty and 5% VAT in Vietnam.\textsuperscript{30} Mark-ups throughout the supply chain increase the price in the public sector for those without health insurance and the private sector. In the Philippines, medicines are subject to 5% custom duty and 12% VAT. Another factor affecting cost of medicines is the availability of generic versus branded products. In both countries, health care workers and people with diabetes stated their mistrust of generics.
Table 4. Median Purchase Price and International Reference Price of Oral Medicines for Diabetes in the Philippines

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Median Price (US$)</th>
<th>International Reference Price (US$)</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metformin (500 mg)</td>
<td>0.11</td>
<td>0.021</td>
<td>5.1</td>
</tr>
<tr>
<td>Glibenclamide (5 mg)</td>
<td>0.16</td>
<td>0.005</td>
<td>32.0</td>
</tr>
<tr>
<td>Gliclazide (80 mg)</td>
<td>0.18</td>
<td>0.045</td>
<td>4.0</td>
</tr>
<tr>
<td>Mixed insulin (10 mL)</td>
<td>17.4</td>
<td>5.716</td>
<td>3.0</td>
</tr>
<tr>
<td>Insophane insulin (10 mL)</td>
<td>25.3</td>
<td>5.380</td>
<td>4.5</td>
</tr>
<tr>
<td>Regular insulin (10 mL)</td>
<td>26.1</td>
<td>5.480</td>
<td>4.8</td>
</tr>
</tbody>
</table>

Table 5. Costs of Different Aspects of Diabetes Care in the Philippines and Vietnam

<table>
<thead>
<tr>
<th>Mean Cost of Aspect of Diabetes Care to the Individual (US$)</th>
<th>Insulin (per Month)*, Median</th>
<th>Oral Medicines (per Month)*, Median</th>
<th>Travel (per Visit), Median</th>
<th>Syringe (Unit), Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philippines</td>
<td>19.59</td>
<td>13.36</td>
<td>0.87</td>
<td>0.22</td>
</tr>
<tr>
<td>Vietnam</td>
<td>7.35</td>
<td>30.61</td>
<td>4.90</td>
<td>0.09</td>
</tr>
</tbody>
</table>

*In the Philippine survey, actual monthly expenses for insulin and oral medicines were not asked. Monthly expenses were calculated from unit prices and daily doses in patient answers. Calculation is based on an assumption that the patient takes medicines according to the prescription. In Vietnam, this is the cost per visit, including individuals who received insulin for free. For oral medicines this is cost per month, again including those who received all or part of their treatment for free.

Cost of Diabetes Care for the Individual

People with type 2 diabetes in Vietnam who reported having insurance stated that cost of treatment was not a problem, but other costs such as transportation were sometimes a barrier, especially for people living away from major urban centers. Those without insurance described the financial burden of diabetes, especially type 1 diabetes, as the main obstacle to proper care. Consultation fees at public facilities are free or inexpensive, but the purchasing of medicines and paying for laboratory tests were the major barriers to regular care for the majority of respondents in the Philippines as these are not covered by PhilHealth benefits. Costs of the different aspects of care are detailed in Table 5.

The private sectors in Vietnam and the Philippines were extremely well supplied with medicines for diabetes. In the private sector in Vietnam and the Philippines, medicines were about 30% and 300% more expensive, respectively, than in the public sector.

Information, Education, and Diabetes Associations

Printed information developed by hospitals and pharmaceutical companies was also available in both countries. The main factor identified as leading to a lack of patient education was shortage of time, with doctors needing to see many patients. Also the health insurance schemes do not cover patient education and counseling. This combined with the high cost of medicines led to poor adherence.

Different organizations involved with diabetes were present in both countries. In Vietnam, the Vietnam Diabetes Association is only for doctors and provides a chance for doctors to meet and discuss different issues surrounding diabetes. There is also a Diabetes Educators Association and anyone can join who has an interest in diabetes. These are mainly active in Hanoi and Ho Chi Minh City.
Diabetes clubs exist at different facilities with special diabetes clubs established for children with type 1 diabetes and their families. Their aim is to provide support and education to people with diabetes. These organizations are very dependent on health care workers at these facilities to manage their activities.

Diabetes-related activities varied among the surveyed provinces in the Philippines. In 2 of the 5 areas visited, no diabetes patient support club existed. Establishing and continuing a club seemed to rely on the availability and leadership of physicians in the area. Clubs and their organization varied with some clubs officially registered as an organization and others just gathering patients on a diabetes clinic day. Some clubs routinely (monthly or annually) also collected money from members to support activities.

**Policy Environment**

A decision by the Vietnamese Prime Minister in 2002 approved a program to control NCDs for the period of 2002 to 2010. This led to a preliminary National Plan for Diabetes prepared for the years 2006 to 2010. The plan highlighted the increasing burden of diabetes in Vietnam and the challenges that Vietnam will face because of this.

Because of the increase in burden of lifestyle-related diseases in the Philippines, the importance of healthy lifestyles has been recognized by the Department of Health. This led to the creation of the National Centre for Disease Prevention and Control in 2000 and a diabetes-specific office at this center. Reduction of mortality and morbidity from lifestyle-related diseases, including diabetes, is listed as one of the goals in “the National Objectives for Health 2005-2010.” Because of decentralization, the level of commitment to implement the program varied among the local government units visited.

The Vietnamese national target program for diabetes and hypertension has recently been approved and receives special funding and attention from the central government. As in the Philippines, because of decentralization, curative activities not effectively linked to promotion and prevention activities, and hospital autonomy, the impact of policy decisions at the central level on actual practice in Vietnam is hard to quantify.

In the Philippines, many policies have focused on the issue of medicine prices (eg, Generics Act of 1988 and Universally Accessible Cheaper and Quality Medicines Act of 2008). Because of a long history of failure in reducing medicine prices, people interviewed were skeptical about the effectiveness of these policies. No such policies have been developed in Vietnam.

**Discussion**

This comparative study is based on the use of similar methods in Vietnam and the Philippines carried out during the same period of time and therefore allow comparison of 2 similar health systems in Asia.

In both countries, the average cost of overall diabetes care was extremely high, thus having a direct impact on adherence with cost of treatment and medicines being a major barrier. In Vietnam, the average monthly cost of transportation and medicines alone equaled US$34.41, equivalent to 18% of monthly per capita gross national income. The cost of medicines in both the Philippines and Vietnam are passed on to the individual or the insurance system, and therefore procurement practices will affect this cost. Poor procurement practices were present in both countries, leading to high costs of medicines compared with the international market prices as detailed in studies carried out by the World Health Organization and Health Action International.

Another factor affecting adherence in both countries was inadequate patient education because of a variety of factors, including overburdened staff, materials not adapted to sociocultural context,
lack of trained staff, and a lack of involvement of nurses and other health personnel in managing diabetes.

Once people have registered with the respective insurance schemes these schemes seem to work well, but are often viewed as confusing to register with in the Philippines and to not always be value for money in both countries. Some people in Vietnam said that even though they had or were eligible for health insurance, they preferred to pay out of pocket as they felt they received better service. Health insurance and the aim of achieving universal coverage are an opportunity and a threat to improving the organization of the health system. It is an opportunity as the health insurance scheme could regulate referrals, tests, and medicines being available at different facilities and relieve the burden of cost to the individual. However, this may also have a negative impact as hospitals will keep people in their patient population as they are viewed as a source of income.

This also affects referral systems, which are important for long-term care because as seen in Vietnam, hospitals are individual entities whose sources of income comes from the government (central and local), out of pocket payments, and payments from insurance. In addition, away from major cities diabetes care is problematic because of a lack of specialized staff as well as inadequate infrastructure. With decentralization and the organization of the health system, each facility and its relationship with other facilities higher and lower in the overall system may not be clear. This affects referrals, especially from provinces to larger urban centers.

Conclusion

As countries in Asia develop the means to provide health care to the majority of their populations, the challenge of diabetes and other NCDs cannot be neglected. These conditions will not only burden individuals but also the health systems and economies of these countries. A recent strategy published by the World Health Organization addresses both the issue of high out of pocket payments and how these act as a major barrier to achieving universal coverage in Asia. This strategy document provides clear guidance on how to achieve universal coverage, but to address the increasing burden of diabetes and NCDs, creativity is needed. In this changing disease burden, the role of health insurance should be increased from one that simply reimburses medical care to one that actively tries to prevent chronic diseases. Linking this approach to decentralization, national and local governments need to adapt guidance from the central level to effectively address a health concern that affects all levels of society and therefore clearly define their role in the struggle to prevent and deal with the increasing burden of diabetes and other NCDs.

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References

2.7. Developing a hierarchy of needs for Type 1 diabetes


Summary
This qualitative research study had as its aim to identify the needs of individuals with Type 1 diabetes and relate them back to what health systems provide. For the survival of an individual with Type 1 diabetes the context needs to provide a health system, policies favouring diabetes management, insulin and tools for its delivery, diagnostic tools, healthcare workers and information and education that enable the individual to survive. These are clearly needs delivered by the health system. At the next level of the hierarchy of needs for Type 1 diabetes other health system factors remain important, such as healthcare workers and information and education. However, at this level it is important that these professionals adapt their knowledge to the individual and that care, information and education become tailored to the individual. Factors outside the health system such as family, peers and community also need to be included. At higher levels of the hierarchy the health system needs to facilitate aspects such as acceptance and being open, but this cannot be provided as a tangible output of the health system. Rather this is the accumulation of the health system meeting the individual’s needs in parallel to integrating a wider view of health and management of Type 1 diabetes.

What this adds to the argument of the overall thesis
As can be seen in this study a wide range of needs is necessary for people with Type 1 diabetes. In high functioning health systems one could argue that the health system plays a diminishing role for people with diabetes as survival needs are a “given”. Overall this final study included in this thesis has as its aim to:

1. Highlight the wide range of needs people with Type 1 diabetes have
2. That the health system only plays a small overall role in meeting these needs
3. That across health systems these needs evolve
4. Across the lifespan of individuals needs evolve
The hierarchy presented here might be a useful tool for integrating this range of needs into health systems and developing health systems and their response taking into account people’s needs. In some contexts as those described in Sections 2.1, 2.5 and 2.6 survival needs are still lacking. Health system factors are important and essential for addressing these needs, but providing a response focused only on the health system will not be sufficient. Due to the nature of chronic conditions and that people manage their conditions on a daily basis in a variety of environments a range of needs falling outside the traditional remit of the health system must to be included.
Research: Educational and Psychological Aspects
Developing a hierarchy of needs for Type 1 diabetes

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Abstract

Aims The aim of this study was to use the concept of Maslow’s hierarchy of needs and apply this to Type 1 diabetes.

Methods Qualitative methods were employed using semi-structured interviews with 101 people from 13 countries. Grounded theory was used for data collection and analysis, with thematic analysis employed to identify the interviewees’ needs.

Results Sixteen needs were identified and links between these were mapped. Aligning these with Maslow’s hierarchy allowed for a hierarchy to be developed for Type 1 diabetes with ‘Policies’, ‘Organization of health system’, ‘Insulin’, ‘Delivery of insulin’, ‘Control’, ‘Healthcare workers’ and ‘Information and education’ at the base, as they were needed for survival. Next came ‘Community, family and peers’ and changing roles for ‘Healthcare workers’ in their approach to care and delivering ‘Information and education’. This enabled people to learn how to use ‘Insulin’, ‘Delivery of insulin’ and ‘Control’ flexibly. People’s ‘Experience’ and ‘Personality’ then helped them ‘Adapt’ and ‘Be open’ about their diabetes, allowing for ‘Acceptance’ and viewing ‘Diabetes as something positive’.

Conclusions Despite limitations, this work highlights that some needs are required for survival and others for well-being. Some are tangible as they can be directly provided, whereas others are intangible and cannot be provided directly by the health system. These results might be used for policy and practice in identifying needs that are met within a health system or what needs are lacking for the individual to then implement targeted interventions.

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Introduction

As Type 1 diabetes is a chronic condition, the health system has to focus on trying to prevent complications and the negative psychosocial impact of this condition [1,2]. From the healthcare worker’s perspective, the focus is on clinical outcomes, such as blood glucose [1]. For the individual, being diagnosed with Type 1 diabetes is a ‘biographical disruption’, as management includes changes to daily life and how the person views themselves, but that person still wants to be able to do what they want and not be limited by their diabetes [1,3,4]. Some of the factors necessary for this fall outside the health system and therefore there is a need to shift the perspective of health and disease to take into account the individual’s needs [5].

Abraham Maslow developed a hierarchy of needs and proposed that, as basic needs are met, the satisfaction of higher needs is sought [6]. This hierarchy is often presented as a pyramid including five levels: (1) physiological needs; (2) safety needs; (3) love/belonging needs; (4) esteem needs; and (5) self-actualization. Maslow’s hierarchy has been utilized for prioritizing needs, as a theoretical framework, and policymaking [7–11]. In relating Type 1 diabetes to Maslow’s pyramid, some people with Type 1 diabetes still face physiological or ‘survival needs’ of accessing insulin, syringes and testing equipment [12]. In parallel, others compete to the Olympics and climb Mount Everest [13], which are clear examples of self-actualization, as they live in settings where survival needs are met because of economic development, organization of the health system and government policies. The aim of this research was to gain insight into what the needs of people with Type 1 diabetes are and to use the concept of Maslow’s hierarchy and apply this to Type 1 diabetes.

Research design and methods

‘Grounded theory’ was used for data collection and analysis as it is flexible and helps create theories ‘grounded in the data’ [14–17]. Theoretical sampling was used, as in grounded theory unrelated groups can be sampled and compared in order to get an overall picture of a given topic [18].
What’s new?

- Very few studies have looked at the needs of people with Type 1 diabetes in multiple settings.
- To address this, a qualitative study in 13 countries comprising 101 individuals with Type 1 diabetes was designed to identify their needs.
- The aim of this research was to develop an initial conceptual framework of ideas around the issue of needs for people with Type 1 diabetes from their perspective and also prioritize these in a hierarchy.
- The resulting hierarchy of needs for Type 1 diabetes could be used in policy and practice to address needs that are lacking.

A topic guide was developed as grounded theory uses open questions to enable the interviewee to discuss all issues around a given topic [15]. The investigator (DB) piloted the tool in Belgium, France, Mozambique, the UK and USA. This allowed for more focused areas of questioning to be developed and the concept of ‘abnormal days’ to be included. ‘Abnormal days’ were described during the pilot as days when the individual’s routine was changed and impacted diabetes management. The final tool used ‘Grand tour questions’ [19], which included the following areas:

1. diagnosis;
2. consultations;
3. daily life;
4. ‘abnormal’ days.

Interviews were organized by DB in 13 countries representing different health systems and socio-economic development (Table 1). Eight people with no specification of age, age at diagnosis, duration of disease or sex were asked by local contacts to participate. When children and adolescents were interviewed, this was carried out with their parents present and authorization, or a joint interview with parents and children or just parents. Other studies have used parents instead of children to assess care [20].

Ethical clearance was obtained from University College London (project 0025/001). In Singapore and South Africa, additional ethical requirements were complied with. The concept of ‘voluntariness’ was applied for this research, as agreeing to participate in research amounts to consenting [21].

All participants were informed by DB about the study, emphasizing that they were free in their participation. Participants were then asked if the interview could be recorded, highlighting that no note would be taken of any personal details and that any mention of names in the actual interview would not be included in the transcript. In Indonesia and Singapore, only three and seven people were interviewed, respectively, because of logistics. In South Africa and Argentina, nine and 10 people were interviewed, respectively, as they expressed an interest in participating. Interviews lasted an average of 52 min and took place in a single meeting. Prompts were used throughout the discussion to gain a better understanding of the person’s needs, which also enabled interviewees to discuss the range and scope of their experience.

Individuals were identified with a code highlighting their country (AR, CH, IN, KG, MZ, NIC, SA, SN, TH, TZ, UK, USA and VT), sex (F, female; M, male) and age; for example, CHF24 is female, age 24 years from Switzerland.

In Indonesia, Kyrgyzstan, Thailand and Vietnam, DB used professional translators for all interviews. When using translators, DB asked the question in English, which was

<table>
<thead>
<tr>
<th>Country</th>
<th>Income level [23] (International gross domestic product per capita, $US) [28]</th>
<th>Location of sampling</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argentina</td>
<td>Middle (17 700)</td>
<td>Diabetes association and hospital in capital city</td>
<td>10</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Middle (4700)</td>
<td>Individuals</td>
<td>3</td>
</tr>
<tr>
<td>Kyrgyzstan</td>
<td>Low (2400)</td>
<td>Diabetes association</td>
<td>8</td>
</tr>
<tr>
<td>Mozambique</td>
<td>Low (1100)</td>
<td>Diabetes association and main referral hospital</td>
<td>8</td>
</tr>
<tr>
<td>Nicaragua</td>
<td>Middle (3200)</td>
<td>Diabetes association</td>
<td>8</td>
</tr>
<tr>
<td>Singapore</td>
<td>High (59 700)</td>
<td>Diabetes association</td>
<td>8</td>
</tr>
<tr>
<td>South Africa</td>
<td>Middle (11 000)</td>
<td>Diabetes association</td>
<td>8</td>
</tr>
<tr>
<td>Switzerland</td>
<td>High (44 500)</td>
<td>Diabetes association</td>
<td>8</td>
</tr>
<tr>
<td>Thailand</td>
<td>Low (1400)</td>
<td>Diabetes association</td>
<td>8</td>
</tr>
<tr>
<td>UK</td>
<td>High (56 300)</td>
<td>University Teaching Hospital, diabetes association and individuals</td>
<td>8</td>
</tr>
<tr>
<td>USA</td>
<td>High (48 300)</td>
<td>Diabetes association and individuals</td>
<td>8</td>
</tr>
<tr>
<td>Vietnam</td>
<td>Middle (3400)</td>
<td>Main pediatric referral hospital</td>
<td>8</td>
</tr>
</tbody>
</table>
then translated, with the interviewees’ response translated back into English. For interviews in English, French, Portuguese and Spanish, the discussion guide was translated into the relevant languages and administered by DB.

Interviews were transcribed verbatim and entered into NVivo software (NVivo 7; QSR International, Melbourne, Vic, Australia) by DB and analysed using thematic analysis. This approach allows themes to be identified, analysed and reported within transcripts [17]. A theme is an element from the transcripts that ‘captures something important’ in terms of a research question [17]. There is no set measure to state that one theme carries more weight vs. another, unlike in quantitative research where this would be the number of occasions of this theme [17]. Coding was verified by an expert with vast experience looking at chronic diseases in children, using both qualitative and quantitative research methods.

**Results**

A total of 101 interviews (56 female; 45 male) were carried out with an age range of 1.2–61.0 years of age (median 22.0 years) (Fig. 1). Thirty-two interviewees came from ‘low’, 38 from ‘middle’ and 31 from ‘high’ income countries [22]. Median age at diagnosis was 11.0 (range 0.1–36.0) years. Of the sample, 33.7% had Type 1 diabetes for more than 10 years (range: newly diagnosed–55.0 years; median duration: 7.0 years). Sixteen needs were identified. By mapping the different needs in each interview, linkages were found, highlighting that some were required for others to be as described in Fig. 2.

**Health system**

‘Policies’ impact the ‘Organization of the health system’ (Fig. 2, link A) as these determine the environment in which the person will be diagnosed and cared for. ‘Insulin’, ‘Control’ and ‘Delivery of insulin’ are also impacted by ‘Policies’, as these may need to be paid for (links B–D). For example, in Argentina, social insurance covers all of these elements, albeit imperfectly, compared with Vietnam where these elements have to be bought. In other settings, insulin and syringe access was problematic, highlighting problems with the ‘Organization of the health system’.

‘Control’ was either present at health facilities or people had their own blood glucose meters. Interviewees in Mozambique and Vietnam did not have access to blood glucose meters, mainly because of cost. In addition, the health system needs to have ‘Healthcare workers’ (link E) able to identify diabetes, provide initial treatment and ‘Information and
education' (link F). This 'information and education' needs to enable the person to know enough to 'survive' (link G).

Tangible tools and skills and the role of support

Interviewees had different management of their insulin dosage, from strict to completely flexible. This change happened using the blood glucose meter, not just as a way to measure blood glucose, but in a more operational way (link 13). This was highlighted by a 39-year-old man from Thailand (ThM39), ‘back then the use was for control, but right now I use it to adjust the dose [of insulin]’. Also, ‘information and education’ (link G) delivered by ‘healthcare workers’ in an adapted way to the individual with active support and interactions helped with this. As stated by a 47-year-old man from the USA (USM47), it is important not to have the ‘typical physician transaction where you go to the doctor’s office and they go hey you didn’t do this right, where they are dictatorial if you will. It’s really got to be a partnership and a series of learning’.

‘Family support’ (link L), ‘Community support’ (link J) and ‘Peers’ (link K) also help with day-to-day management, ‘information and education’ and the opportunity to share ‘experience’. ‘Community support’ was influenced by ‘Family support’ (link L) and ‘Peers’ (link M) with and without diabetes. A major element of ‘Community support’ is the diabetes association. The overall support from community and family was depicited by a 27-year-old man from Argentina (ARM27) as ‘the environment around me that helped [me manage my diabetes]’. Family support forms part of what a 24-year-old woman from Switzerland (CHF24) described as a ‘protective environment at home’. An 18-year-old woman from Switzerland (CHF18) said that the people with diabetes she interacted with were her ‘second family’ and that this was ‘something that helped her’ manage and accept her diabetes. Peers without diabetes also helped the interviewees, an 18-year-old woman from Singapore (SINP18) telling how her friends are ‘understanding’ and an 18-year-old man from Nicaragua (NICM18) saying that his friends ‘look out for me’.

Individual factors

‘Family support’ influences the ‘personality’ of the person (link N) helping with diabetes management, which is also shaped by ‘experience’. As a 27-year-old man from Thailand (THM27) said ‘I learnt from experience’ and a 22-year-old man from the USA (USM22) added ‘once you get experience with the disease you are able to make these decisions for yourself’. This experience helped with insulin dosage, managing diet, exercising and ‘Knowing your body’ (42-year-old man from Mozambique; M24M42) (i.e. the symptoms of hypoglycaemia and/or hyperglycaemia). Personality traits that people used to describe themselves that had an impact on their diabetes were a 41-year-old man from Argentina (ARM41) describing himself as ‘optimistic’, a 34-year-old man from Switzerland (CHM34) having a ‘fighting spirit’, a 61-year-old man from Switzerland (CHM61) being a ‘perfectionist’, a 24-year-old woman from Nicaragua (NICF24) a ‘fighter’ and a 42-year-old man from the USA (USM42) describing himself as having ‘strong internal drive’. ‘Maturity’ was described by a 19-year-old man from Argentina (ARM19) and a 15-year-old young woman from Singapore (SINF15) as helping them manage their diabetes.

‘Adapting’ (link O) includes both the adjustment to day-to-day use of insulin and other ‘treatment’ aspects of diabetes, but also the change in perspective the person has, as they now have a chronic condition. A 42-year-old man from Mozambique (M24M42) expresses how he ‘had to adapt to this reality’. Another aspect of ‘Adapting’ is how ‘Insulin’, ‘Delivery of insulin’ and ‘Control’ are used. In looking at ‘Insulin’, it goes from being something for survival to something that can be used more actively to ‘adapt’ to any situation. ‘Adapting’ and ‘Experience’ are joined in that they mutually help each other (link P) and, as said by a 27-year-old man from Thailand (THM27), ‘the dosage [of insulin] will be adapted to my eating and activity and it is also based on my experience’. ‘Adapting’ helps people gain ‘Experience’, and through this ‘Experience’ they are able to adapt to new and different situations. A significant element that impacted ‘Experience’ was learning from others with diabetes (link Q).

‘Being open’, ‘Acceptance’ and ‘Diabetes as something positive’

‘Being open’ was a secondary result of ‘Adapting’ (link R) in that, by fully participating in ‘normal’ life and activities, for example, school, meant that teachers needed to be informed. ‘Being open’ was described by a 22-year-old man from the USA (USM22) as ‘almost part of a hello in our conversation. I did not feel like I had to hide something’. A 61-year-old man from South Africa (SA61) stated ‘you can’t hide it [having Type 1 diabetes]’.

An 18-year-old man from the UK (UKM18) describes how he ‘don’t hide it, which I used to do at one time’ and ‘I am open with it’. ‘Community support’ helped in both serving as an example that ‘Being open’ was not a problem through the experience of peers with diabetes, or strong support from family and friends (link S). ‘Personality’ also had an impact on ‘Being open’, with some people saying they were very open while others were not (link T). Another factor needed for ‘Being open’ was the need for ‘Policies’, not to cause people with diabetes to be stigmatized or discriminated against; for example, with regards to employment health checks in Argentina or diabetes still being considered a disability in Kyrgyzstan (link U).

‘Acceptance’ required, on the other hand, practical aspects of diabetes management (‘Adapting’ (link X) and, on the other hand, social aspects of the individual (‘Being open’).
A 24-year-old woman (ARF24) and a 19-year-old man (ARM19), both from Argentina, an 18-year-old woman from Switzerland (CHF18) and a 27-year-old woman from Thailand (THF27) describe acceptance as a process. Family support, healthcare workers and peers play an important role in ‘Acceptance’. The importance of healthcare workers was highlighted by a 60-year-old woman from the USA (USA660): ‘One of the most helpful things is that if healthcare workers are honest with people, telling them that diabetes can be a very hard disease and it is a life-changing disease, but if you follow what you are supposed to do [it can be managed]... [this] will help someone gain acceptance about having what they have’. A 39-year-old woman from Argentina (ARF39) describes how, at a diabetes camp, ‘we were 40 children all with Type 1 diabetes of different ages and the basic thing they taught us was that we were normal children’.

Once all these needs were met, the interviewees then viewed Diabetes as something positive (link Y). This was described by the interviewees not only as accepting their ‘intrinsic situation’, but also helping others through being diabetes counsellors, creating diabetes associations or support groups, fundraising for diabetes-related organizations, or deciding to work in the area of diabetes.

Linking Maslow’s hierarchy with the findings above is presented in Table 2 and allows for a presentation of these results as the hierarchy of needs for Type 1 diabetes presented in Fig. 3. The first level of Maslow’s hierarchy relates to survival needs, for example, food and shelter. The elements from the hierarchy of needs for Type 1 diabetes include ‘Insulin’, ‘Delivery of insulin’ and ‘Control’, ‘Healthcare workers’ and ‘Information and education’, ‘Policies’ and ‘Organization of health system’. The next level in Maslow’s hierarchy of needs is ‘Safety’. In the hierarchy of needs for Type 1 diabetes, this ‘Safety’ is provided through support from family, peers and the community, but also through increased information and education from this community, as well as healthcare workers.

Following from the hierarchy of needs for Type 1 diabetes and the link to ‘Safety’ needs, it could be argued that the

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Table 2 Comparison between Maslow’s hierarchy of needs and hierarchy of needs for Type 1 diabetes

<table>
<thead>
<tr>
<th>Maslow’s Hierarchy of Needs</th>
<th>Hierarchy of Needs for Type 1 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiological needs</td>
<td>Healthcare workers’ and ‘Information and education’</td>
</tr>
<tr>
<td></td>
<td>‘Insulin’, ‘Delivery of insulin’ and ‘Control’, e.g. blood or urine glucose</td>
</tr>
<tr>
<td></td>
<td>‘Policies’ and ‘Organization of health system’</td>
</tr>
<tr>
<td>Safety needs</td>
<td>Healthcare workers’ and ‘Information and education’</td>
</tr>
<tr>
<td></td>
<td>‘Community support’, ‘Family support’ and ‘Peers’</td>
</tr>
<tr>
<td>Belonging needs</td>
<td>‘Experience’ and ‘Personality’</td>
</tr>
<tr>
<td></td>
<td>‘Insulin’, ‘Delivery of insulin’ and ‘Control’, e.g. blood or urine glucose</td>
</tr>
<tr>
<td></td>
<td>‘Adapting’</td>
</tr>
<tr>
<td>Self-esteem needs</td>
<td>‘Being open’</td>
</tr>
<tr>
<td>Self-actualization needs</td>
<td>‘Acceptance’</td>
</tr>
</tbody>
</table>

‘Diabetes as something positive’

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FIGURE 3: Hierarchy of needs for Type 1 diabetes.

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support from family, peers, community and healthcare workers also form the basis of ‘Belonging’. The main need identified with regards to ‘Belonging’ in the hierarchy of needs for Type 1 diabetes is ‘Being open’. ‘Belonging’ also happens when people are able to ‘Adapt’ and take part in ‘normal’ activities. As described by Maslow, the limits between levels of the hierarchy are not meant to be rigid and there may be overlap [6].

Self-esteem needs include ‘desires for strength, achievement, adequacy, mastery, compensation, confidence, independence and freedom’ [6]. These elements are part of the ‘Acceptance’ needs detailed in the hierarchy of needs for Type 1 diabetes, in that all these factors contribute to people ‘accepting’ diabetes. Self-actualization is the highest need defined by Maslow and is described as ‘acceptance of the person’s own intrinsic nature’ [23] and the ‘desire of self-fulfillment to push ones potential to the limit’ [6]. The people that describe ‘Diabetes as something positive’ do this, in that they not only accept their ‘intrinsic situation’ of having diabetes, but also help others and, in some cases, as a 25-year-old man and a 42-year-old man from the USA (USAM25 and USAM42) push the limits in terms of athletics to a level that most cannot achieve.

This study has many limitations. As the individuals participating were self-selecting, this may lead to bias in terms of the type of individual responding. In addition, they are not a representative sample of people with Type 1 diabetes in their respective countries. The economic bandings by country do not reflect individual variations in income, but the aim was to look at health systems in these different countries, which are impacted by the overall country income level. Cultural factors were not taken into account and may impact on perceptions of care. However, the aim of this research was to get the experience of individuals, and each individual and their experience is unique. Again, this overall impression of needs meant that analysis by age group was not carried out.

Conclusions

Because of the design and limitations, further work would need to be carried out to assess if these 16 needs can be used universally. However, this work offers an insight into the varying needs that individuals have and how these can be presented as a hierarchy.

Bay [24] argues that Maslow’s hierarchy of needs can be used in order to provide a framework for meeting needs and setting priorities. Therefore, it helps in defining political development, as more basic needs need to be met before higher needs [7]. The higher up the pyramid, the less meeting that particular need is required for survival and necessary for well-being [25]. Not meeting the needs of belongingness, esteem and self-actualization lead to poor social well-being, whereas not meeting physiological needs leads to ill health and death [26]. The same is true for the hierarchy of needs for Type 1 diabetes, with insulin needed for survival, but ‘Being open’ requisite for social well-being.

Some needs are also tangible, in that the health system can provide these; for example, insulin. ‘Experience’ and ‘Personality’ are intangible and cannot be provided by the health system. However, healthcare workers need to take into account ‘Experience’ of the individual and their ‘Personality’ in order to adapt their approach to providing care.

The hierarchy of needs for Type 1 diabetes can have implications for policy and practice. From a policy perspective, the important messages are that:

1. survival needs go beyond purely providing insulin and syringes;
2. once these survival needs are met other needs are required;
3. higher needs are more difficult for only a health system to address.

For example, Nicaragua has to a certain extent achieved the first level of the hierarchy and is well advanced into the second segment with ‘Community support’ being well developed, but the other two elements demanding further work [27]. Therefore, policies and programmes need to strengthen the first element of the pyramid and start working on the second level.

For clinical practice, an assessment of where the individual is on the hierarchy of needs for Type 1 diabetes could be carried out during a consultation. For example, given the result of a self-assessed questionnaire based on the hierarchy of needs for Type 1 diabetes, a healthcare worker may see that the need of ‘Being open’ is not met. The ‘intervention’ would then be the healthcare worker finding ways to facilitate or help this person ‘be open’.

Maslow [28] argued that society plays a role in meeting the basic needs of its people. He stated that the definition of a ‘good society’ is the degree to which it satisfies the basic needs and offers the possibility of self-actualization to its population. By using the results from the hierarchy of needs for Type 1 diabetes in both policy and practice to improve diabetes care would help towards making ‘Diabetes as something positive’ for all people with Type 1 diabetes.

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Competing interests

None declared.

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References
3. Conclusion and perspectives

Given the lack of resources in LILMICS each element that composes a health system should be assessed in parallel in order to assess how it is working as an individual component as well as within the overall health system as presented in Section 2.1. For example although sufficient insulin was purchased there were issues in its distribution. These two components must be understood in order to identify the issue and propose a concrete solution. The 11 elements described in Section 2.2 show the overall components that are required to be integrated as well as the areas where opportunities for integration with other sectors exist, e.g. the role of the community as a whole, but also in specific areas for example with patient education and empowerment.

This framework using the 11 elements was used in developing an integrated response in Mozambique (Section 2.3) and how in designing a response an integrated approach was necessary cutting across these different elements. Again as weaknesses exist in each element of the system, any improvements in one area require attention to be given on other elements. This is due to the lack of resources and responsiveness of health systems in LILMICs. For example training of health professionals required improving access to medicines and diagnostic tools in health facilities.

As described by Bury (145) chronic diseases are a “biographical disruption” meaning that the health system is required to respond to the individual’s needs. Many of these needs are not traditionally seen as the remit of the health system, but should be integrated, as the individual will be managing their health mainly outside the confines of the formal health system. (Section 2.4) The examples of Kyrgyzstan (Section 2.5), the Philippines and Vietnam (Section 2.6) show that changes in policy must be integrated into the local context and reality of diabetes management. In Kyrgyzstan although there was a diabetes law in existence it was not integrated into practice due to the overall cost of such a policy. The aim of decentralisation of care in the Philippines and Vietnam is a necessary policy change in order for these countries to achieve UHC, but there are limitations in terms of the different 11 elements that hamper this implementation for diabetes, e.g. the organisation of care still focusing on specialist services.
Throughout an individual’s diagnosis, treatment and follow-up the care provided should be tailored to their needs and these needs integrated into management. (Section 2.7) For example a child with newly diagnosed Type 1 diabetes will have a very different set of needs to an adolescent who has had Type 1 diabetes for five years or a 50 year-old who has had diabetes since they were five years of age. One could argue that the 11 elements that the health system is expected provide are the same, but different in terms of their content and priority for given individuals at given times. In the discussions about integration this has sometimes been referred to as the client pathway in that each individual based on their needs will have a different path within the system and use a variety of the services offered (146). For example at the time of diagnosis survival is key and therefore the health system has to ensure that certain needs are met. Once the person has these needs met the health system and community then satisfy a variety of other needs that enable individuals to reach higher levels of “need” in terms of accepting and being open about their diabetes.

In order for integration to be successful this ought to take place at four levels (Figure 5). At a global level this integration has to be crosscutting. The MDGs took a very vertical approach in improving different areas of health, e.g. reduction of child mortality, whereas the SDGs offer the promise of a more horizontal approach to improving a variety of social, economic, environmental and health issues. This is a consistent with the WHO’s concept of “health in all policies” (127). For example SDG 3 aims to improve health and well being taking into account the issue of UHC, but will also have to integrate other areas such as poverty, the environment and gender. Another element within the global agenda and SDGs is PHC (147). The concept of PHC as defined by the WHO integrates the aim of UHC, focuses services on people’s needs, integrates of health in all policies and includes models for collaboration at a policy level and the involvement of different stakeholders (129). This involvement of different stakeholders is also an important component in terms of a wider view of which areas might impact health and the different actors that are involved in this as well as ensuring that global policy is relevant and can be translated into local action.
Figure 5 – Integration at global, national, health system and individual level for improved management of chronic disease

| Global | ← | Horizontal integration: Health in all policies linked to SDGs; Involvement of different stakeholders | → |
| Macro (National Policy) | ← | Horizontal integration: Health in all policies; Involvement of different stakeholders | → |
| Meso (National Health System and Community) | ← | Horizontal across these 11 elements: | → |
| Health System role | Vertical taking into account all these elements within each level of the health system | Community role | Vertical taking into account all these elements within the community |
| Micro (individual) | ← | Diagnosed something positive | → |
| | ← | Acceptance | → |
| | ← | Adapting; Being Open | → |
| | ← | Experience and Personality; Insulin, Delivery of insulin and Control e.g. blood or urine glucose | → |
| | ← | Healthcare workers and Information and education; Community support, Family support and Peers | → |
| | ← | Healthcare workers and Information and education; Insulin, Delivery of insulin and Control e.g. blood or urine glucose; Policies and Organisation of Health System | → |
| | ← | Across the individual’s pathway with diabetes: Age; Clinical; Daily Life | → |
Health in all policies also plays an important role at the national/Macro level. Here integration is also with how global policy debates are integrated into national realities. For example UHC can be achieved through different means of financing and covering of health related costs, which populations and which services are covered (132). Other aspects are for example the development of national NCD plans in line with the WHO’s Global Action Plan for the Prevention and Control of Noncommunicable Diseases with some adaptations to address local needs (148). Again local stakeholders, such as diabetes associations, should be included in policy discussions in order to help shape policy and its translation into health system responses.

It is necessary for these policies to be integrated into the delivery of services and are part of having an overall positive policy environment. This can range from preventive measures to the provision of free medicines and care. At the health system/Meso level vertical integration is both the role of each level of the health system (primary, secondary and tertiary) as well as the integration of the 11 elements, described in Section 2.2, into a comprehensive whole. This includes the functions that the community can play, through for example peer groups, outreach, patient associations and traditional healers. Horizontal integration at the Meso level is having a wide range of skills and community services present to meet the needs of the individual at each level of the health system. This approach is linked to the priority given to PHC (129) and addressing factors impacting adherence, patient education and empowerment utilising PHC and community resources within the individual’s community.

Finally at the individual/Micro level integration has to take into account the individual with all their needs, their family situation and ensure that the health system as well as the community supports this. Wagner et al. (73) highlight the requirement of “continuous relationships” between people with chronic conditions and their care team. This integration at the Micro level also includes the continuum of care (diagnosis, treatment and follow-up) for all diseases the individual may have, prevention of complications, as well as taking into account the life-course of the individual and how they grow with their disease(s). Policies here are also important, for example the provision of free insulin. For the individual/Micro
level horizontal integration relates to having all the health needs met by a variety of services in an easily accessible way. Vertical integration for the individual is having their wide range of needs met in different contexts (health system, school, community and workplace) in an integrated way through policies, health system responses and community support.

“Three overlapping galaxies” have been described by Lewis and Dixon (149) and Bodenheimer et al. (150) as necessary for the management of a chronic disease. The first “galaxy” is the individual who requires care for him or her self by adhering to a treatment regimen, which may include medicines as well as lifestyle indications. Healthcare workers providing care in a multidisciplinary approach are the second “galaxy”. The final “galaxy” is society as a whole, which has to create a positive setting by creating healthy environments and removing social and cultural barriers to the management of chronic diseases. This is important as for example in Zambia Hapunda et al. (151), found that a series of stressors impacted diabetes management. These stressors included: poverty, discrimination, keeping diabetes a secret, lack of family support, stigma and worrying about the future. Only one of these stressors was directly linked to the actual management of diabetes emphasising the importance of wider issues that go beyond the health system in impacting diabetes. With the increase in the prevalence of diabetes and NCDs as well as the chronic nature of some communicable diseases such as HIV/AIDS health systems and their organisation have to integrate a variety of factors. In parallel there is the issue of multi-morbidity that means that the integration has to take place at the level of the individual and not the individual diseases, e.g. the management of diabetes and tuberculosis. It is important in looking back at the definition of health given by the WHO that health goes beyond the absence of illness and includes “total social, psychological and physical well-being.”(138) For Type 1 diabetes the definition of the health system should be changed in order to encompass the wider issues that impact and are impacted by people having a chronic disease. The health system has to integrate other elements to ensure that care for the person goes beyond the provision of medicines, dietary advice and consultations and encompasses the social and psychological factors that may ultimately impact the health of individuals.
4. Appendices

Appendix 1 – List of LILMICs with economic and diabetes related data

<table>
<thead>
<tr>
<th>Country</th>
<th>WB Income Group(7)</th>
<th>Total population million(8)</th>
<th>GNI per capita ($) (8)</th>
<th>Percentage of population below national poverty line (8)</th>
<th>Mean diabetes related expenditure per person with diabetes (US$)(6)</th>
<th>Type 1 diabetes cases (0-14)(4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afghanistan</td>
<td>LIC</td>
<td>31.6</td>
<td>$680</td>
<td>35.8%</td>
<td>102</td>
<td>1047</td>
</tr>
<tr>
<td>Armenia</td>
<td>LMIC</td>
<td>3.0</td>
<td>$4 020</td>
<td>32.0%</td>
<td>187</td>
<td>268</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>LMIC</td>
<td>159.1</td>
<td>$1 080</td>
<td>31.5%</td>
<td>41</td>
<td>14256</td>
</tr>
<tr>
<td>Benin</td>
<td>LIC</td>
<td>10.6</td>
<td>$890</td>
<td>36.2%</td>
<td>66</td>
<td>764</td>
</tr>
<tr>
<td>Bhutan</td>
<td>LMIC</td>
<td>0.8</td>
<td>$2 370</td>
<td>12.0%</td>
<td>143</td>
<td>7</td>
</tr>
<tr>
<td>Bolivia</td>
<td>LMIC</td>
<td>10.6</td>
<td>$2 870</td>
<td>39.1%</td>
<td>185</td>
<td>111</td>
</tr>
<tr>
<td>Burkina Faso</td>
<td>LIC</td>
<td>17.6</td>
<td>$700</td>
<td>46.7%</td>
<td>67</td>
<td>1312</td>
</tr>
<tr>
<td>Burundi</td>
<td>LIC</td>
<td>10.8</td>
<td>$270</td>
<td>66.9%</td>
<td>41</td>
<td>236</td>
</tr>
<tr>
<td>Cambodia</td>
<td>LIC</td>
<td>15.3</td>
<td>$1 020</td>
<td>17.7%</td>
<td>81</td>
<td>95</td>
</tr>
<tr>
<td>Cameroon</td>
<td>LMIC</td>
<td>22.8</td>
<td>$1 350</td>
<td>39.9%</td>
<td>116</td>
<td>1418</td>
</tr>
<tr>
<td>Cape Verde</td>
<td>LMIC</td>
<td>0.5</td>
<td>$3 450</td>
<td>26.6%</td>
<td>228</td>
<td>38</td>
</tr>
<tr>
<td>Central African Republic</td>
<td>LIC</td>
<td>4.8</td>
<td>$320</td>
<td>62.0%</td>
<td>30</td>
<td>342</td>
</tr>
<tr>
<td>Chad</td>
<td>LIC</td>
<td>13.6</td>
<td>$980</td>
<td>46.7%</td>
<td>64</td>
<td>968</td>
</tr>
<tr>
<td>Comoros</td>
<td>LIC</td>
<td>0.8</td>
<td>$790</td>
<td>44.8%</td>
<td>68</td>
<td>20</td>
</tr>
<tr>
<td>Côte d’Ivoire</td>
<td>LMIC</td>
<td>22.2</td>
<td>$1 450</td>
<td>46.3%</td>
<td>133</td>
<td>1460</td>
</tr>
<tr>
<td>Korea (Dem. People’s Republic of)</td>
<td>LIC</td>
<td>25.0</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>348</td>
</tr>
<tr>
<td>Congo (Dem.)</td>
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<td>Mean diabetes related expenditure per person with diabetes (US$)(6)</td>
<td>Type 1 diabetes cases (0-14)(4)</td>
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Appendix 2 – Description of how PHC fits into the overall health system copied from WHO 2008 (129)
Appendix 3 – UHC model copied from WHO 2010 (132)
5. References

146. Mowat Centre and KPMG. The Integration Imperative: reshaping the delivery of human and social services. Geneva: Mowat Centre, School of Public Policy and Governance at the University of Toronto and KPMG, 2013.