DIABETES CARE AND RESEARCH IN EUROPE:

IMPLEMENTATION OF THE ST VINCENT DECLARATION

WORLD HEALTH ORGANIZATION
REGIONAL OFFICE FOR EUROPE
COPENHAGEN

TARGET 4

REDUCING CHRONIC DISEASE

By the year 2000, there should be a sustained and continuing reduction in morbidity and disability due to chronic disease in the Region.

TARGET 31

QUALITY OF CARE AND APPROPRIATE TECHNOLOGY

By the year 2000, there should be structures and processes in all Member States to ensure continuous improvement in the quality of health care and appropriate development and use ot health technologies.

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DIABETES CARE AND RESEARCH IN EUROPE:

IMPLEMENTATION OF THE ST VINCENT DECLARATION

Report on a joint WHO/IDF meeting

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9–11 March 1992

1992

EUR/HFA targets 4 and 31

ABSTRACT

Diabetes affects some 30 million people in the European Region, and WHO first joined the International Diabetes Federation (IDF) in a meeting on care for and research on the disease in 1989, which resulted in the St Vincent Declaration, later followed by guidelines on how to implement the targets it set. In 1992 they met again to review progress. Bringing together health authorities, diabetic people's organizations, insurance, industry, health professionals and the mass media, they reviewed country programmes and initiatives, epidemiological studies and issues in care and lifestyles, including education and quality assurance. The meeting ended with the Budapest Statement that urged each country to set up a national diabetes task force to formulate and execute a national programme for diabetes treatment, prevention and education.

Keywords

DIABETES MELLITUS – prevent/control
QUALITY ASSURANCE, HEALTH CARE
EUR

CONTENTS

Introduction

The Joint WHO/IDF Meeting on Diabetes Care and Research in Europe: Implementation of the St Vincent Declaration for Improvement of Diabetes Care was held in Budapest from 9 to 11 March 1992. The participants comprised representatives of government health authorities, diabetic people's organizations, insurance and industry, health professionals and the mass media. Four representatives were invited from each European country. Over 300 observers also attended. Different people chaired each of the plenary sessions; Annexes 1 and 2 list the working papers and the participants, respectively.

The Budapest meeting is the most recent step in a process begun two and a half years ago. People with diabetes mellitus number about 30 million of the approximately 850 million people who live in the WHO European Region. Recognizing the increasing importance of this health problem, the WHO Regional Office for Europe joined the International Diabetes Federation (IDF), European Region to hold a meeting on care for and research on the disease in St Vincent, Italy in 1989. The first fruit of this alliance was the St Vincent Declaration. It has two general goals – improving the health and increasing the quality and quantity of life of people with diabetes, and intensifying research to prevent and cure the disease and its complications – and 11 targets for achievement within five years. One of these urges the prevention of complications: the reduction of diabetic blindness, end-stage renal failure, amputation and coronary heart disease, and the improvement of pregnancy outcome for diabetic women. Two other targets call for monitoring and control systems for quality assurance and for urgent action on the Declaration.

The St Vincent Declaration has won wide acceptance for a number of reasons, beginning with the usefulness of its goals and concrete targets. Further, diabetic people's organizations and the diabetic drugs and equipment industry were involved from the start. The commitment of IDF and WHO was another important factor. The Declaration has special importance to WHO: while using the principles of health for all to attack an important health problem, it gives an example that could be applied to other noncommunicable diseases.

As a result, considerable action followed the issuing of the Declaration in 1989. Countries made or modified health policies to support the Declaration, and used it to guide their programmes and research. IDF mobilized its networks of member organizations in countries. WHO won support for the Declaration from organizations representing physicians, nurses, pharmacists and schools of public health. WHO programmes, such as the Healthy Cities project and the countrywide integrated noncommunicable disease intervention (CINDI) programme, also took part in the implementation of the Declaration. As the Regional Committee for Europe, the Member States of the WHO European Region passed a resolution in 1991, endorsing the principles of the St Vincent Declaration and urging WHO to support countries in the development of programmes to prevent and control diabetes.

In addition, WHO staff joined representatives of IDF to form a Steering Committee of the St Vincent Declaration Action Programme. The Steering Committee prepared guidelines for the achievement of the five-year targets, established a network of country liaison people nominated by WHO's Member States, cooperated with study groups of the European Association for the Study of Diabetes (EASD), and reported on its activities.

The Budapest meeting was the next step in the process begun at St Vincent. The participants met to review the progress made in care for and research on diabetes and to determine the steps that should follow in the implementation of the St Vincent Declaration, particularly the practical measures needed to establish countrywide diabetes programmes. Special attention was paid to conditions and future action in the countries of central and eastern Europe.

Discussion

The participants held lively discussions on a number of topics in plenary sessions. In general, these topics fell under four headings: country programmes and initiatives, European epidemiological studies, issues in care and lifestyle, and future action. In addition to the work presented, dozens of posters describing other initiatives were displayed just outside the hall in which the meeting was held.[a]

[a] The content of these posters is given in a volume of abstracts (see Annex 1).

Country programmes and initiatives

The presentation of country programmes and initiatives revealed many differences between countries in conditions and in approaches to diabetes care and the implementation of the St Vincent Declaration. Nevertheless, in addition to a variety of initiatives, a number of common themes and problems appeared. The themes included a reliance on the St Vincent Declaration as a guide and on law as a means of implementation, and stress on research, education and cooperation. The problems were: a lack of data on the dimensions of the problem posed by diabetes, poor communication among the parties involved, a lack of funds and poor organization of care.

Bulgaria has had a national programme on diabetes since 1987, but revised it in the light of the Declaration. The network of centres for specialized diabetes care has been strengthened and a new centre for children opened. New organizations for people with diabetes have been established and information is spread through a newsletter and an instruction book. Information on diabetic complications is needed to monitor progress towards the St Vincent goals.

Action on the St Vincent Declaration in Germany has taken three forms. The first is contributions towards concerted European action on research, training for health professionals and education for people with diabetes. The second is epidemiological studies within the country. Third, a number of organizational improvements have been made. Centres for education and outpatient care have been introduced, standards for the quality of care and education have been developed, and two aspects of care – diagnostic tests and education – have been integrated into health care law.

In Greece, four laws have been passed to improve conditions for people with diabetes. Two 1990 ministerial decrees set down the requirements for the establishment of outpatient and hospital diabetology clinics, and a third specifies the requirements for the training of all health professionals working with diabetic people. In addition, a new health law will found a centre for diabetes research and care.

Legislation is also an important tool in Italy. The St Vincent Declaration harmonizes with a 1987 law on the prevention and cure

of diabetes, which has prompted a number of activities focusing on research and integrated care.

Hungary's programme on diabetes has five aims. Diabetologists are to see all diabetic people on diagnosis, to be responsible for the care of those with insulin-dependent diabetes and to supervise the care of those with non-insulin-dependent diabetes. Specialized care is to be offered for complications and teams of specialists are to care for diabetic women throughout pregnancy. In addition, all health professionals dealing with diabetes need further training.

In Spain, more than 30% of people with insulin-dependent diabetes and 50% of those with non-insulin-dependent diabetes receive no education on the disease or self-management. Nevertheless, many monitor their levels of blood glucose. A national programme on diabetes, to be organized at the district level, has been proposed to the Government. Taking account of the St Vincent Declaration, the proposal specifies the content of care and the teams to provide it, and calls for working groups to tackle special topics.

The St Vincent Declaration has won considerable support in the United Kingdom. Extensive cooperation is under way between health authorities, the national diabetes association and organizations of health professionals, particularly on the development of standards and guidelines for care.

European epidemiological studies

The epidemiological data presented at the Budapest meeting were the preliminary results of the European Community Concerted Action on the Epidemiology and Prevention of Diabetes (EURODIAB). This programme employed standardized protocols and received some financial support from the European Community. The programme had three parts. Area A focused on the epidemiology and pathogenesis of insulin-dependent diabetes, area B, on complications and mortality in insulin-dependent diabetes, and area C, on the use of routine health information in the epidemiology of diabetes.

Data from area A contradicts the usual view of the geographical distribution of insulin-dependent diabetes in Europe, in which incidence is seen as high in the north and low in the south. The true picture appears to show regional differences, with incidence being

highest in the north, lowest in the east and intermediate in central and southern Europe. The reason for these differences is unknown; perhaps it is a combination of genetic and environmental factors. Research in this area will continue under the name of EURODIAB ACE.

Research in area B focused on the distribution, risk factors and nutritional aspects of diabetic complications. About four million people with insulin-dependent diabetes are at serious risk of developing complications. Focusing on retinopathy, nephropathy and neuropathy, the study gives useful information on the status of these complications in each country. The data gathered could help justify the targets of the St Vincent Declaration and be used to measure progress towards their achievement. The most important risk factors for diabetic complications are: the combination of proteinuria and hypertension, high levels of cholesterol, smoking, ketoacidosis and severe hypoglycaemia.

Nutrition was studied as part of an examination of regional differences in environmental factors in insulin-dependent diabetes. The results show that dietary patterns differ between regions; the incidence of complications is likely to differ accordingly. Further, dietary intake varies widely from recommended levels. People with insulin-dependent diabetes need to change their diet to improve their health.

The researchers working in area C of EURODIAB used a mass of already collected information to examine patterns of antidiabetic treatment and to compare prescribing habits in nine countries: Belgium, France, Germany, Italy, Luxembourg, Malta, Romania, Spain and the United Kingdom (Northern Ireland). The prescription of insulin, sulfonylureas and biguanides (alone or in combination) and of diet only was examined. Insulin is the most widely used drug, and the average prescribed daily dose is about 40 units per patient per day. The prescribed daily doses of the oral agents vary more than that of insulin, but the average is about two tablets per patient per day. The results also show large differences in prescribing habits, and no clear European pattern or policy.

Issues in care and lifestyle

Participants also described a number of initiatives to improve care for and the quality of life of people with diabetes. The first topic discussed was the prevention of complications. All the speakers

re-emphasized an important principle of the St Vincent Declaration: that good preventive care would not only reduce the burden of human suffering but also reap large savings in financial and material resources. In particular, participants stressed the value of the foot clinic in preventing amputation and of the home monitoring of blood glucose, glucose and ketones in urine and other indicators of risk. Self-monitoring is of great value in maintaining good metabolic control, allowing people to manage their disease and thus preventing diabetic complications. The importance of microalbuminuria as an indicator of the risk of diabetic nephropathy was also discussed. Screening for microalbuminuria would be costly, but would yield economic benefits by allowing either the prevention or the early detection of nephropathy (when treatment can be most effective).

Education

The participants repeatedly stressed the importance of a well informed diabetic person as an active or even the leading partner in good care: another principle of the St Vincent Declaration. People need self-confidence and skill to manage their diabetes. Technical innovations, such as strips for the self-monitoring of blood glucose, require users to know how to read them, to interpret the results and to adjust their treatment accordingly. Enabling the diabetic person to become an active partner in care requires education for both the users and the providers of services.

The question is, how best to offer the necessary knowledge and skills. People guide their behaviour through knowledge gained from experience. The challenge for diabetic education programmes is to change abstract facts from sources outside the learner into personal knowledge. Research shows that interactive programmes, involving exercises and given to groups of people, give better results than simply telling a person the facts. Because the effects of education gradually fade, programmes must be offered regularly and repeatedly. A programme incorporating these principles was described to the participants.

The EASD Diabetes Education and Study Group has developed a structured treatment and teaching programme, intended eventually for use on a countrywide basis. The programme has been given in

hospitals to groups of people with insulin-dependent diabetes. It consisted of five days of interactive learning and stressed metabolic control through self-monitoring and a dietary regimen. The German Government financed a three-year trial of the programme in 10 nonspecialist hospitals in Germany; the project had good results. Metabolic control increased and remained good, and admissions to hospital and episodes of severe hypoglycaemia decreased. Other benefits included savings in the costs of hospital care and sickness absenteeism, and a better quality of life for the people involved.

The programme was then tested in two cities in central and eastern Europe – Bucharest and Moscow – with equally encouraging results; it will also be used in Budapest and Sofia. The effects fell into a pattern: a considerable and sustained drop in hospital admissions, in levels of glycated haemoglobin and in severe ketoacidosis, with severe hypoglycaemia remaining about the same. The results of the programme in Moscow, for example, followed the pattern. Levels of glycated haemoglobin fell to near normal in 55% of the study population, and 97% reported much better management of their diabetes. Both severe ketoacidosis and severe hypoglycaemia declined. The follow-up of this programme one year later showed that these benefits had persisted.

How can such a programme be extended throughout a whole country? EASD is planning training workshops over the next two years, focusing on the countries of central and eastern Europe. Workshops are planned for Bulgaria, Czechoslovakia, Poland, Romania and the Russian Federation. It is hoped that this will lead to the development of countrywide programmes based on valid data. This will provide a model for the implementation of the St Vincent Declaration through national diabetes programmes whose composition is based on proof of effectiveness.

In addition, good diabetes education needs nurses to take an important role. Technical developments and the trend towards outpatient treatment required an educator who can give both technical and psychosocial guidance and can work in different settings with a variety of people. National health plans should provide for this educational work, and nurses should be reimbursed for it. The work of the specialized diabetes nurse has benefits – to patients and in reducing the costs of care through prevention – that outweigh the costs.

Quality assurance

Information systems. The importance of quality assurance in the St Vincent Declaration has already been mentioned. The participants addressing this issue at the Budapest meeting discussed the use of information technology to improve the quality of care, and three studies on particular areas of care. The participants repeatedly stressed the importance of information to evaluate countries' progress towards the goals of the Declaration.

An exploratory survey showed gaps in information systems for diabetes care. The gaps are widest in hospitals, narrower in primary health care and narrowest in self-care. Computer-supported cooperative work is the key to better care. Information systems in all areas need to be completed and then linked. The challenge is to accomplish this task throughout Europe.

The Steering Committee of the St Vincent Declaration Action Programme has established a group to prepare guidelines and develop tools for the continuous improvement of the quality of diabetes care.[a] The aim is to enable the providers of care to collect data on and compare their performance. In 1991, the group established a basic data set and prepared the DiabCare basic information sheet and computer program. Then the group studied the usefulness of these tools in different health care settings and countries. The feasibility study included the development and testing of methods of data aggregation. The study was completed just before the Budapest meeting; 47 centres in 17 countries took part.

The DiabCare group used indicators of the outcome, structure and process of care to evaluate the data received. The participating centres received results that allowed comparisons of their performance on three levels: with that of other centres, the country as a whole and Europe in general. Because this feedback system did not include information on the characteristics and clients of the centres, however, it did not permit the evaluation of any centre by people outside it.

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[a]The guidelines are given in full in the implementation document of the St Vincent Declaration action programme (see Annex 1).

The results of the study confirmed the feasibility of using the DiabCare tools in quickly aggregating data from many centres, evaluating them according to the targets of the St Vincent Declaration and related indicators of quality, and returning the results to the centres. The next step is to encourage country authorities to name centres to form a European network for the continuous improvement of care. Each centre can use data collected through the network for local discussion, involving both the users and providers of care, to find means of improvement.

Three studies. In addition, the participants discussed quality assurance initiatives in two countries. A study in Sweden examined the quality of diabetes care in a particular community. It showed the values of the principles of the St Vincent Declaration: flexibility, the involvement of diabetic people as well as health professionals, and the need to provide basic services and monitor the outcome.

Reports were then made on two studies in the United Kingdom. The first was a survey of consultant ophthalmologists in England and Wales. These specialists have an important role in diabetes care. Diabetes is the third most common reason for attendance at an eye clinic, and such clinics perform 70% of the screening for diabetic retinopathy. The survey showed that screening services are inadequate, particularly for people with non-insulin-dependent diabetes, who are seen only by general practitioners. As to attendance at an eye clinic, large numbers of people have to wait longer than ideal for a visit and for treatment. Consultant ophthalmologists treat proliferative retinopathy appropriately and promptly, but many fail to treat maculopathy or treat it too late. As a result of the survey, the British College of Optometrists is organizing workshops on the treatment of maculopathy.

The second study tested a new approach to the treatment of children on diagnosis of insulin-dependent diabetes. A group of such children was treated as outpatients instead of being admitted to hospital, which is the usual practice. The number and length of later admissions to hospital for diabetes-related causes were half of those of a group treated in the usual way, with no bad effects on metabolic control.

Lifestyle. Insurance is a problem for many people with diabetes. Coverage is difficult and expensive to get. A project in Denmark is trying to secure coverage and nearly normal premiums for diabetic people. Thousands of people have secured life and accident insurance, and only one accident, whose cause is unknown, occurred in the first nine months. Normalized premiums will be set for accident insurance in the next six months and for life insurance in the next three years. This is a large step towards social equity for diabetic people in Denmark.

Future action – implementation of the St Vincent Declaration

Incorporating many of the principles of health for all, the St Vincent Declaration means that existing knowledge can be used to improve diabetes care and management and relieve diabetic people of a heavy burden of unnecessary suffering. It is a social charter, detailing both rights and responsibilities. After their review of progress since the St Vincent meeting and other current issues, the participants at the Budapest meeting turned their attention to future action to implement the Declaration. The discussion involved many participants and ranged from the lively to the impassioned.

The implementation of the document plainly needs to be as multisectoral as its creation was. The partners in this task will work on a number of levels. The representatives of WHO and IDF comprising the Steering Committee, for example, have several tasks before them in the European Region. The Committee will continue to stimulate health authorities and the organizations of diabetic people to implement the St Vincent Declaration through national or regional programmes and to adopt the implementation guidelines (see Annex 1). It will also support a European diabetes register, epidemiological studies, education activities and a consensus meeting on insulin-dependent diabetes, and ask IDF to promote the social rights of people with diabetes. In addition, three directions for future research were identified. These are: the prevention of insulin-dependent diabetes, the prevention of complications through the optimization of care, and the pathogenesis of non-insulin-dependent diabetes.

In countries, the chance for savings offered by the St Vincent Declaration should win the support of governments for its implementation. The role of government should be to supply the means for and facilitate the process. The task of diabetic people is to demand that their needs be met, and that of health professionals, is to provide the services needed.

The participants favoured national diabetes programmes as the best means of implementation. Such programmes can create the broad social movement needed to accomplish the goals of the St Vincent Declaration. Each country could establish a task force, comprising representatives of all the parties concerned, to develop the programme. Considering both the Declaration and the country's circumstances and needs, the task force could choose the appropriate methods and speed for implementation.

WHO has prepared a structured model for a national programme that countries could find useful (see Annex 1). The guidelines cover such topics as the types of data to use in constructing a programme, and many practical issues in preparing, delivering and evaluating it. In addition, the participants suggested that all programmes include an evaluation component and that only those meeting certain standards should be able to use the name of the Declaration.

The participants endorsed the principle of shared care. Such care should be designed to meet the various needs of diabetic people, and allow them to take the more active role required for the better management of their disease. The participants endorsed no single system of care, because none could meet the needs of all European countries.

The European Region appears to be divided in its problems and needs in diabetes care, although better education is needed everywhere. In western Europe, current needs seem to centre on the psychosocial factors of coping and making better use of the existing structure of and facilities for care. In the countries of central and eastern Europe, work to implement the St Vincent Declaration has to contend with the current economic crises and social and political changes. Participants questioned whether these countries could reach the St Vincent targets within the specified period.

The countries of central and eastern Europe are the home of about half of the diabetic people in the Region. They differ in culture,

history and economic structure, but all are striving towards democracy, a strong economy and a sound social and welfare system. The central issue in diabetes care is the task of meeting basic needs. There is a lack of drugs and equipment, for example, ranging from insulin, syringes and diagnostic tools to tools for the specialized treatment of complications. Recognizing these problems, the participants suggested measures such as twinning to bridge the gaps between countries.

Further, it was hoped that the effects of the St Vincent Declaration would extend beyond Europe to the rest of the world, including developing countries. There are fewer differences than before between these countries and those of the European Region. Most developing countries lack the means for the surveillance and evaluation of care, and the means of home monitoring and the treatment of complications. The goal for these countries will be to use the St Vincent Declaration to establish good basic care.

Conclusion

The participants at the Budapest meeting summarized their views in the following statement:

> We – people with diabetes, members of European diabetes associations, health care professionals and representatives of national government health departments from all the countries of Europe – met in Budapest in March 1992. The meeting was convened by the WHO Regional Office for Europe and the International Diabetes Federation, European Region, to review the progress made since the 1989 St Vincent Declaration on diabetes care and research in Europe and to launch its full implementation phase.
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> The St Vincent Declaration drew attention to the social and economic discrimination against people with diabetes and the serious disabling burdens of the disease, and set clear goals for their alleviation. Successful implementation will relieve much human misery and greatly reduce the costs of diabetes to the community.
>
> The countries of Europe have widely differing conditions and priorities for their health care services. Each country must fashion

its own approach to the achievement of the St Vincent targets; an implementation document was prepared to assist this process. At the national level, close and active liaison between local diabetes associations, health professionals and health departments is vital to get things moving. In participating countries there is also strong sentiment for effective mutual support.

We unanimously adopt the implementation document of the St Vincent Declaration and strongly recommend that each European country assemble a national diabetes task force. This should consist of representatives of diabetes associations including some people with diabetes, health and social science professionals, representatives of national government health departments, and other concerned people. This diabetes task force should formulate and execute a national action programme for diabetes treatment, prevention and education which should recognize the crucial need – in health and social terms – for patient education.

We seek the speediest possible implementation of the recommendations of the Budapest meeting and the achievement of the goals of the St Vincent Declaration.

Annex 1

WORKING PAPERS

Diabetes care and research in Europe: implementation of the St Vincent Declaration for improvement of diabetes care. Abstracts. Copenhagen, WHO Regional Office for Europe, 1992 (unpublished document).[a]

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Kohner, E.M. & Porta, M., ed. *Screening for diabetic retinopathy: a field guide-book.* Copenhagen, WHO Regional Office for Europe, 1992 (unpublished document).[a]

Reiber, G.E. & King, H. *Guidelines for the development of a national programme for diabetes mellitus.* Geneva, World Health Organization, 1991 (unpublished document WHO/DBO/DM/91.1).

[a] Copies of these documents can be obtained free of charge from the Quality of Care and Technologies unit, WHO Regional Office for Europe, Scherfigsvej 8, DK-2100 Copenhagen Ø, Denmark.

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