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Review

Global Diabetes Survey—An annual report on quality of diabetes care

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SUMMARY

Adequate quality of diabetes care and the best concept for the implementation of national diabetes plans remain controversial. In September 2011 the United Nations High Level Meeting on Non Communicable Diseases agreed on a consensus that national plans for the prevention and control of diabetes should be developed, implemented and monitored. The Global Diabetes Survey (GDS) is a standardised, annual, global questionnaire that will be used to assess responses of representatives from 19 diabetes-related stakeholder groups. It was designed with the goal of generating an annual report on the quality of national diabetes care and to compare findings from different regions and countries. The findings will be freely available for everyone's use and will be used to inform politicians and stakeholders to encourage the improvement of the quality of diabetes care in its medical, economical, structural and political dimensions.

Contents

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1. Introduction

Currently we are experiencing an epidemic growth in the number of people with diabetes worldwide [1]. An estimated 366 million people, corresponding to 8.3% of the world's adult population has diabetes today but the prevalence is expected to grow to 552 million by 2030, corresponding to 9.9% of the adult population. It goes hand in hand with ''westernization'' of lifestyle, with consuming more energy-dense food as well as with decreasing physical activity. Driven by this development, diabetes affects more and more young people, especially in their working age. The growing economic burden in complex socioeconomic structures becomes obvious. The development of the diabetes epidemic is predicted to have a significant impact on the global economic growth [2].

This situation requires different approaches from national health care systems depending on national health care structures and their medical, environmental, social and economic means. In order to respond rapidly in a coordinated fashion to the health threat type 2 diabetes and its associated co-morbidities, it is necessary to assess the quality and structures of diabetes care in a standardized way presenting the goals, processes, responsibilities, availability and accessibility of diabetes care before implementation of a national diabetes plan (NDP) [3].

At the United Nations High Level Meeting for Non Communicable Diseases (NCD) in September 2011 in New York Ministers of Health requested an international cooperation and policy decisions on diabetes according to the present context of globalization of health issues [4]. There was a consensus across countries that national plans for prevention and control of chronic diseases be developed and implemented and that strategies to monitor progress on implementation be established. In May 2012 the European Diabetes Leadership Forum was held, hosted by the OECD and the Danish European Presidency, to discuss developing strategies on political, medical and patient centered level for improving diabetes prevention and care. Kofi Annan said at the meeting ''*There is no other option than to act – to improve quality of diabetes care*.'' Key actions to improve the quality of diabetes care worldwide are seen as (1) implementation of diabetes prevention programs, (2) development of chronic care management programs in primary care, and (3) development of monitoring instruments and quality management strategies for diabetes prevention and care [5].

Adequate quality of diabetes care and the best concept for the implementation of national diabetes plans remains controversial. We need to improve our understanding about best ''quality of diabetes care'' to successfully translate existing knowledge into a sustainable comprehensive diabetes strategy [6].

2. The puzzle of quality of diabetes care

2.1. *Care structures*

Firstly the health care structures in many countries are known, but there is still a big variation in health care structures and systems. The response to ask a colleague about their quality of diabetes care will be that ''its good'', but a comparative benchmarking about care structures and processes does not exist internationally. The Euro Consumer Diabetes Index provided information about a very high variation of patient perceived quality of diabetes care in Europe [7]. Structures of diabetes care were assessed and further developed by projects like DE-PLAN [8] and monitored through the ''Policy Puzzle'' initiative [9]. The health care structures in other countries worldwide including developing countries differ significantly in a number of aspects [10]. In many countries diabetes disease management does not exist or is poorly understood. Chronic care management is often far away from developing [11]. The International Diabetes Management Practice Study showed lack of access to health care, cost of medications, and poor insurance coverage and lack of reimbursement for preventive care and diabetes education are major system level barriers to diabetes prevention and control [12]. Provider-level barriers include lack of guidelines for multiple chronic diseases and adherence to guidelines, failure to prioritize among multiple chronic medical issues and fragmentation of care and poor integration of physicians. Patient barriers are primarily related to therapy adherence, lack of diabetes education, low health literacy, lack of motivation, out-of-pocket medication costs and adverse side effects of recommended treatment [13,14].

2.2. *Health policy development*

Secondly health policy development is nationally driven with various competing competences and interests leading to a large variation of National Diabetes Policies [15] and is often lacking an evidence base of standardized assessment of the health care situation and conceptualization. Current projects from the IDF (BRIDGES) and also European projects like SWEET, DIAMAP [16] and GIFT indicate that this heterogeneity will be surpassed by the variation of determinants for policy development especially in low- and middle-income countries. Here a systematic investigation of the main components for the NDP implementation could provide a basis to optimize conditions under which diabetes policy and NDP development can be initiated.

2.3. *Health care professional education*

Thirdly health care professional education is well standardized in Europe (Bologna process) and medical education is standardized in many countries worldwide. A current

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European funded Public Health Project (IMAGE) [17] has developed a standardized intentionally applicable curriculum for prevention managers [18,19]. This work identified that health care professional education varies significantly in performance, certification, quality management and educational standards worldwide. Key elements that determine the quality of the health system with regard to diabetes care processes includes the availability and structure of health care professional education with multidisciplinary competences and evaluation of the services to strengthen competences and excellence of the services. A comparative overview and structured recommendation for educational services is lacking.

2.4. National diabetes plans

Finally one of the critical success factors to tackle the diabetes epidemic is the implementation of structured chronic care management programs as part of national diabetes plans [11]. A number of countries have developed NDP's with various success [15]. Successful NDP's are often built on the extensive knowledge of the structure-, process- and outcome-quality of diabetes care as well as consensus between all relevant stakeholders about the implementation process to target action for NDP development [11]. The IDF has been very active in encouraging the development of NDP's [1]. Over the last 25 years they continuously called for global action on the prevention and control of diabetes in a number of resolutions [20] and declarations [21,22] committing in 2006 to the final instalment of the United Nations UN Resolution 61/225 [23] on diabetes calling for "*...Member States to develop national policies for the prevention, treatment and care of diabetes in line with the sustainable development of their health care systems...*". National diabetes plans need to play a major role in answering the call of the UN-Resolution from 2006. The IDF Task Force on National Diabetes Policy and Action analyzed the existence, content and implementation status of NDP's [15,24]. Taking all countries into account showed that less than 25% of countries have a national diabetes plan, but in a much smaller number this plan is implemented. Nothing is known about the quality of the national diabetes plans, which seems to vary considerably.

Summarizing the aspects mentioned above there is an urgent need to assess the variation of quality of diabetes care between countries to identify differences and to use this information to develop best practice models for chronic care management applicable to countries worldwide. The Global Diabetes Survey will address this need and perform an annual standardized and structured assessment of the quality of diabetes care aiming to generate a representative picture in 90% of countries worldwide within the next 5 years.

2.5. The Global Diabetes Survey

The GDS is designed to provide data on the quality of diabetes care in different countries worldwide, with the aim of comparing and providing a benchmark for the quality of diabetes care.

2.5.1. Objectives of the GDS

- To annually assess the quality of national diabetes care in each participating country.
- To identify gaps and barriers in diabetes management in participating countries and combine inter- and intra-country comparisons of best practice, with the goal of providing targeted evidence to decision-makers for the planning, management and organisation of NDPs.
- To annually analyse the changes of the quality in diabetes care by using follow-up GDS data.

2.6. Methodology of the GDS

To achieve these objectives, two conditions must be met:

(1) A standardised set of questions that adequately represents the quality of diabetes care in different countries must be developed.
(2) These questions must be answered by GDS stakeholders representing all relevant areas and focus groups in diabetes care.

2.7. Development of the GDS-questionnaire

The GDS-questionnaire is intended to assess the quality of diabetes care and diabetes prevention. To explore these constructs a review of the existing literature (diabetes guidelines, literature on NDPs and diabetes quality indicators) was conducted. Subsequently, items which should be included in the questionnaire were discussed with experts in the field of diabetes care. The resulting draft questionnaire comprised 12 domains and was reviewed by registered participants using two rounds of a Delphi-like procedure. Comments were discussed and changes were incorporated in the questionnaire after a consensus based expert discussion. This resulted in different domains receiving different weights to influence the GDS score according to their relevance to diabetes care. Finally, a score was developed setting the highest quality of diabetes care equal to 100.

2.8. Participants in the GDS – diabetes stakeholders

To achieve representative data from each country, a sufficient number of representative stakeholders from 19 diabetes-related groups will be invited to participate in the survey. These stakeholder groups include individuals involved in diabetes care and disease management:

- Patients
- Patients' relatives
- Representatives from patient organizations
- General practitioners
- Diabetes specialists (diabetologists/endocrinologists)
- Diabetes nurses
- Pharmaceutical specialists (i.e. pharmacists)
- Educators in the area of diabetes (i.e. diabetes educator, diabetes coach, diabetes navigator)
- Nutritionists/dietitians in the area of diabetes

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- Experts in physical activity and exercise education
- Psychologists
- Medical staff for the treatment/prevention of diabetes complications (i.e. ophthalmologists, nephrologists, cardiologists, neurologists, podiatrists, specialized shoemakers)
- Prevention specialists (all occupations that are primarily dedicated to diabetes prevention)
- Other (i.e. nurses, elderly care nurses, health workers, social workers)
- Politicians or public health authority employees
- Scientists
- Health insurance
- Pharmaceutical industry
- Other (i.e. media, students)

The ultimate goal is to recruit one person in each group per 250,000 patients with diabetes per country. In countries where it is not possible to invite stakeholder groups, different groups must be represented. Participants will register and complete the survey online. Our initial experience indicates that this is possible in developing countries. To date, more than 2000 stakeholders from more than 132 countries have already registered with the GDS at www.globaldiabetessurvey.com.

2.9. *Completion of the GDS*

The GDS will be performed annually in September/October, with the goal of completing data analysis by World Diabetes Day on November 14.

2.10. *Standardized analysis of the GDS data*

The first analysis of the GDS collected data will be done centrally at the University of Dresden, Germany. A GDS score will be evaluated based on participant answers for each country and each volunteer group per country, if representative. As part of the analysis, similarities and differences will be analyzed as well as the stakeholders' groups view on the national diabetes management. This analysis will be presented in comparison to the results of other countries with respect to prevalence, incidence and diabetes-related health care budget and shown as a global map on the quality of national diabetes care. This can be used to identify best practice examples with the most sustained quality of diabetes care and to target countries with the strongest needs to increase their quality of diabetes care.

2.11. *Communication of the Global Diabetes Survey results*

The project results will be made available on November 14th at World Diabetes Day in scientific and lay press, and via international partner organizations (IDF) and ultimately invite other partners to use the experiences and results of the project to build capacity for better diabetes care in their countries. The results will be condensed in a report, which will provide politicians with evidence for prioritizing chronic care management for people with diabetes mellitus.

3. Current stage – the Global Diabetes Survey questionnaire

The GDS-questionnaire contains 12 domains and 132 items:

Domain	Question	Response format
Equality of access to diabetes care	How do you perceive the equality of access to diabetes care in your country?	Rating scale (very unequal – equal)/unsure
	Differences in equality of access exist between regions/urban and rural areas/gender/age groups/income groups/ethnic groups/religions/health insurance coverage/other	No/rather no/rather yes/yes/unsure
Public health	How often do you receive updated information about diabetes, its causes and its complications in your country (press, advertising, educational activities)?	Rating scale (never – very often)/unsure
	Do you know an advocacy group for diabetes care providers (professional organization, scientific organization)/an advocacy group for people with diabetes/a diabetes telephone helpline/a national diabetes campaign/a media campaign targeting a healthy lifestyle	No/yes/unsure
Prevention I	How much of a priority is the prevention of diabetes mellitus type 2 in public policy in your regional community?	Rating scale (very low priority – very high priority)/unsure
	Do you know education in schools about a healthy lifestyle/price incentives for healthier foods (taxes on unhealthy food or subsidies for healthy food)/food labeling for most of the products/policies promoting healthy lunches for most students in kindergartens, schools and universities/occupational health care and prevention programs/policies promoting physical activity in specific settings at school, workplace, environment/policies promoting physical activity in the community (bike lanes, etc.)	No/yes/unsure
	How many people in your regional community are reached by the above activities?	None/few/approximately half/many/all/unsure
	For how many people in your regional community are healthy food choices affordable?	None/few/approximately half/many/all/unsure

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Prevention II	How important is the early identification of people at increased risk for diabetes mellitus type 2 in your regional community?	Rating scale (not relevant – very important)/unsure
	Do you know a national program to identify those at increased diabetes risk in your country?	No/yes/unsure
	Do you know any regional activity to identify those at increased diabetes risk?	No/yes/unsure
	Are any activities to identify people at increased diabetes risk routinely performed in your regional community?	No/yes/unsure
	Are specific screening tools for the early identification of diabetes risk factors available to general public?	No/yes/unsure
	Are specific screening activities for the early identification of diabetes risk factors routinely used by health care professionals?	No/yes/unsure
	How many people in your regional community are reached by the above activities?	None/few/approximately half/many/all/unsure
Prevention III	How important are targeted interventions to prevent diabetes mellitus type 2 in your regional community?	Rating scale (not relevant – very important)/unsure
	Do you know any activity supporting a healthy lifestyle/specific interventions targeting people at high diabetes risk/a practice guideline for diabetes prevention/enough qualified personnel to perform interventions	No/yes/unsure
	How many people in your regional community are reached by the above activities?	None/few/approximately half/many/all/unsure
Early detection	How important is the early detection of undiagnosed diabetes mellitus in your regional community?	Rating scale (not relevant – very important)/unsure
	Do you know general programs for early detection of patients with undiagnosed diabetes mellitus?	No/yes/unsure
	Do you know targeted screening programs for gestational diabetes/in at-risk populations (e.g. relatives of people with diabetes, obese people, people taking medications that predispose them to diabetes)/in children/in specific ethnic groups/in specific age groups	No/yes/unsure
	Are specific screening activities for the early identification of diabetes mellitus routinely used by health care professionals?	No/yes/unsure
	How many people in your regional community are reached by the above activities?	None/few/approximately half/many/all/unsure
Therapy	What is your estimate of the percentage of people with diabetes mellitus who receive adequate diabetes care in your country?	Rating scale (0–100%)/unsure
	Are the following available as needed? Metformin/sulfonylurea/glinides/modern oral antidiabetics (e.g. DPP4 inhibitors, SGLT2, fixed combination products)/GLP-1 analogues/short-acting insulins/intermediate-acting/long-acting insulins/mixed insulins/insulin analogues/insulin pump therapy/glucagon/blood pressure medication/lipid lowering medication/regular self-monitoring of blood glucose for people with diabetes taking insulin/regular self-monitoring of blood glucose for people with diabetes not taking insulin/continuous glucose monitoring/disposable syringes/insulin-pens and adequate needles/laser therapy for retinopathy/dialysis for chronic renal failure/special footwear for the diabetic foot/psychotherapy for people with diabetes/appropriate facilities and specialists for diabetes care for children/appropriate facilities and specialists for diabetes care/hospitals specialized in diabetes care/rehabilitation centers specialized in diabetes care/	No/yes/unsure
	Adequate diabetes care is always available for children/adolescents/pregnant women/people with type 1 diabetes/people with type 2 diabetes/elderly with diabetes mellitus/people with special forms of diabetes	No/yes/unsure
Process of care	How would you rate the overall quality of diabetes care in your country?	Rating scale (very poor – very good)/unsure
	How often are the following assessments performed as part of regular diabetes care? Assessment of the patient's self-care knowledge and beliefs/discussion about healthy lifestyle adaptation and wishes (including nutrition, physical activity, smoking)/psychological status of the patient/patient's self-monitoring skills and equipment the patient uses/review of patient's blood glucose self-monitoring records/body weight and/or waist circumference/HbA1C/blood pressure control/blood lipid control/cardiovascular risk/erectile dysfunction/neuropathy/foot condition/eye/fundus/kidney function/review of the medication the patient is using	Never/less than once per year/yearly/multiple times per year/unsure

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Care management	How would you rate the collaboration between different health care providers in diabetes care?	Rating scale (very poor – very good)/unsure
	Do you know a national diabetes plan in your country/national or regional diabetes guidelines defining the standard of care	No/yes/unsure
	Are the majority of the following patient groups treated according to the existing diabetes guidelines? People with type 1 diabetes/people with type 2 diabetes/other	No/yes/unsure
	Does your county have a disease management program for people with diabetes?	No/yes/unsure
	Is this disease management program mandatory for most of the people with diabetes in your country?	No/yes/unsure
	Are referrals to a diabetes specialist possible and made in a reasonable timeframe?	No/yes/unsure
	Do the majority of people with diabetes have personal diabetes documentation (i.e. diabetes-pass)?	No/yes/unsure
	Are the patient's medical records accessible to all diabetes care providers?	No/yes/unsure
	Is there a certification for qualified diabetes care providers/an evaluation for qualified diabetes care providers	No/yes/unsure
	Is there a mandatory quality control organized by national authorities for medications used in your country/equipment and supplies for people with diabetes/laboratory diagnostic procedures and techniques	No/yes/unsure
Research/diabetes registry	How important is diabetes research in your country?	Rating scale (not relevant – very important)/unsure
	Is diabetes research performed in your country?	No/yes/unsure
	Is there health services research performed in your country?	No/yes/unsure
	Is diabetes research publicly funded in your country?	No/yes/unsure
	Is the number of people with diabetes mellitus in your country regularly ascertained? Based on a registry/based on other sources on what scale? Nationally/in your regional community	No/yes/unsure
Education	How important is diabetes-related training for health care professionals in your country?	Rating scale (not relevant – very important)/unsure
	Are there targeted trainings in your country for experts in diabetes prevention (i.e. prevention manager)/specialists for diabetes patient education (i.e. diabetes educators)/diabetes-specialized physicians/diabetes-specialized nurses/podiatrists/doctors and personnel in other medical specialties about diabetes topics/medical students about diabetes	No/yes/unsure
	Are standardized curricula for these trainings available?	No/yes/unsure
	Is there continuing medical education for all diabetes specialists in your country?	No/yes/unsure
	Is diabetes prevention a significant component of the curricula above?	No/yes/unsure
Self-management	How important is patient self-management in your country?	Rating scale (not relevant – very important)/unsure
	Do the majority of diabetes specialized health care providers provide support for self-management to patients?	No/yes/unsure
	Do structured diabetes education courses exist in your regional community for children/adolescents/people with type 1 diabetes/people with type 2 diabetes/other	No/yes/unsure
	Do diabetes education courses promote patient empowerment for better self-management?	No/yes/unsure
	Are there educational courses promoting a healthy lifestyle for people with diabetes?	No/yes/unsure
	Do you know diabetes support groups?	No/yes/unsure
	At what time point do the majority of patients attend a diabetes education course?	One time/following diagnosis/based on need/on an ongoing basis/never/unsure
	How many patients take these courses? Children/adolescents/people with type 1 diabetes/people with type 2 diabetes/other	None/few/approximately half/many/all/unsure

4. Discussion

Concerted action and commitment is needed to fulfil the recommendations of the United Nations Declaration on Non-Communicable Diseases [6,25] The GDS is the first initiative that will provide benchmarks on the quality of diabetes care worldwide, including standardized information about the structure and process of quality of diabetes care. The strategic methodology will provide holistic and realistic information about diabetes care in each participating country. The adequate communication of the results has the potential to empower national or regional decision-makers in the planning, management and organization of health systems

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through the contribution of a GDS evidence base. The project will strengthen the ability of targeted diabetes policy development to address the need for better diabetes care. This will build capacity to develop NDP's and allow national and regional decision makers to better translate knowledge, empirical data and operational experience into policies and planning for more effective, efficient and equitable health systems and services and finally to make the quality of diabetes care better.

By using the diabetes survey, the assessment will identify gaps and barriers related to effective disease management in participating countries and will enable inter-country comparisons of both quantitative and qualitative approaches about best practices with a view to increasing and sustaining universal health coverage. This is the main aspect in which the GDS is different from previous initiatives. The Euro Consumer Diabetes Index invited only randomly chosen patients, but also used statistical data [7]. The IDF Task Force on National Diabetes Policy and Action [15,24] and the Policy Puzzle [9] has tried to ask administrative stakeholders from public and political institutions about their perception of diabetes care. The International Diabetes Management Practice Study [12] asks selective health care providers, but none of the initiatives were able to combine the stakeholder groups and to extract information being generated directly in the diabetes care processes.

By its strategic methodology the GDS will provide holistic information about the quality of diabetes care in each participating country. The more volunteer stakeholders who participate, the more specific the country-based picture will be. Benchmarking diabetes care between different countries will, especially with the annual follow-up and communication of results, provide strong evidence to politicians on the gaps in diabetes care.

Adequate communication of the GDS results should empower national and regional decision-makers to plan, manage and organize health systems by giving them an evidence base. The results will strengthen the ability to develop targeted diabetes policy that addresses the need for better diabetes care and will help to develop NDP's for diabetes care. It will also help national and regional decision-makers to better translate knowledge, empirical data and operational experience into policies and plans that improve the effectiveness, efficiency, and equitability of health systems and services.

This GDS will clarify the status quo of national diabetes care worldwide for the first time and will allow progress towards the United Nations Declaration on NCD. The success of the GDS depends on the participation of enough volunteers and so we warmly invite you to participate in it, no matter where you live. Your participation will be particularly valuable if you belong to any of the named stakeholder focus groups. If you would like to participate, please go to www.globaldiabetessurvey.com.

Conflict of interest

The authors declare that they have no conflict of interest.

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