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The 3C Study: Coverage cost and care of type 1 diabetes in China—Study design and implementation

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ABSTRACT

Aim: To describe coverage, cost and care of type 1 diabetes (T1D) in 2 regions of China – Beijing and Shantou – including:

Estimating the numbers of people with T1D diabetes.
Estimating the economic burden of T1D and financial barriers to care.
Identifying scale of necessary government investment to improve health care coverage.
Defining the burden of disease based on clinical outcomes.
Describing the education and care experience of people with T1D with comparison to selected clinical practice guidelines.
Describing the information processes associated with diabetes care and education.

Methods: This is a mixed-methods descriptive study with three arms – coverage, cost and care. It is taking place in 4 tertiary hospitals, 3 secondary hospitals and 4 primary health facilities in Beijing, and 2 tertiary hospitals, 2 secondary hospitals and 2 primary health centres in Shantou, China. Two additional hospitals are involved in the coverage arm of the study. T1D participants are recruited from a 3-year list generated by each hospital and from those attending the outpatient clinic or admitted to the inpatient ward. Participants also include health care professionals and government officials. To determine coverage of care, a list of people with T1D is being developed including information on diagnosis, age, sex and vital status. The age and sex distribution will be compared with the expected distribution.

To estimate the economic burden of T1D three groups of costs will be calculated – direct medical costs, direct non-medical costs and indirect costs from different perspectives of analysis (patients and their families, health system, insurer and societal perspective). The data are being collected from people with T1D (patient–parents face-to-face interviews), hospital billing departments, medical records and government officials using a combined ''top-down, bottom-up'' approach developed to validate the data. Quality of life is assessed using the EQ-5D tool and burden of disease is measured based on clinical outcomes and complications. Standard care will be defined, costed and compared to the cost of current care identified within the study to determine the investment required to improve outcomes.

The third arm includes three components – health policy, clinical care and education, and information management. Face-to-face, semi-structured interviews are conducted with people with T1D (for those <15 years of age parents are interviewed), health care

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professionals, senior hospital management and government officials. The core Summary of Diabetes Self-Care Activities Measure plus an additional 6 questions from the revised SDSCA scale are used to assess patient self-care. A medical records audit tool is used to assess care [7]. Clinical outcomes and self-care activities will be analysed for associations with care and education. Information management and care processes will be described using the Standard for Integration Definition for Function Modelling (IDEF0) [8].

Progress to date: At the time of writing (early October) the 3-year case list includes 1269 people with type 1 diabetes from Beijing and 481 people for Shantou, a total of 1750. In addition, two hundred and twenty people with T1D or their parents participated in face-to-face interviews in Beijing and 183 in Shantou, a total of 403.

Practical preliminary conclusions: Key implementation considerations were identified early in the project. Project success is dependent on strong local partnerships with local opinion leaders and key officials. It is important that a physician is the first point of contact to build the case list and recruit participants. July, August and January are peak months for recruiting school-age children in the Children's Hospital as this is school vacation period when they are more likely to attend clinics.

1. Background

As the economy in China strengthens, the government and opinion leaders are increasing their focus on healthcare and creating opportunities for change. Data drives policy decisions and investment, however very little data exists on type 1 diabetes (T1D) in China. The incidence of T1D in children age 0–14 years is estimated at 0.5 per 100,000 [1]. Evidence suggests that approximately 41% are diagnosed after admission for symptoms of diabetic ketoacidosis [2], and access to insulin and specialized care varies based on medical insurance possession, income and place of residence. The direct and indirect costs of current care for people with T1D and the investment required to improve care is not known.

This article describes a collaboration between the International Diabetes Federation and the Chinese Diabetes Society designed to improve clinical outcomes for people with T1D.

2. Aim

To describe coverage, cost and care of T1D in 2 regions of China – Beijing and Shantou.

3. Study Design

The study will invite all patients with T1D to participate in the study up to a maximum of 1000 participants. Patients will be invited sequentially; there will be no random selection. The recruitment of study participants with T1D will be open to all who attend the selected facilities and no maximum limit will be set.

Although it is recognized that children spend a significant amount of time in school, this study will not examine how diabetes is managed in the school setting.

3.1. Coverage

Objective

To estimate the numbers of people with T1D.

Methods

Coverage of care for people with T1D and the consequences of gaps in coverage will be examined by comparing their age and sex distribution with those who do not have T1D. This will be done by establishing basic demographic details of people with T1D attending major health facilities in Beijing and Shantou and patients registered over the previous 3 years.

Existing medical records, either electronic or manual, have been used to create a simple spreadsheet at each facility with basic identifiers for each person. A questionnaire collects additional information on national ID, insurance ID, date of birth, year of diagnosis with T1D, county of birth, and current county of residence, and year of migration, if appropriate, to the study region. The date of birth, year of diagnosis and county of birth are used to create a unique ID which will be used to identify people who attend more than one health facility within the study.

Patients with T1D attending the health facilities during the study period are recorded in the register and invited to participate in the other parts of the study.

A large proportion of those who are registered with the tertiary health facilities and who are likely to attend the clinic at some time in the year were expected to do so in the months of July and August. Now that this period is over, efforts are being made to contact all T1D recorded in the hospital systems within the previous three years, using contact information in the medical records. Up to three attempts are made to determine the status of each person with T1D. Status is recorded as: alive (and current county of residence), deceased, unknown.

The list of patients with their current vital status will be used to create a population structure of people with T1D. Population modelling will be used to examine the total effect of differential mortality patterns and to see if there is a critical age at which mortality increases.

3.2. Cost

Objective

To determine the economic burden of T1D in China and the burden of disease based on clinical outcomes including: