

Diabetes Self-Care Activities and Health-Related Quality-of-Life of individuals with Type I Diabetes Mellitus in Shantou, China

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Abstract

Objective: To assess diabetes self-care behaviours and health-related quality-of-life (HRQoL) in people with type I diabetes mellitus (T1DM), in China.

Methods: Individuals with T1DM underwent face-to-face interviews over a 7-day questionnaire period. The Summary of Diabetes Self-Care Activities (SDSCA) was used to assess self-care behaviours. EQ-5D-3L was used to quantify HRQoL.

Results: Of self-care activities, individuals ($n = 322$) were most likely to adhere to treatment and least likely to perform foot care. A total of 78.9% of participants did not examine their feet and 33.9% of participants did not monitor blood glucose during the questionnaire period. Moderate/severe anxiety or depression was reported by 28.6% of participants; 23.9% reported moderate/severe pain or discomfort. The individual's level of diabetes education, insulin injection regimen and HbA1c were independently associated with total SDSCA score. Household income and age were independently associated with EQ-5D index.

Conclusions: Enhancing diabetes education in individuals and implementing strict insulin regimens could improve self-care behaviours in people with T1DM in China.

Keywords

Diabetes self-care activities, health-related quality-of-life, type I diabetes mellitus, summary of diabetes self-care activities, 3C study

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Introduction

Type 1 diabetes mellitus (T1DM) is a major chronic disease in children and adolescents, the prevalence of which is increasing globally, particularly in Asia.¹ A 2011 study by

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the International Diabetes Federation (IDF) to investigate the coverage, cost and care of T1DM in China (3C study), found an incidence of 1.1–1.5 cases per 100 000 children per year.^{2,3} In addition, the mean glycosylated haemoglobin (HbA1c) level in people with T1DM in Shantou, China, was found to be ~10%,⁴ which is higher than the recommended levels of <7.5% in children/adolescents and <7% in adults,^{5,6} possibly due to a lack of day-to-day diabetes management. Self-care is important to maintain optimal glycaemic control and prevent complications,⁷ including both microvascular (e.g. retinopathy and neuropathy) and macrovascular complications (e.g. myocardial infarction, angina pectoris and stroke), which can negatively affect health-related quality-of-life (HRQoL)^{8,9} and have fatal consequences.¹⁰ Self-care requires frequent monitoring of blood glucose levels (at least three times per day), monitoring and controlling carbohydrate intake, frequent insulin administration (four injections per day or infusion via pump), altering insulin dose to match diet and activity patterns, participating in moderate-intensity physical activity for ≥ 150 min per week, and checking urine for ketones when necessary.⁷

Living with T1DM affects the psychological and emotional wellbeing of affected individuals and their families. HRQoL assesses the individual's perception of health and is a useful measure of overall disease burden. It is a multidimensional concept, comprising physical, emotional and social components.⁸ The most important outcome measure in T1DM may not be glycaemic control, but perceived HRQoL.¹¹ People with T1DM may have varying HRQoL burdens at different life stages, such as loss of flexibility or overprotection in childhood, future worries and school work in adolescence, and work, marriage and reproduction issues in adulthood. In addition, diabetes self-care behaviours is closely associated with metabolic control,¹²

but it is unclear which behaviours have the most influence over glycaemic control. Understanding the factors influencing self-care behaviours and HRQoL will help healthcare providers design interventions to improve the wellbeing of people with T1DM.^{13,14}

The aim of the present study was to assess self-care behaviours and HRQoL of individuals with T1DM who participated in the 3C study at the Shantou Centre.^{2,3} It was hypothesized that these people were weak in some aspects of self-care, that diabetes had a negative effect on HRQoL, that self-care behaviours and HRQoL varied between people at different life stages, and that some controllable influencing factors could be identified that could guide clinical management.

Participants and methods

Study population

The study was designed by the IDF² and included primary (four in Beijing, two in Shantou), secondary (three in Beijing, two in Shantou), and tertiary (six in Beijing, two in Shantou) health care facilities with active diabetes outpatient clinics and the willingness and capacity to participate in the study. Study subjects were recruited sequentially from outpatient clinics and inpatient wards, or by invitation from a list of people diagnosed with T1DM in a 3-year retrospective record review. Participants or their parent(s) (if <15 years of age) underwent face-to-face, personal, interviews. People aged <6 months at T1DM diagnosis were excluded.

This analysis included people from health care facilities in Shantou. Trained investigators performed interviews during July/September 2011 and January/February 2012; the questionnaire period covered 7 days. Venous blood samples were taken and tested for HbA1c at local hospital laboratories using pressurized liquid

chromatography. Detailed project design and implementation information was as described.²

The study was approved by the Human Ethics Committee of Shantou University Medical College, Shantou, China. All participants provided written informed consent.

SDSCA

Diabetes self-care activities were assessed using the Chinese version of the Summary of Diabetes Self-Care Activities (SDSCA) questionnaire, which has been showed to have high reliability and validity.¹⁵ Scores were calculated for six items: following a healthy diet; physical activity; adherence to recommended medications; self-monitoring of blood glucose; foot care; smoking. Using a continuous scale ranging between 0 and 7, the numerical scoring of items was based on the number of days of the week that the behaviour was performed; the mean of each item score was determined to find an overall score for each self-care activity. Since smoking is uncommon in children and adolescents in China¹⁶ this parameter was not included in the present study.

EQ-5D

Health-related quality-of-life was assessed using EQ-5D-3L, a standardized scale used in a wide range of health conditions and treatments as well as in the general population.¹⁷ Respondents classify their health status at three levels of severity (no, moderate, or severe problems) in five dimensions (mobility; self-care; usual activities; pain/discomfort; anxiety/depression), resulting in scores that can be converted into a single index value for health status (1 = full health; 0 = dead). The index value was assigned using a Japanese time trade-off value set,¹⁸ since no Chinese value set is available. Participants also completed the EQ-VAS, which records self-rated health on a visual

analogue scale ranging between 100 (best imaginable health state) and 0 (worst imaginable health state).

Statistical analyses

The sample size of the 3C study was calculated by the IDF, who determined that a minimum of 320 participants were required at each study centre (Beijing and Shantou).²

Data were presented as median (25th, 75th quartile), mean \pm SD or *n* (%). Differences and associations between variables were analysed by one-way analysis of variance (ANOVA), multiple ANOVA, χ^2 -test or Spearman's product-moment correlation. Reliability was assessed using Cronbach's α -coefficient, and the coefficients of the SDSCA and EQ-5D questionnaires were 0.72 and 0.77, respectively. Multiple linear regression analysis was used to identify factors associated with total SDSCA score and EQ-5D index. Independent variables included age, sex, diabetes duration, household income, residence, presence/absence of medical insurance, number of daily insulin injections, HbA1c level, presence/absence of group diabetes education, and presence/absence of individual diabetes education. The significant variables were included in a forward stepwise approach. Statistical analyses were performed using SPSS[®] version 19.0 (SPSS Inc., Chicago, IL, USA) for Windows[®]. *P*-values < 0.05 were considered statistically significant.

Results

The study included 322 participants (158 male/164 female; median age 23 [16, 33] years; age range 3–65 years). Demographic and clinical characteristics of the study population are shown in Table 1.

Data regarding SDSCA and EQ-5D scores are shown in Table 2. Of the self-care activities, participants were most likely to adhere to treatment and least likely to

Table 1. Demographic and clinical characteristics of people with type 1 diabetes mellitus in Shantou, China, included in a study evaluating self-care behaviours and health-related quality-of-life ($n = 322$)

Characteristic	Value
Male	158 (49.1)
Age, years	23 (16, 33)
<13	53 (16.5)
13–20	80 (24.8)
>20	189 (58.7)
Disease duration, years	3 (1, 6)
<5	199 (61.8)
5–9	77 (23.9)
≥ 10	46 (14.3)
Household income, US\$/year	
<3000	289 (89.8)
3000–10000	29 (9.0)
>10000	4 (1.2)
Medical insurance	289 (89.8)
Only child	105 (32.6)
Residence	
Urban	109 (33.9)
Rural	213 (66.1)
Insulin dose, IU/kg	0.72 ± 0.29
HbA1c, %	9.97 ± 2.72
BMI, kg/m^2	18.36 ± 4.73
Diabetes education	
Individual	22 (6.8)
Group	86 (26.7)
None	214 (66.5)
Number of daily insulin injections	
1–3	286 (88.8)
4/pump infusion	36 (11.2)

Data presented as n (%), median (25%, 75% quartile) or mean \pm SD.

perform foot care. During the 7 days included in the questionnaire period, 254/322 participants (78.9%) did not examine their feet and 109/322 participants (33.9%) did not monitor blood glucose. Moderate/severe anxiety or depression was reported by 92/322 participants (28.6%) and 77/322 (23.9%) reported moderate/severe pain or discomfort.

There were no significant between-group differences in self-care behaviours when participants were stratified by age (children

aged <13 years [$n = 53$]; adolescents aged 13–20 years [$n = 80$]; adults aged >20 years [$n = 189$]; Figure 1). When participants were stratified according to HbA1c, adherence to self-monitoring of blood glucose was significantly higher in participants with $\text{HbA1c} \leq 7.5\%$ ($n = 61$) than in those with $\text{HbA1c} > 7.5\%$ ($n = 261$; $P < 0.05$; Figure 2). There were no statistically significant between-group differences in any other SDSCA parameter.

Self-care data for participants stratified according to insulin treatment regimen are shown in Figure 3. Adherence to self-monitoring of blood glucose was significantly higher in participants receiving ≥ 3 daily injections/pump infusion ($n = 209$), compared with those receiving <3 daily injections ($n = 113$; $P < 0.05$). There were no other statistically significant between-group differences.

Data regarding EQ-5D in people stratified by age are shown in Figure 4. EQ index was significantly lower in adults than in both children and adolescents ($P < 0.05$ for each comparison). Children and adolescents had significantly better HRQoL related to pain and discomfort than adults ($P < 0.01$ and $P < 0.05$, respectively), and children had significantly better HRQoL related to anxiety/depression compared with both adolescents and adults ($P < 0.05$ for each comparison).

Multiple regression analysis found that individual diabetes education ($P = 0.012$), insulin injection regimen ($P = 0.001$) and HbA1c ($P = 0.034$) were independently associated with total SDSCA score. Household income ($P = 0.040$) and age ($P = 0.005$) were independently associated with EQ-5D index.

Discussion

The present study of diabetes self-care behaviours and HRQoL found that both foot care and self-monitoring of blood glucose were poor in people with T1DM in China. In addition, T1DM had an adverse

Table 2. Summary of Diabetes Self-Care Activities (SDSCA) and health-related quality-of-life (EQ-5D scale) data in people with type I diabetes mellitus in Shantou, China (*n* = 322)

Data sett	Value
SDSCA ¹⁵	
Healthy diet	4.25 ± 1.7
Physical activity	3.14 ± 2.4
SMBG	2.45 ± 2.6
Foot care	0.78 ± 1.7
Adherence to treatment	4.69 ± 2.1
Total	39.12 ± 13.3
EQ-5D ¹⁷	
Mobility difficulties, none/moderate/severe	289/27/6 (89.8/8.4/1.9)
Self-care difficulties, none/moderate/severe	305/14/3 (94.7/4.3/0.9)
Usual activity difficulties, none/moderate/severe	293/26/3 (91.0/8.1/0.9)
Pain/discomfort, none/moderate/severe	245/74/3 (76.1/23.0/0.6)
Anxiety/depression, none/moderate/severe	230/90/2 (71.4/28.0/0.6)
EQ-VAS	75.02 ± 18.5
EQ-5D index	0.79 ± 0.1

Data presented as mean ± SD or *n* (%).
 VAS, visual analogue scale.

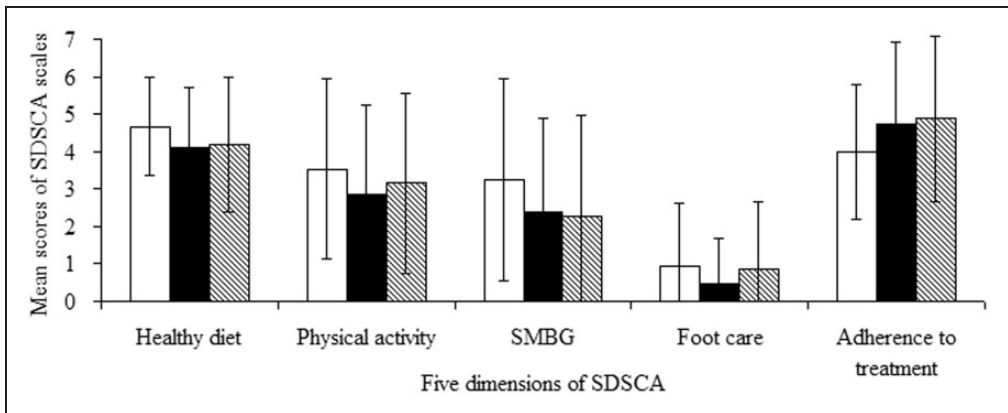


Figure 1. Summary of Diabetes Self-Care Activities (SDSCA)¹⁵ data in people with type I diabetes mellitus in Shantou, China, stratified according to age (children aged <13 years [*n* = 53; white bars]; adolescents aged 13–20 years [*n* = 80; black bars]; adults aged >20 years [*n* = 189; striped bars]). SMBG, self-monitoring of blood glucose.

impact on HRQoL, and the HRQoL of adults was significantly worse than that of children and adolescents.

It is known that people with T1DM who have suboptimal glycaemic control pay

insufficient attention to diabetes self-care practices.^{19,20} A majority of participants in the present study (78.9%) reported having not examined their feet in the previous 7 days, despite this being the simplest to

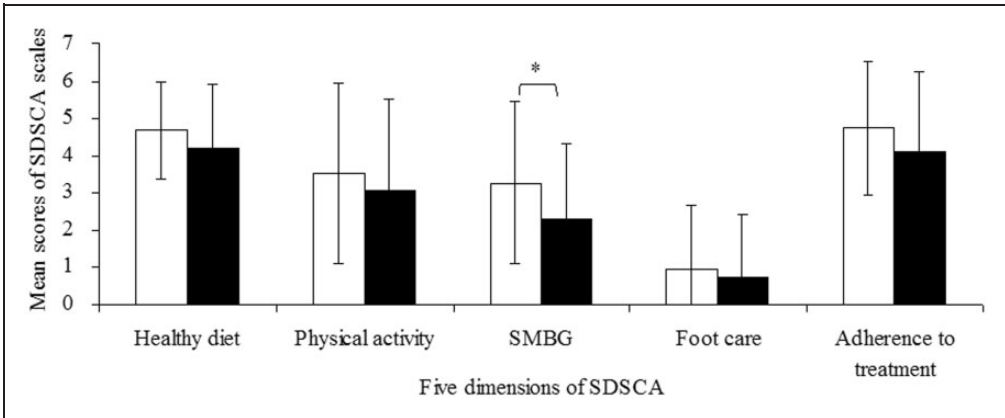


Figure 2. Summary of Diabetes Self-Care Activities (SDSCA)¹⁵ data in people with type I diabetes mellitus in Shantou, China, stratified according to glycosylated haemoglobin (HbA1c ≤ 7.5% [n = 61; white bars]; HbA1c > 7.5% [n = 261; black bars]). *P < 0.05; one way analysis of variance. SMBG, self-monitoring of blood glucose.

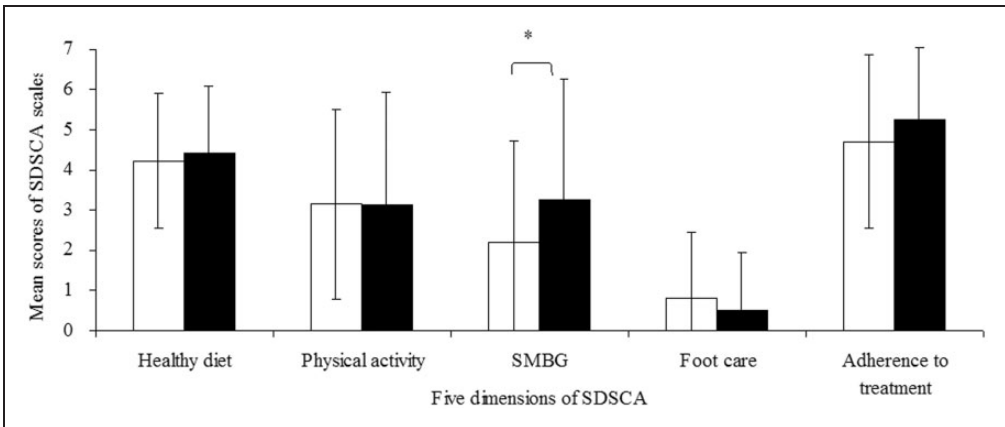


Figure 3. Summary of Diabetes Self-Care Activities (SDSCA)¹⁵ data in people with type I diabetes mellitus in Shantou, China, stratified according to insulin injection regimen (<3 daily injections [n = 209; white bars]; ≥3 daily injections/pump infusion [n = 113; black bars]). *P < 0.05; one way analysis of variance. SMBG, self-monitoring of blood glucose.

perform of the self-care activities. It is possible that participants may not have been aware of the need for foot care, due to the low rate of diabetes education in the study group (66.5% had received no diabetes education). In addition, cost is a substantial barrier to the use of blood glucose self-monitoring equipment in

China.³ Few people with diabetes are able to afford such equipment, and their blood glucose levels must be monitored in hospital.

Diabetes had a significant impact on HRQoL. The proportion of participants in the present study who reported moderate or severe problems was significantly higher than in the general population of China.²¹

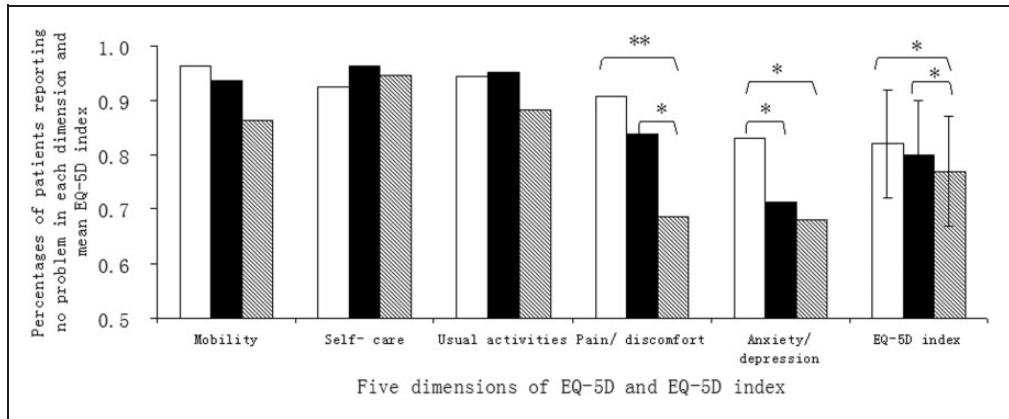


Figure 4. Percentage of people with type I diabetes mellitus in Shantou, China, reporting no problem in categories of the EQ-5D¹⁷ health-related quality-of-life scale. People stratified according to age (children aged <13 years [$n = 53$; white bars]; adolescents aged 13–20 years [$n = 80$; black bars]; adults aged >20 years [$n = 189$; striped bars]). * $P < 0.05$, ** $P < 0.01$; one way analysis of variance.

This result was consistent with most studies,^{8,9,14,22,23} but not all.²⁴ Participants in the present study commonly reported problems with pain/discomfort, in accordance with the findings of others.^{25–27}

Older people with T1DM have been shown to have poorer self-care behaviours than children with the condition, especially after leaving home and becoming focused on study or work.^{28–30} There were no significant differences between age groups in self-care behaviours in the present study, however, this is probably due to the small numbers of children and adolescents in this cohort.

Our finding that adults had significantly lower EQ-5D index than children and adolescents was consistent with other studies.³¹ This may be related to the presence of diabetic complications, since nephropathy has been shown to reduce HRQoL in people with T1DM.⁸ In addition, adults reported significantly worse anxiety/depression compared with younger people in the present study. Adults are generally independent in this society and experience burdens in factors including work, marriage, pregnancy or childrearing. Adolescents and adults with T1DM have been shown to have a higher

rate of depression and lower self-esteem than children with the condition.^{6,32}

Education is important in the self-care of people with T1DM.⁶ It is of interest that individual diabetes education had a substantial effect on total SDSCA score in the present study, but group education did not. It is possible that group education may generate resistance and could ignore what is most important to people with T1DM. In contrast, individualized diabetes education emphasizes the importance of increasing patient autonomy and independency, which help people with T1DM to discover and develop their inherent capacity to be responsible for themselves.³³ Family behavioural interventions are known to be more effective than conventional education programmes in influencing self-care behaviours in adolescents with T1DM.³⁴

The type of insulin injection regimen also had a major impact on self-care behaviours in the present study. People with an insulin pump or basal-bolus insulin regimen with four injections per day must self monitor glucose levels frequently and receive more diabetes education compared with other people with T1DM. Studies have indicated

that both individual and group lifestyle interventions have positive effects on diet and self-care behaviours in people with diabetes, with group settings being most effective.³⁵ Integrating education and other therapies, such as intensified insulin regimens, is an approach that is likely to achieve the most effective diabetes control.³⁶

Self-care activity score was independently related to HbA1c level in the present study. Guidelines emphasize that effective self-care is an essential component of metabolic control.⁶ All self-care behaviours were equally important, but self-monitoring of blood glucose was most effective at influencing the individual's HbA1c level in our study. Frequent and accurate blood glucose monitoring, and concomitant optimal adjustment of insulin to carbohydrate intake and exercise, are required to attain (and maintain) ideal glycaemic control.^{37,38} The frequency of self-monitoring is associated with improved HbA1c,^{39,40} but it was one of the least frequently performed self-care behaviours in the present study.

Income and age were independent predictors of HRQoL in the present study. Poor HRQoL causes suffering, can seriously interfere with daily diabetes self-management, and is associated with poor medical outcomes and high costs.⁴¹ Improvement in quality of care (determined by care practices that improve outcomes) will decrease the overall lifetime cost of diabetes and normalize life expectancy, by decreasing acute and chronic complications. More importantly, improving outcomes will improve HRQoL for both people with T1DM and their families. In people with T1DM in the USA, HRQoL was associated with a primary insurance source of Medicaid or another government-funded insurance scheme.⁴² We suggest that the Chinese government increases medical investment, subsidizes health insurance and reduces medical care costs as soon as possible, in order to improve HRQoL in people with T1DM.

This study is limited by the fact that participants were recruited using convenience sampling from six hospitals in Shantou, possibly affecting the generalizability of results. Further studies should include larger, more diverse populations.

In conclusion, the majority of people with T1DM in this region of China exhibit poor self-care behaviours and HRQoL. Self-care behaviours could be improved by enhancing individual diabetes education and implementing strict insulin regimens. Increasing the frequency of self-monitoring of blood glucose may improve metabolic control.

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Declaration of conflicting interest

The authors declare there are no conflicts of interest.

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