ORIGINAL ARTICLE

Reliability and validity of the Malay translated version of diabetes quality of life for youth questionnaire

Jalaludin MY, Fuziah MZ, Hadhrami MH, Janet YH Hong, Jamaiyah H, Mohamad Adam B

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Authors:

Mohamad Adam Bin Bujang, Bsc(Hons) Statistics, MBA
(Corresponding author)
Biostatistics Unit
Clinical Research Centre
MMA House
124 Jalan Pahang
53000 Kuala Lumpur
Malaysia
Tel: +60193454379
Email: adam@crc.gov.my

Muhammad Yazid Jalaludin, MBBS, MPaeds
Paediatric Department,
Universiti Malaya Medical Center,
Kuala Lumpur,
Malaysia

Fuziah Md Zain, MBBCh, Specialist in Pediatric (Belgium)
Paediatric Department,
Putrajaya Hospital,
Putrajaya,
Malaysia

Hadhrami MH,
Faculty of Medicine,
Universiti Kuala Lumpur,
Royal College of Medicine,
Perak,
Malaysia

Janet Hong Yeow Hua, MD, MRCP(UK)
Paediatric Department,
Putrajaya Hospital,
Putrajaya,
Malaysia

Jamaiyah Haniff , MD, MSc(Clin Epid)
Clinical Research Centre,
Kuala Lumpur Hospital,
Kuala Lumpur,
Malaysia

Abstract

Introduction: Many studies reported poorer quality of life (QoL) in youth with diabetes compared to healthy peers. One of the tools used is the Diabetes Quality of Life for Youth (DQoLY) questionnaire in English. A validated instrument in Malay is needed to assess the perception of QoL among youth with diabetes in Malaysia.
Objective: To translate the modified version, i.e., the DQoLY questionnaire,into Malay and determine its reliability and validity.
Methods: Translation and back-translation were used. An expert panel reviewed the translated version for conceptual and content equivalence. The final version was then administered to youths with type 1 diabetes mellitus from the universities and Ministry of Health hospitals between August 2006 and September 2007. Reliability was analysed using Cronbach's alpha, while validity was confirmed using concurrent validity (HbA1c and self-rated health score).
Results: A total of 82 youths with type 1 diabetes (38 males) aged 10-18 years were enrolled from eight hospitals. The reliability of overall questionnaire was 0.917, and the reliabilities of the three domains ranged from 0.832 to 0.867. HbA1c was positively correlated with worry (p=0.03). The self-rated health score was found to have significant negative correlation with the "satisfaction" (p=0.013) and "impact" (p=0.007) domains.
Conclusion: The Malay translated version of DQoLY questionnaire was reliable and valid to be used among youths with type 2 diabetes in Malaysia.

Introduction

Diabetes mellitus is a chronic disease without a cure. In patients with type 1 diabetes mellitus (DM), there is lack of endogenous insulin production. Hence, these patients need to be given insulin through injections 2-4 times per day. They need to perform regular blood glucose monitoring and follow a strict diet to maintain good glycaemic control and avoid long-term complications. These lifestyle modifications may affect the quality of life (QoL) of patients. Therefore, the QoL questionnaire is an important tool to measure patients' perception of their health status and one of the tools used is the Diabetes Quality of Life (DQoL) questionnaire in English. As Malaysia is a multi-ethnic society with Bahasa Melayu (Malay) being the national language, it is important to have a validated tool in Malaysian language to measure the QoL of youth with type 1 DM.

It is ideal to develop a culture-sensitive QoL instrument. However, resources and time involved often make this difficult. Researchers often use the practical option of choosing a tool developed in another language and translating it into the target language. However, the translation process is challenging as concepts developed for use in one culture and language often contain semantic, idiomatic, and cultural differences. A simple word-for-word translation of the DQoL for Youth questionnaire (DQoLY) from English to Malay may produce a questionnaire that has no real meaning to Malay speakers.

The DQOL was developed in the early 1980s for use in the Diabetes Control and Complication Trial (DCCT) which intended to evaluate the satisfaction, impact, and worries associated with the treatment of DM. This questionnaire contains 60-items and can be use for both type 1 and type 2 DM.- The DQoL consists of four inter-correlated subscales: (1) satisfaction to treatment, (2) impact of treatment, (3) worry about the future effects of diabetes, and (4) worry about social/vocational issues (worry can also be combined into a single subscale) and one last item on general well-being (Table 1). This single item was derived from national surveys of quality of well-being and can be used to compare subjects with a wide variety of patients. Hence, the DQoL have both diabetes-specific and generic QoL items. Ingersoll et al. modified the scales to develop an instrument that is suitable for youths. Table 1 describes the modification process.

Items in the DQoL are scored using a 5-point Likert scale. There are two formats: one on frequency of negative impact of diabetes or its treatment (i.e., with 1 being never and 5 being all the time); the second is about satisfaction (i.e., with the response of 1 being very satisfied and 5 being very dissatisfied). Regardless of formats, higher scores indicate poorer QoL.

DQoL has excellent internal consistency (r = 0.8–0.9), high test-retest reliability for both adolescents and adults with r ranged between 0.8 and 0.9. It was also found to have good convergent validity for all four subscales in both type 1 and type 2 DM. The level of correlations was between 0.3 and 0.7, indicating that the DQoL is related but not identical to psychological well-being, affective balance, and adjustment to illness.[3]

The purpose of this study was to translate the original DQoL into Malay and to ensure that the translation was as meaningful and understandable as possible for the Malay-speaking youths. It also aimed to determine the reliability and validity of this tool.

Methodology

The study process

This study was performed in three phases: Phase 1 was the translation from the original English questionnaire to the Malay version; Phase 2 involved pre-testing of the pre-final Malay version; and Phase 3 was the validation study.

Phase 1 (Translation process of DQoLY)

Permission to use and translate the DQoLY for this study was obtained from the author who also gave permission to the modification of the DQoL to suit the local culture as well as the target age that we intend to apply in our population. The translation process was carried out according to the EuroQoL translation guidelines.[6] The aim was to evaluate clarity, understandability, naturalness, and adequacy of wording while preserving the content and the meaning.

Two forward translations, one by a clinician who had direct involvement in diabetes care in youth and therefore not blinded to the study aim, whereas the second translator was a certified traslator from the Malaysian National Institute of Translation (Institut Terjemahan Negara Malaysia) who was blinded to the study aim. Each produced the M1 and M2

versions, which were later back translated into English independently by another certified translator and another clinician.

An expert panel, comprising researchers and translators, then reviewed all the different versions to produce the pre-final DQoLY Malay version. This was done by comparing E1 and E2 with the original English version. The Malay version that produced a back-translation that was closest to the original English version was chosen. Thus, the reconciled version of M1 and M2 became the pre-final Malay version.

Phase 2 (Pre-test)

The main objective of the pre-test was to get response from children whether they could understand the questions and it formed part of face validity. A pre-test for the DQoLY was conducted between May and October 2006 at three sites: paediatrics clinics in Seremban Hospital and Universiti Kebangsaan Malaysia Hospital,, and physician clinic in Kuala Lumpur Hospital. Pre-test was conducted with 15 adolescents aged 10-18 years who had DM. The subjects underwent a fluency test by reading and translating a short Malay passage from the local newspaper into English. It was assumed that they were bilingual if they passed the test.

During the pre-test, each subject was given five forms: the patient information sheet, assent and consent forms, demographic form, and two versions of the DQoLY. Malay and English versions were given at random sequence to the subjects in a classroom examination style environment. This session was followed by a group random probe discussion on each item of the questionnaires. They were asked four questions: (1) explain what they understood from the question, (2) state whether the question made 'sense', (3) state whether they thought the Malay question was worded correctly, and (4) provide any alternative word that would explain the question better. This was to ensure word suitability and comprehension.

Overall, the patients agreed that the Malay version of the DQoLY was clear, straightforward, and easy to understand. Random probe revealed that for the 'satisfaction' domain i.e. item 11 ('appearance' vs 'rupa bentuk') and 13 ('leisure time' vs 'masa lapang'), the participants felt that the translation was different from the original meaning. The expert panel decided to maintain the original translation which was felt to be correct and the two forward translations were in agreement. Hence, no changes were made.

For the 'impact' domain, in item 7, the participants, preferred the term "kawan" to "sahabat" (both are synonymous with the meaning 'friend'). However, as the actual word in the context of the whole sentence was a noun ('friendship'), 'persahabatan' was used because 'perkawanan' does not exist in Malay. For the 'worries' domain, all items were easily understood and maintained.

Phase 3 (Validation)

This multicentre, cross-sectional study involved eight centres conveniently chosen from Ministry of Health (MOH) and university hospitals in peninsular Malaysia. DQoLY were administered to 82 paediatric patients with type 1 DM.

The final Malay version of the DQoLY was later tested for its reliability and validity. This phase of the study was conducted in nine paediatric clinics around the country, namely, the Pediatrics Institute of the Kuala Lumpur Hospital and various paediatric and medical clinics of the Universiti Malaya Medical Centre, Putrajaya Hospital, Raja Permaisuri Bainun Hospital, Ipoh, Sultanah Nur Zahirah Hospital, Kuala Terengganu, Melaka Hospital, Sultanah Aminah Hospital, Johor Bharu, Sultanah Bahiyah Hospital, Alor Setar and Universiti Sains Malaysia Hospital, Kota Bharu.

Participants and their parents were given patient information sheets prior to the

answering the questionnaire. Both participants and their parent(s) gave their assent and written consent. The questionnaire took up to 20-30 minutes to complete.

Study design

This was a multicentre, cross-sectional study. The study population consisted of children and adolescents with diabetes who were seen in the Ministry of Health and the university hospitals' clinics. Consecutive cases newly referred to the paediatric and medical clinics in the nine study sites were recruited based on the inclusion and exclusion criteria. The inclusion criteria included children and adolescents: (1) aged 10 to 19 years, (2) who can read and write Malay, and (3) who were diagnosed with DM, irrespective of the duration and type of treatment received. There was only one exclusion criterion, that is, patients with cognitive impairment (such as mental retardation) and severe psychosis.

Study instruments

The subjects were given two questionnaires: (1) demographic questionnaire (age, gender, ethnicity, education, etc.), which was designed by the researchers and (2) the final Malay version of the DQoLY. The attending doctor also documented the type of diabetes and latest HbA1c level during the study visit.

Ethical consideration

Ethics approval was granted for all the sites: the Malaysian Research & Ethics Committee, Ministry of Health; Medical Ethics Committee, University of Malaya Medical Centre; and the Ethics Board of the University of Science Malaysia.

Analysis and statistical methods

Face and content validity were performed to validate the translation of the instrument. Face validity was checked based on respondent review, while content validity was checked by expert review. Cronbach's alpha statistics was produced to check the internal consistency of all items and items under each domain (Table 3). Spearman rank test was to evaluate the correlation between general individual item with total DQoLY and HbA1c towards the three domains (Table 4). Independent sample t-test was used to determine whether DQoLY domains ('satisfaction', 'impact' and 'worry') could detect significant difference between individual self-rated scores (in two categories). This to support the discriminative validity where the DQoLY domains scores would discriminate between poor and good QoL of an individual. (Table 5). Statistical analysis was performed using SPSS version 19.0. (IBM Corp. Released 2010. IBM SPSS Statistics for Windows, Version 19.0. Armonk, NY: IBM Corp.)

Result

There were 82 patients who were eligible and participated in the study. Cognitive impairment was the main reason for exclusion. The mean (SD) age was 14.0 (2.7) years and the mean (SD) duration of DM was 6.9 (4.7) years (Table 2). Internal consistency was high for the three domains and ranged from 0.832 to 0.867 (Table 3). HbA1c was positively correlated with worry (p=0.03), that is, patients who were more worried about their disease had higher HbA1c. Self-rated health score (an item in the DQoLY where higher score indicates better health) was found to have significant negative correlation with "satisfaction" (p=0.013) and "impact" (p=0.007) (where higher score indicates poorer QoL) (Table 4). The scores of each DQoLY domain were higher and significant except for "worry" in those who rated themselves as having poor health (Table 5). The correlation coefficient of DQoLY domains was 0.476 (satisfaction and impact), 0.278 (satisfaction and worry), and 0.501 (worry and impact). All correlations were statistically significant with a p value <0.05.

Table 1: A comparison of the original and modified DQoL

Subscale/items	Original (DCCT, 1988)	Modified (Youth) Ingersoll (1991)	Modified (Youth) Yazid et al. (2013)
Satisfaction with treatment	18 items (15 core, 3 adolescents oriented)	Dropped one item, i.e., Item 10 (sexual life) Remainder 17 items	Remain as Ingersoll
Impact of treatment	27 items (20 core, 7 adolescents oriented)	Dropped 4 items 1) item 3 (hypoglycemia) 2) item 10 (sexual) 3) item 16 (tell others of your diabetes) 4) item 25 (being teased by siblings) Remainder 23 items	Dropped 5 items Youth version: 11 items 1) item 4 (insurance) 2) item 6 (going to work) and 3) item 7 (going for vacation) Malay version: drop 2 more 4) Item 1 (get married) 5) Item 2 (have children) Remainder 9
Worry about the future effects of diabetes and worry about social/ vocational issues	14 items (11 core, 3 adolescents oriented)	Dropped 3 items Youth version: 11 items 1) item 4 (insurance) 2) item 6 (going to work) and 3) item 7 (going for vacation) Remainder 11 items	Dropped 5 items Youth version: 11 items 1) item 4 (insurance) 2) item 6 (going to work) and 3) item 7 (going for vacation) Malay version: drop 2 more 4) Item 1 (get married) 5) Item 2 (have children) Remainder 9
General self rating of overall health	1 item	1 item.	Remain as Ingersoll
Total	60 items (including general self-rating item)	52 items (including general self-rating item)	50 items (including general self-rating item)

Table 2: Profile characteristics of patients

	n (%)
Age (years)	14.0 (2.7)*
Duration of diabetes (years)	6.9 (4.7)*
Gender	
Male	52 (46.0)
Female	61 (54.0)
Ethnicity	
Malay	60 (53.1)
Chinese	30 (26.5)
Indian	19 (6.8)
Others	4 (3.5)

**Reported in mean (SD).*

Table 3: Internal consistency measured by Cronbach's alpha of DQoLY (Malay version) domains

	Cronbach's alpha
Satisfaction	0.867
Impact	0.833
Worry	0.832
All	0.917

Table 4: Correlation between DQoLY (Malay version) domains and HbA1C and general individual item

	HbA1c r (P value)	Self-rated score r (P value)
Satisfaction	–0.07 (0.589)	–0.284 (0.013)
Impact	0.05 (0.725)	–0.307 (0.007)
Worry	0.28 (0.030)	–0.157 (0.177)

Test was done using the Spearman rank test.

Table 5: Discriminative validity of DQoLY (Malay version) items and domains with self-rated score

	Revised self-rated score Poor (n = 38) Mean (SD)	Good (n = 38) Mean (SD)	t statistics	df	P value
Satisfaction	41.4 (10.3)	36.2 (10.1)	2.222	74	0.029
Impact	53.8 (9.4)	47.4 (9.5)	2.942	74	0.004
Worry*	17.2 (5.8)	15.0 (5.2)	1.699	73	0.094

Poor = Fair and poor.
Good = Excellent and good.
**n for worry in poor category is 37due to missing.*

Discussion

Besides its original version in English, DQoL had been translated and used in other languages such as Taiwanese, Portuguese, and Turkish.[7-9], The translation was made and applied to adults. This validation study emphasizes on DQoL among youth with DM. DQoLY in Malay version was found to have high reliability and acceptable validity. The internal consistency of the DQoLY was high with the Cronbach's of more than 0.8 for the three domains and 0.917 for all items. The validity of the DQoLY was supported by the following analyses: (1) the correlation between the self-rated score (overall satisfaction towards life) and the three DQoLY domains; (2) the discriminative validity of the self-rated score (in two categories) towards the three domains; and (3) the correlation between HbA1c and the three DQoLY domains.

Based on the correlation of the self-rated score with the three domains, results showed that negative correlation exist where patients with higher self-rated scores (an item in the DQoLY where higher score indicates better health) had better satisfaction with life, and patients with diabetes which had better health had lower negative diabetes impact (where higher score in DQoLY domains indicates poorer QoL). Although we found that there was a negative correlation between the QoL and the 'worry' domain (–0.157), it did not reach statistical significance. This result was supported by discriminative validity shown in Table 5. The results showed that the status of health (poor and good) had discriminated the scores of satisfaction and impact but not for worry. These scores supported that the DQoLY domains differentiate poor and good quality of life of an individual. In addition, if based on HbA1c, we found that patients with higher HbA1c tend to get more worried; however, we failed to prove HbA1c has a correlation with satisfaction and impact.

In addition, strong correlations within the three domains indicate that the convergent validity is strong. This indicates that the three domains have strong correlation among each other and become as basis of convergent validity.

The failure of the DQOLY (Malay version) to correlate with HbA1c levels but correlate with self-perceived health status (life satisfaction) highlights the importance of clinical intervention and education of adolescents with diabetes. Practitioners have a tendency to equate good metabolic control with QoL. While the value of good metabolic control should not be underestimated, the findings from this study suggest that self-perceived QoL holds a very different meaning to adolescents with type 1 DM.

The elements of diabetes regimen that are most often associated with low adherence are those that have the most impact on the individual lifestyle.[10] Psychosocial QoL may constitute a different but important outcome compared to physical QoL, as reflected in good metabolic control. Issues related to the personal meaning of diabetes and its management are particularly salient when dealing with adolescents. Adolescence is a period of personal development, when the individual merge several disparate elements of a sense of self into a new identity. This new identity includes a restructured body image, new cognitive abilities, a revised value system, new peer and intimate relationships and establishment of a sense of adult independence.

When the development tasks of normal adolescent transition are coupled with the task demands for adherence to a diabetes regimen, adolescents may face tasks that are in conflict with one another. When the demands for adhering to diabetes regimens are in conflict with the more salient normal developmental demands of adolescence, the individual may decide not to comply with such a regimen.[11] Recently diagnosed adolescent patients are more likely to perceive their diabetes as having a negative impact on their life. Perhaps those who have had longer duration of diabetes have acquired effective coping strategies.[6]

We proposed few suggestions based on these results. First, DQoLY in Malay version can be used for Malaysian youth with diabetes. Second, self-rated score can be a faster approach to evaluate the satisfaction and impact of diabetes among youths. However, one of the weaknesses using self-reported questionnaire is that the evaluation can be subjective and it depends on the patients' interpretation of the questions. Finally, their worry with regards to diabetes can be an indicator that this group of adolescents might have higher HbA1c level. The limitation of this study is that the sample size was relatively small and not sufficient for authors to pursue with construct validity using exploratory factor analysis. Recent guideline for minimum sample size to conduct factor analysis is at least four sample/subject for one question/item.[12] In other words, DQoLY needs minimum 196 sample/subject. This is subject to the instrument must have strong reliability for each domain. If not, the general guideline is five to ten sample/subject for one question/item.[13]

Conclusion

DQoLY in Malay version has high reliability with acceptable validity. It can be used to measure the QoL among youths with DM in Malaysia.

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