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Background: The Patient Assessment of Care for Chronic Conditions (PACIC-5As) is a questionnaire developed in English and designed to evaluate the health care experiences of people living with chronic conditions such as diabetes.

Aims: This study aimed to translate, culturally adapt and validate the PACIC-5As instrument for the Arab context in a sample of Saudi Arabian people with diabetes.

Methods: The PACIC-5As was translated into Arabic using a forward and backward translation process. The Arabic version was then validated with a sample of 557 Saudi Arabians with diabetes who were recruited from tertiary level diabetes centres in Riyadh between January and March 2018. In order to evaluate the psychometric properties of the Arabic version, Cronbach alphas and item correlations were determined and exploratory factor analysis was performed.

Results: The translated PACIC-5As had good psychometric quality. Cronbach alpha was > 0.9 and the inter-item correlation ranged between 0.36 and 0.56. Exploratory factor analysis showed a single-factor structure.

Conclusion: An Arabic version of the PACIC-5As questionnaire is now available to assess the experience of patients with diabetes. The results of this study can be used to improve the quality of the delivery of health care in Arabic-speaking countries.

Keywords: diabetes, delivery of health care, surveys and questionnaires, translating, Saudi Arabia

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Introduction

Diabetes mellitus is one of the most prevalent chronic diseases. According to the International Diabetes Federation, the number of adults living with diabetes in 2017 was 451 million and this number is expected to reach 693 million by 2045 (1). Diabetes complications, which result from persistently high blood glucose levels that lead to micro- and macrovascular disease (e.g. retinopathy, and cardiovascular and renal diseases), have a devastating effect on those affected and their family members. In addition to the medical burden, the increasing prevalence of diabetes places a high economic burden on the individual, society and the health care system (2). Despite the large expenditure on managing and controlling diabetes worldwide, people living with the disease do not always receive optimal care (3). While some population-based

health system models have adopted a structured and proactive approach to help reduce the incidence and burden of chronic diseases such as diabetes, others are still oriented towards the biomedical model of health care that emphasizes mainly the biological factors and ignores the social and psychological health influences (4).

The management of diabetes requires a comprehensive system of health care that incorporates diagnosis and ongoing medical monitoring and treatment (5). In order to guide the provision of health care for patients with chronic disease, the Health MacColl Institute for Healthcare Innovation developed the chronic care model. This model formulates and organizes the changes required in the health care system and by the patients to improve outcomes (6). These changes are accomplished by the integration of key components of the chronic care model: (i) organization of health care; (ii) delivery system design; (iii) decision support; (iv) patient self-management; (v) community resources or linkages; and (vi) clinical information systems (7).

Complementary to the chronic care model, and to capture the perspective of service users, the Patient Assessment of Care for Chronic Conditions (PACIC) instrument was developed by the MacColl Center for Health Care Innovation. This tool is widely used to assess the “level of CCM-congruent activities that patients receive” (8). The original instrument consisted of five subscales that represent multiple features of providing patient-centred care consistent with the chronic care model. These subscales are: 1) Patient activation (enabling patient participation in their care), 2) Delivery system or practice design (promoting clinical care that is consistent with scientific evidence by sharing information with patient), 3) Goal setting or tailoring (establishing goals and plans with the patient to better manage their chronic condition), 4) Problem-solving (supporting the patient in managing health beyond their medical care) and 5) Follow-up or coordination (linking the patient with other health care services). Shortly after the dissemination of the results of the PACIC tool, six more subscales were added to the instrument. These scales followed the “5As” principle that evaluated a model of behaviour change endorsed by the United States Preventative Services Taskforce. These principles are: assess (assessing the patient’s level of behaviour, beliefs and motivation), advise (advising the patient based on personal health risks), agree (agreeing on a realistic set of goals with the patient), assist (assisting the patient to anticipate barriers and develop a specific action plan) and arrange (arranging follow-up support). The new instrument became known as PACIC-5As (8).

PACIC-5As has been translated into several languages, including (in order of date of translations) Spanish, Danish, French, Bengali and Malay (9–13). Given that seven Arab countries are among the top 20 countries with the highest prevalence of diabetes in the world, it would be useful to translate the PACIC-5As into Arabic (1). The aim of this study therefore was to translate and validate the PACIC-5As questionnaire with a sample of people living with diabetes. Saudi Arabia was a suitable country in which to validate the questionnaire because the number of people with diabetes is increasing there and is expected to continue to increase

in the future (14).

Methods

Instrument

The PACIC-5As has 26 items that can be scored on a 5-point Likert scale: 1 (almost never), 2 (generally not), 3 (sometimes), 4 (most of the time) and 5 (almost always). The first 20 items can be categorized into five subscales based on the key elements of the chronic care model: patient activation (items 1–3); delivery system (items 4–6); goal setting (items 7–11); problem-solving (items 12–15); and follow-up (items 16–20). By including the additional six items, PACIC-5As can also be grouped into the 5As summary score as well as its subscales: assess (items 1, 11, 15, 20, 21); advise (items 4, 6, 9, 19, 24); agree (items 2, 3, 7, 8, 25); assist (items 10, 12, 13, 14, 26); and arrange (items 16, 17, 18, 22, 23). In addition, overall scores can be calculated for the PACIC (items 1–20) and the items related to the 5As (items 1–4 and 6–26) (8).

Forward translation

We followed the World Health Organization's (WHO) recommendation on the translation of instruments written in English into different languages to translate the PACIC-5As items into Arabic using a forward and backward multistep procedure (15). First, an expert panel of Saudi health specialists independently translated the list of items into Arabic. Second, the items were reviewed and compared with the original English terms, and disagreements were discussed and resolved. This process took over a week and resulted in the first draft of the Arabic PACIC-5As. Third, an external team of health researcher reviewed the translated version to evaluate the vocabulary, especially the health terms which might be understood differently by respondents because of dialectical variations in the Arabic-speaking countries.

Content validity

In order to determine whether the language, structure and the content of the Arabic PACIC-5As were appropriate to assess the quality of diabetes care in Arabs countries, we calculated the content validity index. This index consists of two domains: the clarity domain and the representativeness domain. We assessed these two domains for each item (item content validity index) and for the scale as a whole (scale content validity index). The item content validity index represents the proportion of reviewers who rated an item as very or highly relevant, while the scale content validity index is the averages of the scores of all the reviewers. An item content validity index agreement percentage of 78% or more indicates acceptable content validity. We estimated the overall scale content validity index score by taking the average of the items scores (16).

Backward translation

After we had validated the Arabic version of the PACIC-As, an independent professional translator, fluent in both Arabic and English, back translated the instrument into English, and minor changes were made. This translator was unaware of the original English PACIC-5As instrument.

Validation with patients with diabetes

Between January and March 2018, we invited all Saudi Arabian adults with type 1 or type 2 diabetes mellitus attending four outpatient tertiary diabetes centres in Riyadh to participate in the study. These centres provide specialized care for people with diabetes from first diagnosis to management of the condition, as well as preventative education and treatment services. While in the waiting area, we asked each participant to complete the questionnaire, provide the necessary demographic data and return the instrument at the end of their appointment. Previous studies aimed for a sample size of five times the number of PACIC variables (minimum of 130 participants) (9–13); our convenience sampling method resulted in 557 participants.

Statistical analysis

We used SPSS, version 20.0 for data entry and analysis. Statistical procedures included descriptive analysis of the PACIC-5As items, the subscales and the overall scales as well as the demographic characteristics of the participants. The PACIC-5As scores were calculated as means and standard deviations (SD) according to the instrument's instruction (8). Frequencies and percentages were used for the participants' demographic characteristics. We assessed the association between the PACIC-5As scores and the participants' characteristics using Spearman rank correlation. We considered a P-value of ≤ 0.05 as statistically significant for all estimations.

To assess the internal consistency of the PACIC-5As, we calculated the Cronbach alpha for each of the subscales and the summary scores. An acceptable level of the Cronbach alpha is between 0.7 and 0.8. We calculated the inter-item correlation to evaluate the extent to which items on the scales assess the same content; an acceptable level of inter-item correlation is between 0.2 and 0.4 (17). Finally, we performed an exploratory factor analysis using principle component analysis with promax rotation on (eigenvalue 1) and we also made scree plots of the eigenvalues; only variability factors ≥ 0.40 were considered. We examined the sampling adequacy for the suitability of the data for factor analysis by calculating the Kaiser–Meyer–Olkin statistic (Kaiser–Meyer–Olkin ≥ 0.5 which indicates the sampling was adequate).

Ethical considerations

The ethics committee of the University of Surrey approved the study (Reference number: EC/2014/14/FBEL) and we obtained written informed consent from all the participants.

Results

As shown in Table 1, most of the participants were males (62.5%) and 48.7% were between 40 and 59 years old. Four hundred of these participants (71.8%) had been diagnosed with diabetes more than 4 years earlier. We asked the participants to provide their last HbA1c and/or fasting glucose level but only 5.9% (33/557) of them gave the number. We also asked the participants if they thought their blood glucose was controlled or uncontrolled; most (82.2%) thought it was uncontrolled. Controlled blood glucose was defined as having an HbA1c ≤ 7% or fasting blood glucose ≤ 130 mg/dL (18). None of the characteristics of the participants was significantly associated with the PACIC-5As scores (Table 2).

Table 3 shows the results of the descriptive analysis and the internal consistency measures. The overall mean PACIC score was 2.52 (SD 0.74) with the PACIC subscale scores ranging from 2.10 (SD 0.76) (follow-up/coordination) to 3.02 (SD 1.01) (delivery system/practice design). The individual items of the PACIC-5As score ranged from 1.31 (SD 0.59) for item 17 to 3.44 (SD1.25) for item 6. The summary score of the 5As ranged from 1.89 (SD 0.64) for arrange to 2.84 (SD 0.95) for advise.

The content validity analysis showed a representativeness score of 95.3% and a clarity score of 94.8%, which indicated good agreement. The Cronbach alpha (internal consistency) for the overall Arabic PACIC questionnaire was 0.93 and 0.90 for the 5As summary score (Table 3). The Cronbach alpha scores for the subscales ranged between 0.70 and 0.82. The average inter-item correlation ranged from 0.34 to 0.80, with only two items with a value less than 0.4 – Goal setting/tailoring (item 11) and Assess (item 11). Item-total correlation (internal item convergence) was more than 0.4 in almost all items; only item 11 had a value lower than 0.4.

The feasibility of factor analysis (Bartlett test of sphericity) showed a good value (Kaiser–Meyer–Olkin PACIC = 0.86 and Kaiser–Meyer–Olkin 5As = 0.85; P 0.9 .0.56 0.36 .

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