Article

Patient experience on self-management support among primary care patients with diabetes and hypertension

MING TSUEY LIM¹, YVONNE MEI FONG LIM¹, XIN ROU TEH¹, YI LIN LEE², SITI AMINAH ISMAIL¹, and SHEAMINI SIVASAMPU¹

¹Healthcare Statistics Unit, National Clinical Research Centre, Ministry of Health, 3rd Floor, MMA House, 124 Jalan Pahang, 53000 Kuala Lumpur, Malaysia, and ²Clinical Research Ward, Ampang Hospital, Ministry of Health, Jalan Mewah Utara, Pandan Mewah, 68000 Ampang, Selangor, Malaysia

Address reprint requests to: Ming Tsuey Lim. Tel: +60340439300; Fax: +60340439500; E-mail: mtlim2000@yahoo.com

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Abstract

Objective: To determine the extent of self-management support (SMS) provided to primary care patients with type 2 diabetes (T2D) and hypertension and its associated factors.

Design: Cross-sectional survey conducted between April and May 2017.

Setting: Forty public clinics in Malaysia.

Participants: A total of 956 adult patients with T2D and/or hypertension were interviewed.

Main Outcome Measures: Patient experience on SMS was evaluated using a structured questionnaire of the short version Patient Assessment of Chronic Illness Care instrument, PACIC-M11. Linear regression analysis adjusting for complex survey design was used to determine the association of patient and clinic factors with PACIC-M11 scores.

Results: The overall PACIC-M11 mean was 2.3 (SD, 0.8) out of maximum of 5. The subscales’ mean scores were lowest for patient activation (2.1 (SD, 1.1)) and highest for delivery system design/decision support (2.9 (SD, 0.9)). Overall PACIC-M11 score was associated with age, educational level and ethnicity. Higher overall PACIC-M11 ratings was observed with increasing difference between actual and expected consultation duration \( \beta = 0.01; 95\% \text{ CI} (0.001, 0.03) \). Better scores were also observed among patients who would recommend the clinic to friends and family \( \beta = 0.19; 95\% \text{ CI} (0.03, 0.36) \), when health providers were able to explain things in ways that were easy to understand \( \beta = 0.34; 95\% \text{ CI} (0.10, 0.59) \) and knew about patients’ living conditions \( \beta = 0.31; 95\% \text{ CI} (0.15, 0.47) \).

Conclusions: Our findings indicated patients received low levels of SMS. PACIC-M11 ratings were associated with age, ethnicity, educational level, difference between actual and expected consultation length, willingness to recommend the clinic and provider communication skills.

Key words: patient assessment of chronic illness care, self-management, primary healthcare, patient education, shared decision-making

Introduction

Cardiovascular disease and diabetes account for half of all non-communicable disease (NCD) deaths; with hypertension coexisting in up to 78% of patients with diabetes mellitus [1, 2]. The rising burden of diabetes and hypertension, particularly in low- and middle-income countries (LMIC) has spurred the development of
the World Health Organization (WHO) action plan for prevention and control of NCDs [1]. Among the goals in this plan is the need to support patient self-care of their NCDs [3]. This represents a need to shift from conventional healthcare delivery to promote better patient engagement and chronic disease self-management [4]. Self-management is described as the capability of patients to self-monitor their chronic condition to sustain satisfactory quality of life [5]. Studies from high income countries have shown that increase in self-management behavior is associated with better outcomes and reduces healthcare utilization [6, 7].

Self-management is achieved through establishing good relationships between patients and their health providers. Among the tools which measure the degree of patient engagement between providers and patients, the Patient Assessment of Chronic Illness Care (PACIC) questionnaire is commonly used [8]. PACIC comprises a 20-item patient survey and was developed to assess several aspects of chronic care delivery including patient activation, delivery system design/decision support, goal-setting/tailoring, problem-solving/contextual counseling and follow-up/coordination [9].

Limited information on patient-reported quality of care and SMS in diabetes and hypertension is available for LMICs. Previous studies using PACIC in LMICs such as Thailand, Philippines and Turkey had either small sample sizes, focused on hospital-based settings or investigated a wide range of chronic conditions [10–12]. Most of healthcare delivery for type 2 diabetes (T2D) and hypertension occur at primary care, hence patient quality of care assessments should practically be conducted in the primary care setting. Therefore, the aim of this study is to determine the extent of SMS provided to primary care patients with T2D and hypertension and its associated factors.

Methods

Setting and study population

This study used baseline data from a larger study titled ‘Evaluation of the Enhanced Primary Healthcare (EnPHC) interventions in public health clinics’ (EnPHC-Eva), which aimed to determine the effectiveness of the EnPHC intervention package on processes of care and intermediate clinical outcomes in T2D and hypertension. Forty clinics were recruited and matched based on average daily attendances, number of medical doctors and family medicine specialists and geographical location (urban or rural). Consequently, 20 matched pairs were obtained and each clinic within the pairs was randomly allocated to intervention and control arms. Baseline data collection was conducted between April and May 2017 before implementation began in July 2017. The impact of the interventions was evaluated one year after full implementation. The intervention package includes the following:

(i) Community interventions include engaging people through health programs, which are customized based on individual cardiovascular risk. Everyone engaged through this intervention is included into a population health database.

(ii) Person-centered care bundles at public clinics include cardiovascular risk stratification, assignment to family health teams and task shifting from doctors to other healthcare professionals to improve the continuity and comprehensiveness of chronic care.

(iii) An integrated care network where information flow and continuity of care between primary care and other levels of care were improved through standardized referral forms and the role of a care coordinator.

Study outcomes were assessed at three levels: the patient, health provider and facility. At the patient level, data were collected through retrospective chart review and a patient exit survey. The present analysis used data from the patient exit survey and the inclusion criteria were patients aged 30 years and above, diagnosed with T2D and/or hypertension.

Ethical approval was granted by the Medical Research and Ethics Committee, Ministry of Health Malaysia (NMRR-17-267-34768).

Sample size and sampling

The sample size for the patient exit survey was calculated based on 16% effect size (percentage of patients who would recommend the clinic to family and friends), 80% power, alpha value of 0.05 and intra-class correlation coefficient of 0.116 [13]. After accounting for 30% drop-out rate, a minimum sample size of 23 patients per clinic was required. Face-to-face interviews were conducted by trained researchers using a structured questionnaire on mobile tablets. Written consent was obtained. Participants were assured that their responses were anonymised during analysis and that participating in this study would not affect their care.

Survey tool and measurements

The structured questionnaire used in the patient exit survey included information on socio-demographic and clinical characteristics, self-reported health status, provider–patient communication attributes, whether the patient missed an appointment within the past 12 months, the PACIC questionnaire, consultation length and willingness to recommend the clinic to family and friends. The difference between actual and expected consultation duration (actual–expected consultation duration) was calculated and included as a predictor. A higher positive number indicated that patients’ expectations of consultation were met.

There were 20 items and 5 subscales in the original PACIC questionnaire, which addressed patient activation, delivery system design/decision support, goal-setting/tailoring, problem-solving/contextual counseling and follow-up/coordination [9]. An expert group consisting of intervention implementers, family medicine specialists, a population health expert and study researchers have reached a consensus to adapt only the first 11-items of the scale, which fall into the first three subscales of PACIC (patient activation, delivery system design/decision support and goal-setting/tailoring). This decision to focus on the initial steps of SMS was reached after considering the low health literacy level among the study population [14] and overall length of the patient exit questionnaire to prevent respondent fatigue [15].

The English version was translated into Malay (Bahasa Malaysia) using forward and backward translation according to WHO recommendations [16]. Two study collaborators who were fluent in both English and Malay prepared the Malay questionnaire and another two translators independently back-translated the Malay version into English. Then, both versions were compared by the research committee to resolve discrepancies and ensure that no change in context occurred during translation. Pre-testing was done using the agreed version in 10 patients in two public clinics which were not part of the study sample and modifications were subsequently made in accordance to pre-test findings. The PACIC-M11 are scored on a 5-point scale, ranging from 1 to 5 and response options were ‘none of the time’, ‘a little of the time’, ‘some of the time’, ‘most of the time’ and ‘always’ [17]. Patients were asked to
evaluate the chronic care received over the last 6 months and higher scores indicate higher presence of the particular aspect of chronic care.

The translated PACIC-M11 questionnaire was assessed for reliability. Cronbach’s alpha for the overall 11 items was 0.79 while for the pre-defined three subscales (patient activation, delivery system design/decision support and goal-setting/tailoring), they were 0.70, 0.41 and 0.62, respectively. Overall, the internal consistency of the scale was satisfactory except for the delivery system design/decision support subscale. Additionally, confirmatory factor analysis using complete cases revealed satisfactory model fit for the pre-defined three subscales in PACIC. Based on a model which allowed correlations between the subscales, factor loadings ranged between 0.32 and 0.72. A factor loading of 0.32 was deemed acceptable [18]. Model fit demonstrated root mean square error of approximation estimate of 0.06 (acceptable fit is ≤0.06); comparative fit index of 0.93 (good fit is ≥0.95) and Tucker–Lewis index, 0.90 (good fit is ≥0.95); all of which indicated acceptable model fit [19].

### Statistical analysis

Continuous variables were presented as mean and standard deviation (SD) and categorical variables were reported in frequencies and percentages. Statistical significance (alpha) was set at 0.05 for all comparisons. A linear regression using complex survey design to account for clustering was performed to determine factors that influence the PACIC-M11 score. Missing data rates ranged from 0.3% to 5.0% and complete case analysis was used in the regression. Missing rate of ≤5% was regarded as inconsequential [20]. Data analyses were performed using Stata version 14.3 (StataCorp LP, College Station, TX) [21].

### Results

#### Patient characteristics

A total of 968 participants agreed to participate. However, only the 956 participants who completed the survey were considered in the analysis. The patients’ mean age was 59.7 years (SD, 10.9) (Table 1). The patients were predominantly female (60%) and of Malay ethnicity (70%). Almost two-third (70%) had up to lower secondary education and 82% came from lower household income group (<MYR 5000). Majority of patients reported good provider–patient communication attributes where the provider explained things in ways that was easy to understand (95%), showed respect for what the patient had to say (98%) and listened carefully to the patient (97%). However, less than half of patients reported that their providers knew about their living conditions. The average difference between actual and expected consultation length was −1.1 (SD, 4.5) indicating that patients on average received shorter than expected consultation duration.

#### Overall PACIC-M11 and subscale scores

Overall PACIC-M11 score and its subscales are presented in Table 2. The overall mean was 2.3(SD, 0.8) while the subscales’ mean scores were lowest for patient activation (2.1 (SD, 1.1)) and highest for delivery system design/decision support (2.9(SD, 0.9)).

There were consistent responses for ten out of 11 items where half or more patients (range: 44%–76%) reported not receiving the specific aspects of SMS. The remaining item had a reverse distribution of responses where more than 50% of patients reported that they were always satisfied that their care was well organized.

### Table 1 Patient socio-demographic and clinic characteristics

| Characteristic                  | Mean (SD) or n (%) |
|---------------------------------|--------------------|
| Patient                         |                    |
| Age (years)                     | 59.7 (10.9)        |
| Sex                             |                    |
| Female                          | 576 (60.2)         |
| Ethnicity                       |                    |
| Malay                           | 664 (69.5)         |
| Chinese                         | 200 (20.9)         |
| Indian                          | 88 (9.2)           |
| Other                           | 4 (0.4)            |
| Educational level               |                    |
| No formal/primary/low secondary | 659 (68.9)         |
| Upper secondary                 | 239 (25.0)         |
| Tertiary                        | 58 (6.1)           |
| Household income (< MYR 5000)   | 776 (81.9)         |
| ≥MYR 5000/month                 | 171 (18.1)         |
| Chronic illness                 |                    |
| Diabetes                        | 623 (65.2)         |
| Hypertension                    | 808 (84.5)         |
| Hyperlipidaemia                 | 431 (45.1)         |
| Duration of illness (years)     |                    |
| Diabetes                        | 8.2 (7.0)          |
| Hypertension                    | 8.4 (7.9)          |
| Hyperlipidaemia                 | 5.2 (4.5)          |
| Consultation length (min)       |                    |
| Actual                          | 9.6 (5.6)          |
| Expected                        | 10.7 (6.2)         |
| Difference^a                    | −1.1 (4.5)         |
| Postponed visit to clinic in the past 12 months (n = 944) | 253 (26.8) |
| Would recommend this clinic to friends and family | 857 (89.6) |
| Health status                   |                    |
| Poor                            | 32 (3.3)           |
| Fair                            | 477 (49.9)         |
| Good                            | 386 (40.4)         |
| Very good                       | 61 (6.4)           |
| Given advice on                 |                    |
| Eating a healthy diet           | 507 (53.0)         |
| Getting enough exercise         | 381 (39.9)         |
| Maintaining ideal body weight   | 350 (36.6)         |
| Provider–patient communication attributes |                  |
| Provider explained things in a way that easy to understand (n = 949) | 898 (94.6) |
| Provider showed respect for what the patient had to say (n = 950) | 934 (98.3) |
| Provider listened carefully to the patient (n = 948) | 918 (96.8) |
| Provider know about the patient’s living condition (n = 905) | 435 (48.1) |
| Clinic characteristics (n = 40) |                    |
| Geographical location           |                    |
| Rural                           | 18 (45.0)          |
| Urban                           | 22 (55.0)          |
| Attendances/year                | 69 270 (36112)     |

If N is not stated, the percent was calculated with a denominator of total patients who were included for analysis (N = 956), ^Actual—expected consultation duration, SD, standard deviation, MYR, Malaysian Ringgit.

At the item level, ceiling effect, defined as percent of patients selecting ‘always’ exceeding 20% [22], was observed in items #5, #6 (Shown how what I did to take care of my illness influenced my
condition) and #9 (Given a copy of my treatment plan). On the other hand, all items except item #5 exhibited floor effects, defined as percent of patients selecting ‘none of the time’ exceeding 20%.

### Linear regression analysis

Results for the linear regression analysis are presented in Table 3. Age was negatively correlated with the overall PACIC-M11 score. Compared to Malay patients, Chinese patients tended to give lower overall PACIC rating. The overall PACIC-M11 scores increased with consultation time difference \( \beta = 0.01; 95\% \text{ CI (0.001, 0.031)} \), the provider’s ability to explain things in a way that was easily understood by the patient \( \beta = 0.34; 95\% \text{ CI (0.10, 0.59)} \) and whether the provider knew about patients’ living conditions \( \beta = 0.31; 95\% \text{ CI (0.15, 0.47)} \) and patients’ willingness to recommend the clinic to friends and family \( \beta = 0.19; 95\% \text{ CI (0.03, 0.36)} \).

### Discussion

Few studies have evaluated PACIC among patients with diabetes or hypertension in LMICs [23]. To the best of our knowledge, this study is the first to report assessment of chronic care among patients with T2D and hypertension using PACIC-M11 in Malaysia. The mean score for patient activation, delivery system design/decision support and goal-setting/tailoring subscales were consistently lower compared to a study conducted among urban, diabetes patients in Malaysia [24] and those reported in other LMICs [10, 11]. These differences in subscale scores could be explained by differences in health literacy rates, presence of health interventions and method of survey administration (face-to-face interviews versus self-administered). Whilst direct comparisons in PACIC scores between countries should be made with caution due to cultural and language influences [23], comparatively low subscale scores found in this study suggests opportunities for improving SMS among patients.

A significant percentage of participants in this study reported complete absence (i.e. ‘none of the time’) of the evaluated aspect in chronic care SMS. One reason could be patients’ lack of confidence and readiness to take on more active roles in their illness. Moreover, majority of patients with chronic conditions in the present study are older patients. Mah and colleagues found that preference for passive decision-making is more prevalent in older hypertensive patients (≥60 years) which is potentially due to lower health literacy level amongst this group [25].

In addition, low ratings in SMS could also be driven by the paternalistic approach adopted by health providers, which is believed to be the typical approach in Asian countries [26]. A study conducted at an academic primary care clinic showed that doctors tend to underestimate the level of patients’ preferred involvement in managing their illness while patients with hypertension had reported that steps of shared decision-making were not emphasized by their health providers [25, 27]. On the other hand, we found high ceiling effects for the item #5 (Satisfied that my care was well organized). This could partially be explained by the lower expectations for chronic care by patients with low health literacy levels.

Contrary to studies which showed that younger patients tend to give lower ratings on patient-centered care [28], we found that older patients were more likely to give poorer ratings for PACIC-M11. This is possibly because many of the respondents, particular those of older age and lower educational status have difficulty in understanding the information given during consultation. In this study, we also found that rating disparities between ethnic groups. Chinese patients reported poorer scores compared to Malay patients. This might be due to differences in expectations for chronic care between different socio-cultural backgrounds. Other researchers have found that patients who were well-educated, of higher socioeconomic status and had poor health gave lower experience scores [28]. However, we found contrasting results, where patients with tertiary education rated better chronic care than those with lower educational levels while self-reported health and household income had no effect on
As expected, we found positive correlation between good provider–patient communication attributes and patients’ overall experience ratings. We postulate that patients with higher education levels gave better ratings because they were more likely to understand and relate to information provided during consultations. As for the reason to why patients’ perceived health statuses did not affect experience ratings; would require further research.

As expected, we found positive correlation between good provider–patient communication attributes and patients’ assessment of their disease management. This highlights the importance of communication skills such as explaining things in lay person language and knowing about patients’ living conditions to ease customization of treatment plans and behavioral change activities. We also found that patients gave better ratings as consultation time increased relative to their individual expected duration. Our findings are in keeping with those reported by Mah et al., where majority of patients want adequate consultation time with their doctors [25]. We have also explored the effects of clinic geographical location and patient load on patients’ assessment of chronic care and found no correlations.

## Implications for practice, policy and research

The primary care setting is the best place to effect change for self-management in patients with diabetes and hypertension because it is where the bulk of chronic disease management take place. Improving SMS can be done from three respects; first, from the patient or individual perspective. Our findings showed that there is a lack of patient involvement in their disease management, hence empowering patients to take on a greater role in disease management is a necessary step. This can be achieved by providing easily understood information in various formats. Decision aids, web-based education programmes and patient held records are practicable tools to engage patients [23, 29]. A Cochrane review has shown that group-based diabetes education programmes improved intermediate clinical outcomes and diabetes knowledge [30]. These approaches need to account for variability in health literacy levels, socioeconomic status and personal experiences to achieve optimal outcomes.

Second, changing healthcare providers’ response and behavior to adopt patient-centered approach is key in supporting patient self-management. This involves focusing on building a partnership with patients, which will require training in skills such as motivational interviewing, cognitive behavioral strategies and collaborative goal-setting while considering health professionals’ context of work and values [31, 32]. Although some patients are not ready to play an active role in their illness and management, it is important that health providers do not assume patients’ preferences of their level of involvement without checking with them [33].

Third, re-organization of the healthcare system and community would serve as an enabler for self-management by empowering staff, use of technology and changes in the service structure. At the policy level, we need to ensure that patients are fully engaged in their management, and this can be achieved through partners and patient held records.
level, restructuring of the primary care services may be necessary to increase duration and improve quality of consultation between patients and providers. To increase the quality of care delivered, the roles of non-physicians such as nurses, nutritionists, pharmacists, dieticians and other health professionals could be expanded as they are well-positioned to support self-management in chronic conditions [34, 35]. Additional research is needed to determine whether patients’ assessment of care received and healthcare professionals’ perceived quality of service provision are correlated to identify potential mismatches and barriers to efficient delivery of chronic care.

Strengths and limitations
We have demonstrated that PACIC-M11 has good reliability and acceptable internal validity for two of the three pre-defined subscales evaluated in this study. We have also shown that it is a feasible tool for evaluation of chronic care delivery amongst patients with diabetes and hypertension in our current setting. The large sample size allowed sufficient statistical power to explore how patient and clinic characteristics may influence PACIC-M11 score. Another strength of this study is that it is conducted in a sample of clinics which are representative of the public clinics in the country and ~75% of all chronic conditions are managed in the public health sector [26]. The data in this study also had low missing rates. Because majority of the patients with diabetes and hypertension in this setting are older, of lower educational status and health literacy levels, we are unable to exclude the possibility that the questionnaire remained too difficult for some to understand and other researchers have also reported this challenge their studies [12, 36]. Lastly, the findings may not be generalizable to the private clinics as study population were solely from public health clinics.

In conclusion, patients’ assessment of chronic care in public clinics showed great opportunities for improvement in terms of SMS and shared decision-making. Factors associated with chronic care experience were age, difference between actual and expected consultation length, ethnicity, educational level and provider communication skills. Our results showed that healthcare providers have some of the necessary skills in encouraging SMS among patients but also require a new set of competencies such as moving from the paternalistic approach to forming partnerships with patients.

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