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**Are we doing it right? Self-care support for patients with type 2 diabetes in urban areas  
in Malaysia**

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## **ABSTRACT**

**Introduction:** Diabetes educators have been highlighted as the key people to support self-care, however, their practice is not known and the challenges that they faced by in providing intended care is not understood. The purpose of this study is to explore the self-care support provision for patients with type 2 diabetes by diabetes educators and to explore the challenges that they encountered in providing the intended services.

**Methods:** Single embedded qualitative case study design using in-depth individual face to face interviews was adopted. Twelve diabetes educators from three diabetes clinics in urban areas in Malaysia were purposively selected and interviewed within the period of eight months (November 2012 – June 2013). The data were transcribed verbatim and analyzed using Framework technique.

**Findings:** The practice of diabetes educators revolved around the traditional paternalistic approach but emphasize on individualised support . However, their practice was restricted by several factors, including patients' acceptance and interest in self-care, lack of confidence and opportunity to practice, and fragmented health care system.

**Conclusion:** The current practice of diabetes educators is very limited to knowledge provision and rather a generalist. Considering a more specialized role would increase opportunities for diabetes educators to provide high-quality self-care support provision.

Key words: self-care, self-management, type 2 diabetes, diabetes educator

## **Introduction**

Patients with type 2 diabetes are expected to engage in self-care activities in maintaining good glycaemic control<sup>(1)</sup>. Patients often experienced a lack of understanding on the plan of care, a feeling of helplessness and frustration from the lack of glycaemic control, and were overwhelmed by the disease's progression<sup>(2)</sup>. Therefore, patients frequently highlighted the need for continuous support and a collaborative relationship with healthcare professionals in self-managing their illness<sup>(2-6)</sup>. However, patients' satisfaction towards self-care support provision always reported as low and effectiveness of self-care support provision for type 2 diabetes are varied<sup>(7-12)</sup>.

Diabetes educators have been identified as a key person in a multidisciplinary diabetes management team that is most responsible for providing diabetes education and facilitating patients' self-care. Active involvement of diabetes educators in supporting the patients has been shown to have an impact on their self-efficacy, ability to self-manage and their well-being as a whole<sup>(13)</sup>. The importance of diabetes educators in the coordination of diabetes management within the healthcare system has been highlighted in the policies and guidelines in many countries<sup>(14-16)</sup>. In fact, the role and responsibilities of diabetes educators in managing diabetes have been well described by the American Association of Diabetes Educators which become the basis of the practice of diabetes management worldwide<sup>(17)</sup>. However, the support provided by the diabetes educators frequently questionable and this aspect were argued to be due to the different orientation with regards to self-care between patients and healthcare professionals<sup>(18,19)</sup>.

In Malaysia, the importance of diabetes educators in supporting the patients in managing type 2 diabetes has been highlighted within the policy of Malaysian Ministry of Health and clearly spelled out in the clinical practice guideline for the management of type 2 diabetes<sup>(20)</sup>. However, the ability of the patients to engage with self-care and the level of glucose control is still far from satisfactory<sup>(21)</sup>. A lot of questions emerged with regards to the practice of healthcare professionals, particularly the diabetes educators in self-care support provision and diabetes management as a whole. This aspect not yet able to be explained as the research in this area, particularly in Malaysia is still scarce. Therefore, in this study, diabetes educators' perspectives on their practice in supporting self-care of type 2 and the challenges that they encountered in providing the intended services has been explored. The findings provided evidence for the ineffective self-care support provision within the Malaysian healthcare system which becomes the important factor that leads to the poor engagement with self-care among patients with type 2 diabetes in urban areas in Malaysia.

## **RESEARCH METHODS**

### **Study design**

A single embedded qualitative case study approach after Yin<sup>(22)</sup> was adopted in this exploratory study. In-depth semi-structured interviews were employed as it allows for flexibility for the researcher in seeking the description of the case being studied by while maintaining the specific focus of the study<sup>(23)</sup>.

### **Study participants**

The participants were selected from three outpatient diabetes clinics in primary and secondary care settings in urban areas in Malaysia. The inclusion criteria were that the diabetes educators or healthcare professionals who involved directly or indirectly in the provision of diabetes management in the case study settings. The study was conducted in eight months duration started from November 2012 until June 2013. Eligible diabetes educators were identified

through several visits to the clinics, or by reviewing the clinics' organizational charts. Additionally, the diabetes educators were recruited through the snowballing method, whereby the names of eligible diabetes educators were suggested by other healthcare professionals. The introducer helped by introducing the researcher to the respective diabetes educators and helped the researcher to develop rapport and trust with them, which increased their willingness to participate<sup>(24)</sup>. Twelve diabetes educators from three diabetes clinics in urban areas in Malaysia were purposively selected and agreed to participate in the study.

### **Ethical consideration**

Ethical approval was obtained from the Malaysian Medical Research Ethics Committee (MREC) prior to the recruitment of participants and data collection. All participants were provided written informed consent. The participants were reassured that the transcripts would be anonymised and any formed of their identification would be removed throughout the process of data handling, analysis, and presentation.

### **Interview process**

Interviews were conducted by the researcher who was appropriately trained and the pilot interviews was conducted to determine correct interview technique by the interviewer. In maintaining the focus of the interview, an initial topic guide was developed based on an extensive review of the literature, the researcher's knowledge and experience of the research field and the study context, and discussions with the research team. The elements included in the topic guide were participants' clinical experience in managing patients with type 2 diabetes, their current approach/practice with respect to self-care support provision and their perception and satisfaction of their role as diabetes educators. Participants' demographic data were also recorded. The average duration of the interviews was between one and two hours, and each of the participants was interviewed once. With permission from the participants, all of the

interviews were audio recorded and transcribed verbatim. The data had achieved its saturation after ten interviews.

### **Data analysis**

Transcripts were analyzed using framework technique<sup>(25)</sup>. The process of data analysis started with data familiarization and followed by the development of a thematic framework according to the primary topic areas. The framework was continuously refined throughout the process of data familiarization. Each interview transcripts were reviewed, annotated, and labelled according to the themes and sub-themes with the relevant index numbers according to the framework. The process followed by creating thematic charts and subsequently, the data were plotted in the chart accordingly. After the process of charting, the entire data set was clearly visualized, which facilitated the process of mapping and interpreting data across the data sets. Throughout the process of data collection and data analysis, the rigour of the study was maintained through prolonged engagement with the study participants, utilisation Nvivo software in data management and thick description of the research process which allows for an audit trail. The key themes explained the perspective of diabetes educators on their role in managing patients with diabetes which are traditional paternalistic approach and individualised support. Whereas, patients' acceptance and interest in self-care, lack opportunity to practice, and fragmented medical system were perceived as the challenges by the diabetes educators.

### **FINDINGS/RESULTS**

The participants were twelve healthcare professionals who are responsible for self-care support provision in the case study settings. Eleven participants are female and one of them is male. Eleven of them are registered nurse and one is a medical assistant, who carried out the role as

diabetes educators. Out of 12 participants, six of them had undergone six months post-basic training of diabetes management. Their average years of working are 15 years. Table 1 presents the characteristics of study participants.

Table 1 characteristics of the participants

Participants' ID	Role	Years of working
HCP 2	Diabetes educator	11
HCP 3	Health educator	>20
HCP 4	General nurse	16
HCP 5	Diabetes educator	18
HCP 6	Diabetes educator	11
HCP 7	Diabetes educator/Nurse manager	18
HCP 8	Diabetes Educator/Nurse manager	>20
HCP 9	Diabetes educator	15
HCP 10	General nurse	18
HCP 11	General nurse	6
HCP 12	Nurse manager	>20
HCP 16	Medical assistant	17



## **Practice of self-care support**

### **Traditional paternalistic approach**

Diabetes educators perceived that their practice is revolved around providing knowledge and information, which aimed to enhance patients' understanding and enable them to make decisions pertaining to diabetes management:

*'My role in supporting patients with diabetes is to give them knowledge about diabetes and what they should do to manage it. How they should look after themselves at home. For example, in terms of diet and lifestyle, medication, exercise and how they live their lives.'* (HCP 3)

Patients were frequently perceived as having a lack of knowledge and incorrect understanding of diabetes, as they commonly received lay advice from relatives or friends. The diabetes educators recognized that inappropriate information and advice received by patients made them more confused about managing their diabetes and reduced their concern for, and interest in, self-care, as demonstrated in the extract below:

*'Many of these patients frequently received advice from their relatives and friends. For instance, if somebody tells them not to eat rice...they might think that this is right. Some of the patients think that they can't eat sweet drinks so they just avoid them. But they don't know the rationale behind it because they don't have enough knowledge about it.'* (HCP 9)

Moreover, the diabetes educators in this study frequently pointed out that the 'patient blaming' approach was commonly used by the HCPs when providing feedback on the patients' inability to achieve the desired glycaemic control.

*'Patients are usually blamed if they do not follow the advice and their sugar is poorly controlled. When they refuse to do certain tests, urine tests, for instance, we can expect that they are afraid of being scolded'* (HCP 4)

### **Individualised support**

The diabetes educators also recognized the importance of psychological support and motivation in helping the patients to engage in self-care. However, the diabetes educators claimed that this aspect has been frequently hard to manage as patients were frequently reluctant to disclose problems. Furthermore, they acknowledged that patients usually perceived diabetes educators as outsiders who were only responsible for providing advice, without considering their difficulties in dealing with diabetes. Therefore, the diabetes educators frequently claimed that it was hard for them to really understand the patients' life situations and problems that contributed to their inability to achieve the targeted glycemic control.

*'It is really hard to understand the situation that made them unable to follow whatever we suggested. When we give advice, they frequently reply, 'it's easy for you to say it...but I am the one who suffers'. But when we ask about their problems, they are usually reluctant to talk about them.'* (HCP 2)

Individual consultations or 'diabetes counselling' were identified by the diabetes educators as the best approach to developing relationships and understanding the patients' problems in-depth. Furthermore, most of the diabetes educators perceived that individual consultation sessions would allow them to spend more time with the patients and enable them to understand the patients' problems as mentioned in the excerpt below:

*'Patients are frequently reluctant to share their problems. Like this one patient that I attended...it took months...before he felt comfortable to share his problems. So, we need time to see them individually. The first time we see them, not many patients want to share their problems...So it is hard for us to identify what actually is the problem that has made them unable to practice self-care.'* (HCP 7)

Although patients were frequently reluctant to disclose their personal situations, the diabetes educators perceived that spending more time with them and having repeated consultations with

the same diabetes educators would enhance patients' trust and confidence, which would enable them to share their problems.

## **Challenges in self-care support provision**

### **Patients' acceptance and interest with self-care**

The diabetes educators frequently expressed that most patients with type 2 diabetes found it hard to accept the fact that they had diabetes. They frequently conveyed that patients who positively accepted their diagnosis normally had better adherence to self-care compared to patients who were unable to accept it. Patients who accepted the diagnosis were more ready to be involved in self-management, and usually more compliant with the treatment and follow-up schedule. The extract below demonstrates the views of one diabetes educator regarding this issue:

*'...If they can accept that they have diabetes, then the management is easier than if they do not accept their diagnosis. Sometimes their work requires them to travel...so they find it hard to follow our schedule. These kinds of patients usually default on treatment, and their glycaemic control is not very good.'* (HCP 12)

Patients' lack of interest in self-care has been perceived as another reason for the ineffectiveness of self-care support provision. The diabetes educators frequently mentioned that the patients often saw self-care as unimportant, as they usually felt healthy and rarely experienced alarming symptoms. Although the complications of type 2 diabetes were widely emphasized, the diabetes educators perceived that the patients' awareness of the dangerousness of diabetes was still very low.

*'When I ask them why they do not manage it properly, they usually say that they still young, and they think they might not be affected much. They tell me that they have seen so many patients with diabetes, and claim that they know what to do...'* (HCP 6)

The interviews illuminated that, sound knowledge of diabetes does not necessarily result in good self-care practice. Several diabetes educators in this study consistently mentioned that other HCPs also saw diabetes as less dangerous compared to other diseases, and this seemed to develop undesirable behaviour among the patients, as shown in the extract below:

*'They [other HCPs] usually see diabetes as a simple problem and they do not explore it further. This is because they usually hear about other diseases such as cancer, which they think is more dangerous... then only they would concern. But diabetes... they usually think that it is a common problem and just an ordinary disease.'* (HCP 10)

Therefore, it can be suggested that the patients' lack of interest in self-care, as perceived by the diabetes educators, is not only compounded by the patients' perceptions and attitudes towards diabetes, but also by the attitudes of the HCPs, who frequently see diabetes as a common disease and not overly dangerous.

### **Lack of opportunity to practice**

The diabetes educators consistently mentioned the multi tasking that they needed to carry out, which restricted their ability to provide the intended self-care support provision. The extract below is an example of the common views of the diabetes educators regarding this issue:

*'I need to do a lot of things. I need to do foot assessments and counseling on foot care, teach the patients about insulin injections, and so on. I think we need to improve a lot of things. Every step from the beginning...'* (HCP 2)

From the data presented in this section, there is evidence of substandard self-care support provision within the case study sites, as the diabetes educators did not have enough time to practice due to high workloads and multitasking. It, therefore, reduced their job satisfaction and subsequently affected the quality of service provided to the patients.

When asked about their opinion regarding the effectiveness of the advanced diploma course that they attended to prepare them for the role of the diabetes educator, several stated that very minimal input was given regarding the approach to counselling, motivating and dealing with the patients' real-life situations in terms of living with diabetes. This is demonstrated in the extract below:

*'Personally, as a nurse and diabetes educator for the past three years, after back from post basic, I felt nothing. I don't know what my direction is. Just getting post basic for the sake of to have a post basic. We back and work as a normal nurse in the ward' (HCP 6).*

It seems that the diabetes educators were not clear on their job description, which is supposed to guide them to carry out their role. Therefore, their role was frequently embedded within the routine work as a general nurse, and their skills and knowledge as diabetes educators were not being sufficiently utilized. Furthermore, the lack of manpower and high workload in the clinics were frequently mentioned by the diabetes educators as limiting their opportunity to focus on the role of the diabetes educator and provide proper self-care support to the patients.

### **Fragmented health care system**

Diabetes management in Malaysia follows the National Diabetes Prevention and Control Programme, which consists of three levels of prevention (primary, secondary and tertiary). In general, patients with pre-diabetes symptoms and early stages of type 2 diabetes are managed at a primary-care level, whereas patients with more serious conditions and diabetes complications are managed in a hospital setting. Based on the interviews with the diabetes educators, there were vast differences in the focus and approach of diabetes management between primary- and secondary-care settings. Furthermore, it was noted that the differences in the approach led to a lack of coordination in patients' management between the primary- and

secondary-care settings. This situation appeared critical, as it reduced the quality of service delivered. This situation was consistently highlighted by the diabetes educators in the secondary-care setting.

'We frequently experienced patients coming back to us with worsening condition or mismanaged. We need to re-arrange the insulin dosage, get the patient's history and review their activities at home again. Number of patients here is very high, so we need to ask for help from other health clinics to monitor these patients. We don't have enough manpower and the number of doctors here is also low.' (HCP 7)

During the interviews with diabetes educators in the primary-care clinic, several diabetes educators claimed that they were aware of the situation, and also agreed that the patients were often overlooked with respect to certain aspects. However, they perceived that this happened due to a lack of manpower and resources:

*'The thing is not going parallel. Patients are scattered. We try our best to provide the services as stipulated in the CPG. But sometimes there are certain things that we are not able to catch up on because the doctors and nurses are changing quite rapidly. So maybe they miss diagnoses or miss certain aspects.'* (HCP 16)

## **DISCUSSION**

This qualitative case study the diabetes educator in primary and secondary care clinics in urban areas in Malaysia to share their perspectives and experiences in managing type 2 diabetes. Overall, the findings indicate that the diabetes educators were aware of the important aspects in supporting patients with type 2 diabetes. However, they commonly encountered a wide range

of challenges arising from patients, their personal situation, work environment and healthcare system which had restricted their opportunity to provide intended care.

It could be argued that self-care support being practiced within the case study sites revolved around traditional medical model. Although it was mentioned by the diabetes educators that knowledge and education imperative in facilitating patients' engagement in self-care, the approach that the diabetes educators used to provide support to the patients seemed to be detrimental to the patients' motivation and enthusiasm to self-manage their diabetes. Furthermore, the traditional medical model, which incorporates patient blaming, has been argued to be unsuitable in supporting patients with a chronic condition such as diabetes, as they face complex life situations that are psychologically demanding<sup>(26)</sup>. Moreover, a review by van Dam et al. <sup>(27)</sup> reported that a positive patients–providers relationship is essential, and has a strong effect on patients' motivation in behavior modification and health outcomes. Therefore, it seems that despite their awareness of the importance of knowledge and individualized care, the diabetes educators' approach to providing feedback and support can be argued to be another reason for the poor engagement of patients in self-care in the current study.

The findings had also illuminated incongruities in the management of patients between primary and secondary care settings which seemed to be detrimental to the patients' progress. In view of this situation, the Chronic Care Model suggests that a lack of coordination in care between primary care and secondary settings is detrimental to the success of chronic disease management and support<sup>(28)</sup>. Furthermore, healthcare system coordination has been identified as a common problem in developing countries due insufficient manpower and resources<sup>(29)</sup>. Therefore, the lack of guidelines and a framework to facilitate coordination of diabetes

management between primary- and secondary-care settings, alongside critical limitations in clinical practice such as lack of manpower and resources, as highlighted by the diabetes educators, could be argued to explain the fragmented practice within the health care system.

The interviews highlighted the dissatisfaction and frustration of diabetes educators on their practice. Although some of them were aware of their role and practice as diabetes educators, they frequently expressed feelings of dissatisfaction as their opportunities to provide the intended service seemed to be restricted. They also argued that the training that they attended was insufficient to empower them and enable them to carry out the intended role of diabetes educator<sup>(30)</sup>. In parallel, Ramli and Taher<sup>(31)</sup>, who analyzed the management of non-communicable disease (NCD) in Malaysia, reported that there is a lack of trained diabetes educators (referring to nurses and other allied health personnel) in supporting the management of NCD, including diabetes. As such, a higher qualification seems to be crucial for preparing diabetes educators for a more advanced independent role, which would simultaneously increase their confidence and motivation to provide a high-quality service in supporting patients with type 2 diabetes.



## **IMPLICATION FOR POLICY, PRACTICE, AND FUTURE RESEARCH**

The findings of this study illuminated a gap in the practice of the diabetes educators and the need for change in the approach to service delivery and the healthcare organization as a whole. Conducting action research or participatory research would be useful in the implementation of patient-centered care intervention, as it would empower the stakeholders, facilitate their interest and participation and simultaneously increase their sense of responsibility and ownership of the intervention<sup>(32)</sup>. This would also reduce the possibility of resistance to implementing changes in the healthcare system.

## **CONCLUSION**

Management of diabetes and the concept of self-care has become of great concern within the Malaysian healthcare system. However, self-care support provision is limited as service delivery revolves around the traditional medical model with a lack of evidence-based practice. Diabetes educators' opportunities to provide high-quality self-care support provision is limited due to several internal and external factors, which had reduced their satisfaction in practice. The finding had contributed evidence that it is high time for the change of dimension of diabetes management provision in Malaysia from a medical paternalistic to a more patient-centred approach, as this would improve patients' self-efficacy and empowerment in decision making pertaining to the self-management of diabetes.

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