Subjective Assessment to an Educational Tool Used for the
Arabic Population with Diabetes in Australia

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ABSTRACT

Despite a rapid growth of Type 2 diabetes in Arab Australians, the management of diabetes in this population is yet understudied. The first aim of this study is to participants’ views about: taking medicines regularly, knowledge and feelings about diabetes, sources of medicines information, and special needs of being from an Arabic speaking background. The second aim is to explore participants’ feedback about the use of the Diabetes Conversation Map as an educational tool in Arabic. Focus groups were conducted in Arabic-speaking Australians with Type 2 diabetes who were asked about their knowledge and self-care skills of diabetes as well as experience of living with the disease. Common themes emerged from the focus groups included knowledge, state of mind, and needs of the Arabic speaking population. The findings provide valuable information for research in this area by designing interventions that would be translated to clinical practice.

Keywords: Arabic, Australia, Diabetes, Needs, Perceptions, Assessment, Education.

1. INTRODUCTION

Diabetes mellitus is a common chronic disease which results from a complex interaction of genetic and environmental factors. Fuelled by rapid urbanisation, changes in nutrition, and an increase in sedentary lifestyles, the prevalence of diabetes has increased in parallel with the incidence of obesity and metabolic syndrome¹. It has been estimated that 285 million people have diabetes worldwide². In Australia, more than 3 million people or one in four adults over the age of 25 years have either diabetes or impaired glucose tolerance which is pre-diabetes with a very high prevalence of diabetes in the Arabic community². A report by the Australian Institute of Health Welfare found that Australian men born of Middle Eastern or African background reported to be 3.6 times more prone to diabetes than Australians of European or other descent ². However, the difference between Arabic-speaking women and Australian women was not statistically significant².

According to the 2002 data from the NSW (New
South Wales) Department of Health, the prevalence of diabetes in 1997-98 among people born in the Middle East was 8.1% compared with 3.8% for Australian born people. More recent data from the Social Health Atlas of Australia (2011), the prevalence of diabetes in Australia decreased to 3.4%.

Diabetes mellitus is associated with substantial morbidity and mortality, and has significant impact on individuals and their families. The onset of macrovascular and microvascular complications lowers quality of life with an increased burden of illness and the costs of managing the specified complications of diabetes over time.

Diabetes costs the Australian government around AU$680 million per year which is considered a negative influence from the economic perspective as well as from the health wellbeing of the community population. The first aim of this study is to participants’, who are Australian citizens of Arabic-speaking origin, views about: taking medicines regularly, knowledge and feelings about diabetes, sources of medicines information, and special needs of being from an Arabic speaking background.

The second aim is to explore participants’ feedback about the use of the Diabetes Conversation Map as an educational tool in Arabic. The Diabetes Conversation Map was created by Healthy Interactions in collaboration with International Diabetes Federation and sponsored by Eli Lilly and Company Diabetes Department.

The Conversation Map tools offers an interactive and engaging verbal and visual learning experience which can enhance patients’ learning about diabetes disease, macrovascular and microvascular complications, hyperglycaemia, hypoglycaemia, pharmacological and lifestyle management of diabetes mellitus, preventing and managing diabetic complications, and the importance and assignment of goal settings for every patient.

Methods:

Focus Groups

A total of two groups of semi-structured interviews were inducted in this research. In this project, group interviews conducted in Arabic were used to explore group norms in Arabic speaking Australians with diabetes about their feelings of living with diabetes and self management of the condition. The focus group interviews explored four questions with participants: 1) feelings about taking medicines regularly, and having clear instructions about taking their medicines, 2) knowledge about diabetes and feelings about having the illness, 3) the role of their pharmacists, and the 4) special needs of an Arabic speaking diabetic patient.

This study was approved by the Human Research Ethics Committee, Royal Prince Alfred Hospital in March 23rd 2011, and ratified by the Human Research Ethics Committee, The University of Sydney, June 8th 2011.

Patients were purposively selected from the Diabetes Ambulatory Care Centre Royal Prince Alfred Hospital in Sydney/Australia. A target of ten purposively selected patients based on the inclusion and exclusion criteria was planned. The inclusion criteria for this study included patients with Type 2 diabetes, which might range from primarily insulin resistance with relative insulin deficiency to a predominantly secretory deficiency with insulin resistance, aged 18 years or older and Arabic speaking in the Diabetes Ambulatory Care Centre in Royal Prince Alfred Hospital. Exclusion criteria included patients under 18 years, people experiencing Type 1 or gestational diabetes mellitus, and patients with dementia.

This sample was selected as this investigation is a feasibility study to provide evidence to form the basis for a future larger study.

Group discussions were audiotope-recorded with the permission of the participants. Data was thematically analysed. The focus group discussions were transcribed and translated to English. Data were thematically analysed with the assistance of NVivo version 9.2 software. Emerging themes were cross analysed by another researcher in the team and thoroughly discussed until consensus amongst the research team members was reached.
Results:
Recruitment and Sample Population
Participants were recruited from those patients who regularly attended the Diabetes Ambulatory Care Centre in Royal Prince Alfred Hospital. Recruiting for this study was challenging, given a short timeframe and limited access to patient details due to privacy laws applicable to hospital outpatients. After repeated attempts at distributing pamphlets, or sitting in at the clinic to personally invite patients to participate came to no avail, with approval from the RPAH Human Research Ethics Committee ratified by the University of Sydney Human Research Ethics Committee, a list of Arabic-speaking clients was compiled by staff at the clinic. The list consisted of 150 Arabic speaking adult patients with Type 2 diabetes. Each patient was subsequently contacted by telephone, and invitation letters were mailed out, with clear description of the study in Arabic and gift vouchers offered to reimburse for travel/parking costs. However, the majority of those on the list were elderly, with many health related problems (e.g. cardiovascular, renal problems and/or waiting for major surgery), living at distant locations, some with no means to travel conveniently, and some had even passed away. Thirteen Arabic speaking adult patients with Type 2 diabetes agreed to participate in the study, but only seven actually attended the first session. Those who could not attend offered apologies due to sudden illness, change of circumstances or difficulty arranging a convenient time with family or carers. The sub-population investigated in this study was fraught with both health and socioeconomic disadvantages. However, for the purposes of this study we chose to pursue the study plan and establish the feasibility of the intervention design with this relatively small sample of participants.

Sample Demographics
The ages of the seven participants, ranged from 54 to 73 years. Lebanon was identified by participants as the predominant country of birth. Other participants reported they were from Egypt and Syria. Most participants indicated they were literate in Arabic and did not have good command of the English language. Most relied on public transport for everyday living purposes. Due to language barriers, none of our participants had ever had the prior opportunity of goal setting in collaboration with a healthcare professional, or reported that they had received diabetes related education in Arabic. Two patients were lost at follow up, one because of sudden deterioration in their health and the other due to profound disabilities.

Focus Groups Part 1
Questions Asked (Protocol)
The aim of this part of the research study was to explore participants’ views about taking medicines regularly (adherence), knowledge and feelings about diabetes, sources of medicines information, and special needs of being from an Arabic speaking background.

Themes Emerging from Focus Group Part 1 (Pre-intervention)
Seven participated in the first focus group discussion which was facilitated in the Diabetes Ambulatory Care Centre in Royal Prince Alfred Hospital right before the start of the intervention. The focus group was 35 minutes in duration and conducted at baseline before any intervention was introduced, and also served as an introductory session for participants to listen to each other’s stories and understand each other’s perspective. Themes emerging from the data, based on participant agreements on the answers to the study questions, were identified as: knowledge, state of mind, and needs of the Arabic speaking population.

Knowledge
Participants generally demonstrated poor knowledge about diabetes and related topics, which in turn has the potential to affect self management and adherence to medicines. Some participants demonstrated that they knew about issues pertinent to diabetes care, but indicated that they felt their knowledge was technically irrelevant to their traditions, cultural needs and understanding of the disease state.
Relevance

Although some of their treating doctors spoke Arabic, participants expressed a view that the nutrition information they received was based on Western diets leading to unintentional non-adherence to nutritional requirements. Participants reported the importance of their traditional Arabic diet in their lifestyle, family and culture. There was clear agreement among participants that learning about what constitutes a healthy Arabic diet would be beneficial in any discussion with an Arabic speaking health care professional and, if available, having written educational material in Arabic would support this.

“We got information based on Western Cuisine which does not suit our traditional food habits. What kind of Arabic food should we cook?” FG1 Participant 3

Communication with health care providers

All participants described how they looked for and were willing to travel afar to consult Arabic-speaking general practitioners and endocrinologists if possible, as they were the main source of advice about medicines and nutritional for them. This meant they could ask about diabetes in the exchange with doctors of the same language as most participants had poor English language skills. This facilitated patient-health care provider communication thus resulting in more knowledge gained.

“I always asked for and travelled to see my doctor as he speaks Arabic.” FG1 Participant 4

The role of the pharmacist in providing education compared to the doctors was reported to be less important to participants in the focus groups. Participants did not report having good communication with pharmacists, partly because not all pharmacists speak Arabic, thus did not expect nor understood any counselling offered. This effectively resulted in a lost opportunity for having good pharmacy-based consultation services. Most participants reported that Arabic-speaking pharmacists if available, were useful and visited them to enable communication, but noted a shortage of Arabic speaking pharmacists.

“We have never expected to get education from pharmacists because they do not always speak Arabic. We have lost a good opportunity to learn.” FG1 Participant 3

Participants in the study reported that they needed a translator when speaking to non-Arabic speaking pharmacists. In some cases they relied on a family member to translate information, but when that was not possible they could not avail themselves of the pharmacist’s counselling.

“I always go with my daughter to see my pharmacist. She helps me understand his recommendations as I do not understand English very well.” FG1 Participant 4

State of Mind

It was interesting to observe the general reaction to the question regarding participants’ feelings about their illness. Some reported mood changes; others expressed a strong faith, while some were in denial or a mixture of all of the above.

Mood

Self reported periods of low mood were common among participants in this study. This was perceived as being associated with lack of knowledge about self management behaviours, poor glycaemic control, obesity and in particular when having to start insulin treatment. As more medications were added/ changed such as the addition or changing between different types of insulin medication, they thought their condition was worsening, which lead to concurrent depression.

“Taking insulin, being overweight, and having multiple diseases; all contributed to my depression.” FG1 Participant 1

Denial

Most participants were generally concerned with and
actively sought medicines and disease information. However, some did not believe that they suffered from diabetes, stating ‘I don’t have anything’, even though they confirmed having other diseases such as hypertension, and dyslipidaemia. Due to lack of symptoms of diabetes, some even claimed not taking any of their diabetic medicines leading to intentional noncompliance and inevitable deterioration of the condition.

“I still do not feel that I have diabetes even though two doctors confirmed the diagnosis. I feel healthy and I have been living normal life.” FG1 Participant 5

**Needs**

Several measures were suggested to improve the management of diabetes in Arabic speaking patients. Participants suggested that written Arabic consumer medicines information would help in familiarising them with the side effects and contraindications of the medicines taken. Written and verbal nutrition information based on Arabic cuisine was emphasized. They also felt that the availability of Arabic speaking health professionals (e.g. pharmacists) specialised in diabetes would much improve understanding and management of diabetes.

**Arabic speaking healthcare providers**

Of the strategies participants suggested for improving their care was the availability of more Arabic healthcare professionals who specialized in diabetes. This would lead to enhanced verbal and written education and consultation provided by the healthcare professional, thus helping the patient to understand better and thereby increase adherence to self management strategies.

“I wish there were more Arabic healthcare professionals specialised in diabetes as it would be helpful and we could understand better.” FG1 Participant 3

**Therapeutic Needs**

Many of the participants reported that consumer medicines information in Arabic provided by healthcare professional speaking the same language is essential in assisting Arabic-speaking people with medicines usage. It would also provide the necessary information about possible adverse effects, and contraindications thus leading to increased therapeutic knowledge and better quality use of medicines. Participants conveyed how they had searched for such materials in Arabic, but were not successful resulting in disappointment because neither their pharmacists nor doctors knew where to find consumer medicines information in Arabic.

“I would love to see consumer medicines information in Arabic added to the English Version in place. It would help knowing the recommended doses, possible side effects, and contraindications of each medicine.” FG1 Participant 1

**Culturally Relevant Information on Nutrition**

Many participants specifically suggested written information regarding lifestyle recommendations such as nutrition information based on Arabic traditional food and diet be made available. Participants suggested that written Arabic nutrition information would particularly help individuals with diabetes as it would ideally be more culturally and socially sensitive and easier for them to understand. The participants emphasised that they would not be able and not willing to live on Western based diet. It was also emphasised they could never decline food during social and family gatherings as it is socially and culturally unacceptable.

“I cannot live all my life without eating our own food. Information based on Western food like burgers does not give me any benefit. Proper nutrition would never include burgers.” FG1 Participant 3

**Discussion (Focus Group Part 1)**

The first focus group undertaken in this study highlighted a number of important issues for Arabic speaking people with diabetes. Most striking in this cohort of patients was the lack of education about
diabetes and various methods of self-management, including lifestyle and medicines. The most significant barriers identified were language and lack of resources catering for the specific needs of diabetic patients of Arabic speaking background. Clearly more emphasis should be made on providing patient education, such as educating patients about adopting behavioural strategies for healthier eating habits. Lifestyle interventions often involve people with diabetes participating in months of sessions or groups. However, a number of studies in different countries such as the USA proved that improvement in diabetes related outcomes, such as serum cholesterol concentrations and weight, could be achieved in three to four weeks intervention. Pells et al. conducted a study where participants with Type 2 diabetes were enrolled in a four weeks intervention. The emphasis of the multidisciplinary educational program was cognitive-behavioural therapy for achieving weight control, including daily self-monitoring of meals, weight measurements, and performing physical activity. Behavioural strategies included exercise initiation, food planning, grocery shopping, and choosing healthy food in restaurants. Significant reductions were observed after four weeks in average weight fasting plasma glucose concentrations, total cholesterol concentrations and HbA1c (Normal HbA1c is less than 7% for a three months period). These strategies could be also applied during social and family gatherings.

Al-Kaabi et al. concluded that educational programs and information provided in the hospital setting for diabetes could be helpful in facilitating dietary self-management plans. Pharmaceutical care interventions in the USA, and pharmacist-lead educational interventions using goal setting in Australia, and in other countries have led to better clinical and quality of life outcomes. In Australia, this group of Arabic speaking people with diabetes generally reported that they preferred their doctors’ advice. This was attributed to the fact that patients visited Arabic speaking specialists while most pharmacists did not speak Arabic leading to either not understanding the pharmacist’s recommendations or missing opportunities for a pharmacist to educate the patient. Heisler et al. found that patient-healthcare provider shared decision making and patient provider communication were associated with higher self-management outcomes. In other studies it was found that providing tailored education services for ethnic minorities in their own language improved patient provider communication as well as health care outcomes.

Barriers to the access of medication information by people from culturally and linguistically diverse backgrounds (e.g. Australia, USA, UK, Netherlands, and France) include second language, cultural differences and of different health beliefs. Cultural differences also exist between people from different socio-economic classes. Interpreters are often used for people speaking other languages, but this strategy has the potential to lead to miscommunication due to interpreter’s health literacy or lack of medical knowledge. Schaafsma (2003) recommends bilingual healthcare providers (physicians, pharmacists, etc.) to minimise the risk of miscommunication. Important also was the recommendation that when developing written educational materials in various languages, literacy of the target population should be accounted to ensure efficacy. If the target population has poor literacy, written education materials would not be the solution. When translating educational material, the translator should be aware of the dialect of the target population. This could be achieved by an accredited English-Arabic translator where it could then be validated and used in future research. For example, educational material for Australians of Arabic descent in classic Arabic style will not benefit patients because they speak local Arabic dialect. If these approaches are applied by pharmacists, miscommunication would be avoided and access to consumer medicines information would be enhanced.

Important to consider in this group is the issue of perceived depression. Depression could lead to a decrease in diabetic control, non-adherence to self management plan, a reduction in quality of life outcomes, and an increase in diabetes related expenses. Al-Amer et al. found poor medication adherence, and low behavioural...
strategies in Jordanian people with diabetes led to higher incidence of depression. Poor metabolic control may in turn exacerbate depression and diminish response to antidepressant regimens. Cognitive behavioural therapy and selective serotonin reuptake inhibitors are weight neutral and have been associated with better glycaemic outcomes in some studies. Clinicians should address patients’ uncertainty of the diagnosis to improve diabetes specific quality of life. These could be achieved with comprehensive consultation services, providing education on prognostic concepts, self management strategies, and setting specific achievable goals. Bilingual pharmacists would be ideally placed to provide culturally appropriate and well balanced information for the Arabic speaking patients with diabetes in Australia.

**Focus Group Part 2 (Post-intervention)**

The second focus group in this feasibility study was conducted three months after the first in the Diabetes Ambulatory Care Centre in Royal Prince Alfred Hospital, with five remaining participants. The aim of this session was to gain insight into the participants’ views about the intervention, and to integrate feedback about this feasibility study into an improved intervention. Participants were asked about their views about the Diabetes Conversation Map, any changes in their level of knowledge about their condition, the goals they had achieved, and feelings about the intervention in general.

**Impressions about the Diabetes Conversation Map**

**Target Audience**

Participants agreed that the Diabetes Conversation Map would be beneficial for patients who have long standing diabetes, but even more so for newly diagnosed people with Type 2 diabetes, as it had good potential for establishing behaviour change and self management early on, leading to better clinical outcomes. They suggested that initiating the Diabetes Conversation Map educational sessions would have the best benefit when implemented immediately after first diagnosis of diabetes like what is provided for English speaking patients in the clinic. It was also viewed beneficial as it was developed in Arabic, their mother tongue, thus easy to understand and adopt advice provided.

*“The information discussed in Arabic throughout the sessions would be very important for the newly diagnosed people.” FG2Participant*

**Group Education**

Participants enjoyed the education sessions facilitated by the pharmacist using the Diabetes Conversation Map. Participants reported that they found it a valuable interactive approach for learning. They were able to interact with the pharmacist and each other in the discussion, thus forming social and professional integration. During the session, most of the discussion was done by the participants with the pharmacist leading and encouraging everyone to participate. This strategy facilitated learning and led to better health related outcomes.

*“It is an enjoyable interactive group session. I learned about HbA1c, the role of the pancreas, and complications of diabetes.” FG2 Participant*

**Language**

Participants welcomed and appreciated the Arabic version of the Diabetes Conversation Map education sessions and materials. Receiving information in Arabic was of major importance to the participants in this study. This is because they do not speak or spoke relatively little English. This strategy facilitated learning about different aspects of diabetes, and communicating with the healthcare provider (i.e. the pharmacist) and other patients in the discussion.

*“Education provided in Arabic during these sessions led to better engagement and is a valuable strategy for facilitating learning among every Arabic speaking person with diabetes.” FG2Participant*

**Difficulties with the Diabetes Conversation Map**

The researchers reviewed the Arabic version of the
DCM before implementation. The Arabic version was found to have numerous linguistic and diabetes information mistakes. The Diabetes Conversation Map was translated literally word for word rather than contextual translation, without considering the formality of the language, whether lay patients would understand it, and whether the sentences in the cards and the words in the map make sense. It was observed that translations were awkward and in several instances were unclear, incorrect or did not make sense to the Arabic native speaker.

Medications mechanisms of action were too complex and difficult for the layperson to understand. The complexity of the pharmacological part of Part 2 of the Diabetes Conversation Map was found more suited to a healthcare professional with formal education about diabetes, or cardiovascular and microvascular complications management. The language used made it even more complicated.

The nutrition information in the Diabetes Conversation Map was regarded as irrelevant to the Arabic population, as it was a direct translation from the English version which is based on Western foods and diet.

Linguistic mistakes were managed by the researchers by attaching stickers with the correct spelling or expressions in Arabic, over the mistakes in the relevant cards or on the Map itself. An example of such mistakes would be in the target measurements cards included as part of the Diabetes Conversation Map. An English back translation of the title would be “Myths Target Numbers” which would obviously confuse the patient about whether these were myths or the actual targets they should work on to achieve.

After piloting the Diabetes Conversation Map with one of the study participants, it was decided to omit this part of the map as it was regarded unnecessarily complex for participants and would not promote retention of any of its contents.

The researchers educated the patients on information based on Arabic diet from other sources published by Diabetes Australia. This information included facts about traditional Arabic food and ingredients used to prepare appetizers, main course meals, and desserts. The types of food and insulin requirements during fasting days for both Muslims during Ramadan and Christians during Lent were also discussed. At the end of the first session, nutrition and exercise brochures developed in Arabic by Diabetes Australia, New South Wales based on traditional Arabic food and diet was provided to the participants.

**Goals**

Goals were generally set by participants in collaboration with the pharmacist at the end of the first session. A target date was also set for achievement of these goals. Participants were asked about what they have achieved from the goals set in the beginning of the study at the end of the three months period. All participants achieved their goals by the end of the study and were determined to maintain the improvements.

> "I stopped the fatty delicious food that I love, and I am doing moderate level of exercise although it is difficult for me, based on my past medical history.” FG2 Participant

**Discussion: Focus Group Part 2 (Process Reviews)**

Although the Diabetes Conversation Map was viewed as beneficial and interactive by the participants, the researchers found that this tool needed some improvement. Participants greatly appreciated the information and diagrams. In line with the literature and previous studies, it was important to be prepared with such supplemental materials, which provided more information to share about topics explored by the group discussion. Overall, it is important to revise and modify the content of each part of the Diabetes Conversation Map, as well as the order in which the parts could be used to best benefit the target population. The pictures in the Conversation Map were not easily understood by participants and their concepts were a little strange to the participants as they were not culturally directed to the Arabic speaking population.
researchers and participants felt that the subject matter of nutrition and blood glucose levels could have been revisited and discussed at every session. When developing an education program for Arabic-speaking adults with Type 2 diabetes, cultural issues and literacy should be taken into account 29.

Encouraging participants to set goals using the My Goals Card included in the Diabetes Conversation Map led to better health-related outcomes. These ranged from reducing smoking to healthy eating plans. Goal setting has been shown to be a valuable approach for achieving clinical and quality of life outcomes 15.

It was also found that training the diabetes educator is important to achieving proficiency in this new role as a facilitator rather than offering didactic teaching for the targeted population with Type 2 diabetes 28. Healthy Interactions provides online tools and web lectures about the use of the Diabetes Conversation Map 28. Videos of experienced educators in role play using the Diabetes Conversation Map could be also helpful to demonstrate how to deal with different personalities, but they are not yet available 28.

Limitations

This explorative feasibility study had a limitation, which was the relatively small sample of participants, all from the Diabetes Ambulatory Care Centre in Royal Prince Alfred Hospital. This prevented collecting more meaningful data which could have further enriched the analysis. Recruiting for this study was challenging, given a short timeframe, one source of recruitment and limited access to patient details due to privacy laws applicable to hospital outpatients. To increase recruitment and participation in future studies, researchers should seek patients in hospitals in other suburbs where the majority of Arabic-speaking population live. The length of the sessions should also be decreased to make the participants more comfortable, as we found the sessions too long and the participants became tired after long hours of different activities. However for a feasibility study, the information gathered was valuable for developing future studies in this area.

CONCLUSIONS

This systematic approach to analysis of feasibility revealed significant issues with recruitment and retention that would need to be addressed for future studies or if this type of a program were implemented in clinical practice. The evaluation of the feasibility of implementing the Diabetes Conversation Map and focus groups clearly showed that numerous considerations and preparations are required to make a smooth transition into further studies that could be translated into daily practice. Nevertheless, the group-based education using the Diabetes Conversation Map was executed as planned and showed promise to improve diabetes self-management behavior.

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تقييم ذاتي لأدلة تعليمية تستخدم للسكان العرب الذين يعانون من مرض السكري في استراليا

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ملخص

على الرغم من الانتشار السريع لمراض السكري نوع 2 في استراليا، فإن العلاج هذا المرض في هذه الفئة من السكان يحتاج إلى الأبحاث. الهدف هو التماس آراء المشاركين حول: أخذ الأدوار بالنظام والمعارف والشعور حول مرضى السكري، ومصادر لمعلومات الأدوية، والإجابة على أسئلة المرضى الذين يعانون من مرض السكري باللغة العربية. جمعت وسائل تمثيلية تصحة في التحليل الطبي من مرضى السكري. فضلاً عن الخبرة للمصابين بهذا المرض. ظهرت المواضيع المشتركة وشملت المعرفة، حالة المريض، الإجابة السريري. نتائج معلومات

الكلمات الدالة: عربي، استراليا، السكري، الاحتياجات، التصورات، التقييم، التعليم.