Detection, Management and Impact of Diabetes among the Lebanese Community of Sydney: A Qualitative Study

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Abstract

Background: Diabetes is a serious global health issue which is known to be more prevalent among certain cultural and ethnic groups. While genetics may be a contributing factor, the higher incidence or difficulties in managing the disease may be attributable to cultural habits over generations. Studies have found the prevalence of diabetes among the Middle Eastern community is unusually high; however there is lack of information on prevalence of diabetes among Lebanese community in Australia. The aim of this study is to explore this group’s experience of diabetes.

Methods: A qualitative study with in-depth interviews was conducted on Lebanese migrants living in Sydney metropolitan area (SMA) who had been diagnosed with diabetes mellitus at least six months prior to the study. Participants were purposively selected from SMA surgeries serving the primary Lebanese residential communities.

Results: The findings show that lack of communication and education due to the language barrier combined with cultural differences create a difficult environment in which to treat diabetes among this ethnic minority group. It appears that the time taken by doctors and dieticians to explain the causes and effects of the disease to their patients is insufficient, that their understanding of the social and dietary customs of the community is inadequate, the usability of current treatment options is thus limited for this group, and that more appropriate treatment should be given.

Conclusion: Information on diabetes needs to be available to patients and family members in a language they understand and must extend to disease management and control in the context of their daily lives. Only when doctors, educators and public health servants diagnose, treat and teach about the disease in a social and cultural context that is relevant to their specific target group can they work in conjunction with their patients to achieve effective management and control of diabetes.

Keywords: Detection and management of diabetes; Disease risk factors; Dietary habits; Diabetes education; Dietary guidelines; Lebanese population in Australia; Psychological impact of diabetes; Food choices with diabetes

Introduction

Diabetes is becoming an epidemic of global concern. In 2011, the World Health Organization reported that 346 million people were affected by the disease worldwide and projected that mortality would double by 2030 [1]. Diabetes mellitus affects people of all ages, races, and backgrounds. There are multiple types of diabetes, the most common being Type 2, which affects some 85-90% of people with diabetes [2]. In Australia, self-reported data from 2007–08 show that 4% of the population had been diagnosed diabetes, almost twice the proportion reported in 1989–90 [3]. In 2005, diabetes was directly responsible for 3% of all deaths and contributed to a further 6% of mortalities [4]. Certain population groups, such as Australian residents born overseas and native Australians living in areas of lower socioeconomic status, are at higher risk of developing diabetes [4]. Diabetes prevalence rates have been found to be particularly high for the Middle Eastern group whose men have been shown to be 3.6 times more likely to develop diabetes than Australian-born men, and the corresponding ratio for women is 2.4 [5].

There are significant deficiencies in the data on risk factor prevalence and incidence for Type 2 diabetes in Australia [6]. For example, while the prospective Aus Diab study [7] cites the overall incidence of diabetes in Australia at 8 per 1,000 per year, it has insufficient numbers to report on the incidence or the prevalence of risk factors by ethnicity. The 2006 census recorded 86,599 Lebanese-born people in Australia, with 72.8% (54, 502) of all people with Lebanese ancestry living in Sydney, where they make up 2.3% of Sydney’s population [8]. An analysis of self-reported diabetes prevalence using data from the ABS 2001 National Health Survey indicated that the standardised prevalence ratio of diabetes among Lebanese people in Australia was 3.3% [9]. However, findings of a study using multi-stage random probability sampling to investigate the prevalence of diabetes in the population of Lebanon were significantly higher; they showed 11.3% of the population to be affected by Type 2 diabetes, increasing with age [10]. The implications of these findings for Lebanese communities elsewhere are of great concern especially in light of the increasing trend among Lebanese to live overseas and to urbanize, and the increasing prevalence of obesity and physical inactivity among this cultural group. Similarities can be found among all people with diabetes, and the Lebanese population in Sydney experiences many of the same effects of Type 2 diabetes as any other group. However, the fact that members of minority ethnic groups may experience additional culture and situation-specific difficulties must be considered.

The impact of diabetes is all-encompassing and its effects on daily life, work life and social relationships represent a significant impairment of quality of life [11]. This may cause individuals to feel disconnected [12]; for migrants who may already feel alienated from mainstream society, the impact may be overwhelming. Fatigue, the need to go to bed early, fear of losing their job and loss of interest...
in making friends may contribute to lost opportunities for social interaction or compromise their quality and frequency. Many people with diabetes experience difficulties in communication and memory lapses, which may affect conversation, further exacerbating irritation and stress [13]. As yet, nothing is known about the impact the disease has specifically on the quality of life of Lebanese people with diabetes living in the Sydney metropolitan area. However, given the prevalence of diabetes among Lebanese there and elsewhere, the propensity for life-threatening complications with diabetes and the impact of the disease on quality of life, research into this community is vital.

Risk factors and impact of diabetes

Research has shown racial and ethnic origin to determine incidence, prevalence, severity and outcomes of diabetes, mainly due to the prevalence of risk factors such as obesity, physical inactivity, and high-fat diets [14]. The AIHW report A Picture of Overseas-born Australians [5] states that obesity, poor diet and insufficient physical activity are the most significant and modifiable risk factors for developing diabetes, with genetics and environmental factors playing a role. When introduced to a Western culture and lifestyle, prevalence rates of these risk factors varies depending on the individual’s cultural and ethnic background [6]. Ethnic minorities tend to be at a disadvantage regarding their command of the main language spoken, and are often relatively deprived in comparison to the majority community [15]. They are less likely to know about services available to them, to use these for preventive care, or to access health information [16]. The focus of specific public health measures for minority communities tends to be decided by health professionals, with little or no reference to the needs of the communities themselves [15]. Thus the lack of knowledge regarding the specific risk factors and determinants for intervention among Lebanese immigrants in Australia may, in fact, be exacerbating the mortality and morbidities associated with diabetes in this population group. In order to address this gap in knowledge, this study sought to explore the experience of the condition itself, treatment, management and impact of diabetes in the Lebanese community in Sydney. In addition to ethnic predisposition, other factors including general health and wellbeing and the stress associated with their migration experience and resettlement were considered.

Methods

A qualitative study was conducted among 25 Lebanese men and women living in the Sydney Metropolitan area who had been diagnosed with diabetes for at least six months prior. A phenomenological approach was used in this study. Within the phenomenological perspective, experience is constructed within an individual’s social context [17]. An understanding of the phenomenon of experience of diabetes was explored in this study, through the analysis of the lived experiences of the study participants within their social context [17], and how participants themselves make sense of their experiences.

The participants were aged 40-55 years, the age group most commonly diagnosed with diabetes. Due to the small number of potential candidates aged 56+, no one above the age of 55 was included. Eligible participants were recruited from and with the permission of general practice clinics in the St George, Lakemba and Bankstown suburbs of Sydney using convenience sampling. This method involves recruiting participants on the basis of inclusion and exclusion criteria as they become available [17]. In qualitative research the core sample size may be anything from 1-20. The smaller the sample, the more detailed, intense and sophisticated the process of exploring the psychosocial reality needs to be [18]; a small sample size of 25 was deemed appropriate for this study.

Ethical clearance for the study was obtained from the Human Research Ethics Committee of the University of Sydney. Consent and confidentiality were considered a significant issue. A sincere effort was made to communicate the aims and objectives of the study to the participants through the covering letter accompanying the questionnaires in both English and Arabic. Participants were informed that their participation was voluntary and that they might withdraw from the study anytime without prejudice. They were given an information sheet outlining the study, its aims, what participation would entail, and how anonymity and confidentiality of the information they provided would be preserved. All of this information was reiterated before commencing each in-depth interview. Thus participants were well informed regarding the study prior to completing or sharing any information and giving their written consent.

Data were collected using in-depth interviews to explore the effects of diabetes on the participant and their families, including the side effects, management and control of the disease. An interview schedule with eleven guiding questions was used to ascertain participants’ age at diagnosis, how diagnosis was made, a description of their symptoms at diagnosis, how their quality of life was affected, what they found to be the most difficult aspects of the disease, and what the physical and emotional effects of the disease were ( appendix A). Questions were focused to identify major difficulties experienced by participants with the diagnosis and treatment process in order to establish possible ways to improve the overall experiences and outcomes for Lebanese people with diabetes. All interviews were conducted by the first author (WM) in English/Arabic, audio-taped with permission of the participant and then transcribed verbatim. The duration of interviews was between 45 minutes and 1 hour.

The method of analysis for this study was interpretation of meaning based on descriptions of experiences and events. This provides for an analysis that can be explained in day-to-day language and which summarizes events and what they mean to participants. Analysis of the transcripts was undertaken to identify specific patterns and themes and to provide illustrative quotations reflecting these themes. This involved a number of stages: First, the interviews were transcribed to revise and examine them for common or recurring themes and categories; stage two involved further organization of the themes primarily by focusing on responses to a particular question [19]. The validity of this research is dependent on proper interpretation of the data collected from the participants, accurate recording in the form of detailed notes and electronic recording (audio recording), incitement of writing/analysis of data from the beginning of data collection, and inclusion of primary data collection in the final data [20] and results writing.

Results

Background of participants

The 25 participants comprised of both males (n=17) and females (n=8) aged between 40-55 years living in the Sydney Metropolitan area. Over half (52%) of the participants were unemployed at the time of the interview; over three quarters (78%) were in the low income bracket; over two thirds (69%) of participants had received no formal education and were illiterate. All participants were migrants who were diagnosed with diabetes after their arrival in Australia. Most of the participants (82%) had settled in Australia 20-30 years ago. Nearly two thirds of the participants (64%) were married, reminder were widowed/divorced/single, and the vast majority (86%) had a large family (3-4 children) living at home. Nearly all of the participants (92%) experienced some health conditions related to diabetes. Table 1 shows that the most commonly represented age group were 46-50 years and that this
was also the most common age range in which diagnosis of diabetes occurred.

The findings concerning diagnosis and treatment of diabetes, management of the disease and its impact on the lives of participants and their families are presented under the respective headings. Participants' comments are included in support of each of the themes.

Diagnosis of diabetes

All participants were diagnosed with diabetes after migrating to and settling in Australia, and the vast majority (92%) of the participants were diagnosed with Type 2 diabetes between the ages of 40 and 50 years. Their accounts of the process of diagnosis indicate that most of them were experiencing ill-health or not feeling well but were unaware that they had diabetes until diagnosed by a medical professional.

Numerous participants went to their general practitioner based on symptoms typical of diabetes but ones they did not themselves necessarily recognize as being linked to diabetes. For example:

When I started noticing my eyesight getting worse, I thought it was age related. But then I also suffered from a stroke few years back and it was discovered that in addition to cholesterol and hypertension, I was also diabetic. (Participant 21, male, age 50)

I passed out while shopping in a mall. Then I kept feeling disoriented and dizzy for the next twenty-four hours. When I next went to my doctor he wanted me to get my sugar tested, and I was diagnosed with diabetes Type 2. (Participant 17, female, age 51)

I was having frequent urine infections and protein retention problem for quite some time. I also had a wound in my foot that did not heal and then the doctor got me tested. I never initially suspected that I will have diabetes as I have been a fairly healthy person otherwise. (Participant 18, male, age 52)

Other participants initially presented and were diagnosed with other conditions, for example:

I was admitted to the hospital with a heart disease, had pain in the chest. Had nausea and was feeling breathless. After about one month from when I was discharged from the hospital, when I went for a checkup, they also checked my blood sugars and told me that I had diabetes. (Participant 8, male, age 43)

My hypertension was diagnosed by my GP. He gave me medicines. These were working fine, but one fine morning I found that my tiredness is too much. I was not even willing to get out of bed. When I reported to my GP that evening, he suggested tests and found that I have high blood sugars, and that’s it. (Participant 10, female, age 52)

Some participants were aware of the symptoms because family members had the disease, for example:

My father was a diabetic, and the doctor told me to check up frequently. I was very worried since in my country I saw him suffering. In my 40s when I came here, it was very fine to start with. I gained a lot of weight in a short time. When I found that I am passing a lot of urine, I went to the doctor. I was 48 that time. They did blood test to find me to be a diabetic. (Participant 1, male, age 50)

In one instance, diagnosis was purely incidental:

I had applied for an insurance plan and when they asked me to get my medical check-ups, I was diagnosed with Type 2 diabetes. I would not have realized that I had high sugar levels had they not run the tests (Participant 2, male, age 55).

Three women developed gestational diabetes during or after pregnancies when no history of the disease was present and are now suffering from Type 2 diabetes. While almost half of the group was aware of presenting symptoms of the disease, the remainder was unaware that they had any blood glucose abnormalities until the test results were received. These participants were surprised and shocked by their diagnosis and ill-prepared to make the sudden lifestyle changes required managing their diabetes.

Barriers to treatment and management of diabetes

From the in-depth interviews it emerged that participants lacked the understanding of the disease, its implications and its management to adhere to the treatment and self-management plans suggested by their GPs. Numerous factors, such as poor communication, inadequate education and cultural factors contributed to their lack of understanding of what they should be doing but also to a lack of compliance with suggestions that had been understood, together creating an environment in which it is difficult to treat diabetes in this ethnic minority group.

Treatment of diabetes

Participants’ comments reflect some of the problems they encountered with understanding and complying with what is required for the treatment of diabetes. As Lebanese immigrants in Australia, many of the participants did not speak English well enough to fully understand the explanations given to them by their health care practitioners (Table 2 for participants’ comments).

Many participants emphasized the major problems in communication, namely the poor exchange of information between them and health professionals regarding the treatment and management of diabetes. Some noted that their doctor/nurse did not spend enough time explaining the treatment, its implications or the consequences of non-compliance. Participants with limited English experienced problems understanding and complying with what is required by their GPs. Numerous factors, such as poor communication, inadequate education and cultural factors contributed to their lack of understanding of what they should be doing but also to a lack of compliance with suggestions that had been understood, together creating an environment in which it is difficult to treat diabetes in this ethnic minority group.

Unfortunately the participants of the study felt imposed upon when told they must do something without being given reasons as to why they should do so.

Participant 4 (female, age 46) stated that she did not understand the importance of testing her blood sugar often and that Finger sticks can be quite painful. Patients felt testing was pointless because the results seemed inconsequential to them and of no interest to their doctors; as Participant 2 (male, age 55) stated, many doctors never ask to see home records of blood glucose levels. The Lebanese participants with diabetes wanted to be talked to about their disease.
Management of diabetes

Management of diabetes is an important aspect for controlling the disease and maintaining health. Participants were asked about how they managed their diabetes and what problems they encountered with its management. Participants reported being told to take specific medication, to lose weight, exercise more, and make other specific lifestyle changes in order to maintain appropriate glucose levels and manage diabetes. Again, however, participants indicated that communication and the exchange of information between doctor and patient regarding the management of diabetes was inadequate. It was frequently stated that doctors simply did not have enough time to sit down and patiently explain the disease, its complications, its treatment and management. (Table 3 for participants’ comments)

The above excerpts reveal that the majority of the participants were not involved in their care plan and lacked understanding of the suggested diet and treatment related guidelines. Only a few participants said that they could follow the instructions of the doctors and were able to manage the disease. Some explained that their lack of education on diabetes made treatment and management less effective as they did not understand the mechanisms behind the disease. Participants did not state if other family members were included or invited to be part of the management plan; however, they did mention that when family members were involved, their health management was much easier. For example, Participant 13 (male, age 45) stated, Sometimes I have to get hospitalized, but my family are great and they help me out in a lot of ways.

Difficulties with self-management of diabetes: The qualitative data on difficulties with self-management of diabetes show that the greatest difficulty participants experienced was in regard to doing exercise (48%), this was followed by testing their glucose levels (36%), following a healthy diet (36%) and injecting insulin (32%).

Where a participant identified having difficulties with self-managing their diabetes, he or she was asked to elaborate. The twelve participants who found exercise to be the most difficult part of having diabetes explained that they often felt too tired to walk anywhere, let alone to walk for exercise. Even if they felt they had the energy, family duties and work took precedence over exercise. Participant 5 (female, age 42) stated, The daily chores take so much of [my] time that I cannot get time to exercise. I feel very fatigued. As Participant 21 (male, age 50) expressed it: I try to walk as much as I can but am not able to be regular. I just feel tired and perhaps lazy to do much exercise. Also, I am so busy with my office that I hardly get the time to exercise. Instead, I try to control my diet.

Testing glucose levels and injecting can be difficult and painful, and many participants explained that they did not understand their glucose values, and lacked confidence in their ability to give themselves the correct insulin dose: I don’t know how to read and put a shot to myself (Participant 16, male, age 50). As a result, participants often neglected to monitor their blood glucose and did not regulate it with proper insulin injections: The most difficult or tasking part of managing diabetes is doing all the testing at odd times. It truly makes me bound to a routine that I have to adhere to wherever I am (Participant 12, male, age 52).

The other major problem with diabetes for the Lebanese Australian population is maintaining a healthy diet. Patients are advised by their doctors to avoid starch-filled foods, and to cut certain foods out of their diet completely. Patients also face difficulties with understanding their doctors’ advice, which is often communicated in English.

I cannot speak English very well. The doctor asked me about preferences in my food and about how much exercise I do. They suggested some food, but we do not eat these English foods. (Participant 1, male, age 50)

Table 2: Barriers to treatment of diabetes.

There should be someone who sits down and talks to you. Somebody should explain in my language what I shouldn’t do, but there is no one from our community there. So it is very difficult to understand how things should be. They do tell us to make changes in the diet, but they assume that we know all. (Participant 21, male, age 46)

They just say you have got diabetes, take these tablets that’s it. I want to talk to my doctor, but does he have time? My doctor got me to buy one of those things that puts a needle on your finger and do the test yourself. … I am not sure I can do it, …[I] tell him the tablets are giving me headaches, so can I cut it. He is so busy you feel you can’t talk to him. (Participant 6, male, age 43)

I wanted to take care of myself, and it would be good if I can make my own decisions. I go to my GP, but they may not know a lot about the disease and how to treat… I mean as the specialists know. They don’t ever discuss or involve me in my care. A nurse came home to show me how to make an insulin injection, but they are in such a hurry and don’t speak my language making it hard to for me ask any questions. They say don’t walk barefoot, but doesn’t tell why. Ask me to control diet, does not tell what to take. Whatever they say, we don’t take them at home...They don’t understand what it takes to poke the self over and over again and how terrifying it is to become a hypo. (Participant 5, female, age 42)

I already said that one of the important needs at my level for smooth management of this problem is education. My GP does a good job in taking good care about me, but I feel even there my need for being educated about the disease is lacking. Rather than simple advice of exercise, diet, medicines, and side effects of these medications, I often felt that most of these treatments are imposed on me. I could never really feel that I am a part of it. I also feel that I could do better in terms of food if my GP would involve me in the diet plan based on my choices. (Participant 3, male, age 48)

I have been involved in a management plan but I cannot speak English very well... (Participant 1, male, age 50)

I have never been involved in a care programme. In most cases, when I visit the doctors, the nurses would check blood sugars, ignore my records, and inform me how I am progressing towards death. Yes, I say a healthy diet is necessary, but they never have time to ask me what are my preferences or what I can afford. They tell about exercises, but never did show me what I can do with my reduced eyesight. They just don’t bother about you. They say reduce risks, and I am clueless about how to do it. (Participant 6, male, age 46)

I have never been involved in a management plan, they ask us to record sugars at home, but they don’t even see them ever. Involvement in care plan needs talking to the patient; do they have time? (Participant 10, female, age 52)

As I have Type 2 diabetes, my doctor initially gave me a few sessions about keeping my sugar levels under control, diet and activity level. I was given a diet chart and then I started doing my own research on food and diabetes and now have a strict routine and schedule for my day. (Participant 11, male, age 42)

My doctor sat me through and explained what I should expect and what I need to do. He asked about my life and schedule and then made suggestions to modify (Participant 20, female, age 44)

I used to follow my family’s instructions and my wife managed my condition very well throughout the years. Now, I do get involved with my dietician and doctor and try to give my own inputs for helping them advice me better, however is at times hard to understand and communicate due to the language. (Participant 7, male, age 53).

Table 3: Management of diabetes.
their diet replacing them with healthier alternatives. However, food plays in important part in Lebanese culture, be it the food commonly eaten throughout the day or food during festivals. Many of the foods that are recommended in diabetes management are seen as Western and not considered of a proper Lebanese diet. As one participant stated, they suggested some food, but we do not eat these English foods (Participant 1, male, age 50). Since eating foods considered healthy by the patient’s doctor entailed preparing separate food for the family member with diabetes, compliance was difficult; as one Participant 1 (male, age, 50) stated, they told me to stick to a diet with high fibres and vegetables and also told me to cut the carbs, but that is the main item in our food, so not much that I could do. Another reported, They talked about diet to control my body fat and cholesterol, but they ask me to take food which I don’t know or like (Participant 6, male, age 46). Participants indicated that different food options should also be discussed and suggested to make diabetes management more realistically achievable.

Impact of diabetes on quality of life

Diabetes can affect an individual’s life physically, emotionally, financially and socially. This section discusses how participants perceived each of these dimensions to be affected.

Physical health: Patients who suffer from diabetes deal with multiple physical symptoms and side effects of the disease on a daily basis. While the study population is no different in this regard, it is important to analyze which areas of physical health this group is most concerned with in order to understand how these symptoms, along with cultural and family influences, may lead to unregulated or poorly managed diabetes.

As asked how their physical health was affected by diabetes, including complications and side effects due to treatment of the disease, the majority of the participants named tiredness, fatigue and lower energy. Some also reported other health problems such as obesity, high blood pressure, high cholesterol, deteriorating eyesight and dental problems (Table 4 for participants’ comments).

Analysis of the data presented on the impact of physical health of diabetes showed the six most frequently identified side effects or complications due to having diabetes to be: fatigue (46%), deterioration of vision (36%), frequent infections and slow healing (32%), weight gain/obesity (58%), high blood pressure (24%), and high cholesterol (20%). Ninety two percent of the interviewees reported having at least one of the six side effects or complications.

Emotional/mental health: The in-depth interviews also asked questions about the effect of diabetes on participants’ emotional health. Eighty percent of the participants expressed feelings of depression, shame, anxiety, worry, and/or fear, with depression and fear being the most commonly felt emotions associated with the disease. A few participants indicated that they were giving up. As one participant said, You feel that it is easier to die with so many problems, living with this disease is so hard (Participant 18, male, age 52). Many participants articulated a lack of motivation and feelings of apathy towards life (Table 5 for participants’ comments).

The above comments reveal that participants were concerned that diabetes is a lifelong disease (can never be cured), and that they felt depressed, fearful and constrained in being tied down to measuring and managing blood sugars and controlling diets. Only three of the twenty-five participants reported that they suffered no significant emotional problems as a result of their diagnosis. Of interest is that two of the three were in the younger age group (45 years).

Participants expressed frustration with the lack of understanding from their support system of family and friends; many (76%) stated that they felt alienated or isolated from members of their community.

Table 4: Impact on Physical Health.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Participant 1</td>
<td>50</td>
<td>“I am gaining weight, cannot manage my diet the way it is necessary. I feel tired always. The usual chores at home seem very hard now; I feel fatigued. I am fairly irritable”</td>
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<tr>
<td>Participant 5</td>
<td>42</td>
<td>“I have high blood pressures. My cholesterol are borderline.”</td>
</tr>
<tr>
<td>Participant 10</td>
<td>52</td>
<td>“I have lost a lot of weight and at times I am overcome with tiredness. I avoid taking additional responsibilities at office as I cannot cope up with it much.”</td>
</tr>
<tr>
<td>Participant 2</td>
<td>55</td>
<td>“I am weak, tired, gained a lot of weight, have high blood pressures. My cholesterol are borderline.”</td>
</tr>
<tr>
<td>Participant 6</td>
<td>46</td>
<td>“I have to continuously track my food intake and have to be careful about my exercise and activity level.”</td>
</tr>
<tr>
<td>Participant 11</td>
<td>50</td>
<td>“I exercise and eat well and hence am able to control my sugar levels.”</td>
</tr>
<tr>
<td>Participant 7</td>
<td>53</td>
<td>“I have little control.”</td>
</tr>
<tr>
<td>Participant 20</td>
<td>44</td>
<td>“I have little control over my condition.”</td>
</tr>
</tbody>
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Table 5: Impact on Emotional/Mental Health.

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<td>Participant 4</td>
<td>46</td>
<td>“It has affected me emotionally or mentally as I continue to follow a normal life. I monitor my levels and manage my diet and my sugar levels are almost always in control.”</td>
</tr>
<tr>
<td>Participant 5</td>
<td>42</td>
<td>“I feel hard pressed to cope with my condition on top of taking care of my two sons and a husband. My days are so full already, cooking, cleaning and managing the household, and in addition to that I have to be extra careful about how I eat, how I rest and what I do. It looks like too much of work without any help or support from anyone.”</td>
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<td>Participant 6</td>
<td>46</td>
<td>“I have lost all the time all the time, almost am terrified all the time, afraid to go out. I cannot walk fast, heart problem.”</td>
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<tr>
<td>Participant 2</td>
<td>55</td>
<td>“I am definitely overweight now, feel thirsty all the time. I am gaining weight and cannot manage my diet the way it is necessary.”</td>
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<td>Participant 11</td>
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Lebanese families are usually large and extend to many members. In some minds it is unreasonable for a member with diabetes to expect to have separate foods prepared from those that everyone else will be eating. As one participant commented: This disease has affected my confidence and performance. I have ceased to go to social gatherings; mainly I tend to conceal my disease; and in our culture, forcing food in social gatherings is a norm. I want to avoid it. Sometimes I eat in front of them, but later go to the wash room to vomit it out (Participant 17, female, age 51). Therefore the family member with diabetes tends to stay at home instead of visiting relatives and friends to avoid the fuss and difficulty of having dietary restraints. One participant seemed to have overcome this difficulty: We just love to have food together. I avoid even social gatherings earlier. But when I discovered that these are making me alienated, I started attending these gatherings. I don’t feel embarrassed anymore if people ask me questions and I freely share my stories with them. However, I avoid food in these social situations (Participant 7, male, age 53).

Work

Over half (52%) of the participants were unemployed at the time of the interview. Many participants stated that their incomes had decreased significantly as they were unable to do their jobs fully or were unable to work at all. As one stated: My life is that of a convict, waiting for the next dose of insulin and the food. I don’t earn…I don’t work, and I am useless (Participant 2, male, age 55); another said, I cannot work as I would have been able to before. My income is definitely less (Participant 1, male, age 50). Not only did the inability to maintain work affect participants’ financial situation, their self-worth and self-esteem suffered as well. As Participant 18 stated, I feel angry and irritated, it’s unfair that I cannot work. I am now homebound, without work, and home feels like a hospital. When I see other people exercising, I feel very uneasy, I just look away to something else on the other side, and I understand I am no longer up to it (Male, age 52). Participant 4 stated, I have stopped working: my days pass at home thinking about my future and the other diseases yet to come (Female, age 46). However, this was not the case for another participant who found work took her mind off the illness: I work both at home and at my husband’s office, I get great support and love from my family, which more than compensates for my illness (Participant 20, female, age 44).

Social life

Three open-ended questions in the in-depth interview asked participants whether they felt different from people who did not have diabetes, and how the disease had affected their quality of life, particularly economically and socially. Seventy-six percent of participants indicated that they felt isolated and different. Most were uncomfortable or embarrassed by tiring easily and the need for frequent urination. They also expressed irritation and resentment that others did not have to constantly worry about what they ate. Some even felt a sense of shame in having diabetes. Participants also perceived that people who did not share the disease could never fully understand and appreciate its effects. You won’t understand this unless you suffer, nobody understands. Ever since I have been diagnosed my sense of self has been pretty unsettled. Outsiders who do not have diabetes would never understand your problems. Even your doctors would fail to feel your problems. Now I have ceased to tell people that I am diabetic (Participant 2, male, age 55).

The majority of participants felt their lives revolved around their diabetes. The extracts in Table 6, encapsulate the feelings of many participants concerning the effect of diabetes on their social life.

For many participants diabetes had, in a sense, become their life. A diagnosis of diabetes could lead to negative experiences and what amounted to a life sentence of worrying, shame, fear, alienation, pain, and isolation. Younger women found it more embarrassing than the men of their age group, while men 50 and over found hard to socialize.

Discussion

The main aim of this qualitative study was to understand how diabetes, diagnosis of the disease, treatment and management are experienced by and impact on Lebanese people living in Sydney, Australia. In this discussion the key findings of the study are compared with the existing literature and are presented under four major headings: Knowledge and understanding of diabetes, Gaps in education and information provision by health care providers, Self management of diabetes and difficulties encountered, and Impact of diabetes on quality of life.

Knowledge and understanding of diabetes

The results showed that the majority of the participants were diagnosed with diabetes ‘accidentally’, largely because language barriers and lack of knowledge about the disease prevented them from recognizing their symptoms as potential indicators of diabetes. They had little knowledge regarding the implications of diet, exercise and
blood glucose control. The majority of the participants were diagnosed when receiving treatment for or investigating other health problems. Some were diagnosed accidentally. Most were unaware or had no knowledge of symptoms of diabetes, except for those who had a family history of diabetes. A similar observation was reported in a study among an Appalachian population [21]. In their study, participants from the general population knew very little about diabetes, and those with diabetes knew little before diagnosis.

Since many study participants do not speak English well, and have low or no formal education, they are unable to fully understand the disease and its implications as explained to them by their attending health professionals. When people diagnosed with diabetes, for which the treatment and management required are complicated, it is vital that they understand all these details if they are to be both convinced of the necessity and able to comply with the major changes in diet and lifestyle that are required. Given the poor literacy levels among the study participants, reliance cannot be made that they will inform themselves independently of anything they are unclear about. Instead, it is imperative that health care professionals ascertain that their patients have understood everything they need to know and that all their questions are answered in their face-to-face consultations.

**Gaps in education and information provision by health care providers**

Results showed that a number of participants perceived health professionals as lacking an understanding of their ethnic food and cultural practices when recommending diets and planning management of the disease. These findings are consistent with those of Colagiuri and colleagues, who note that the lack of ‘culturally specific knowledge by health professionals has been found to affect access to services across all cultures’ and to result in the same outcomes as evidenced in this study, namely, ‘inappropriate dietary education and treatment advice that is not complied with, resulting in the person being labeled as difficult and the health professional decreasing or withdrawing their assistance’ [6]. They also support findings that language barriers, literacy rates, effects of stigmatization, lack of access to culturally specific care, religious beliefs and cultural practices have been found to contribute to the risk of diabetes and act as a barrier to accessing health care services [9]. In the US, research has shown that ‘language barriers contribute to health disparities among Latinos with diabetes. Limited English proficiency was found to be an independent predictor for poor glycemic control among insured US Latinos with diabetes, an association not observed when care was provided by language-concordant physicians’ [22].

The results of a study conducted amongst ethnic groups in the UK suggested that people were not clear about the nature of diabetes or the importance diet played in its management [23]. Our results corroborate these findings. Most participants found the advice they received from their doctor was in a foreign language (English) while the food they were recommended to eat was Western food they were not used to. Lawton and colleagues [24] concluded that the relevance of dietary advice given to Indian and Pakistani people in the UK was limited because the information focused on European food. Dietary change can only be promoted if recommendations are relevant to people’s usual diets. To increase their understanding of their diet and the disease, people with diabetes should be reviewed by a dietician immediately after diagnosis and at regular annual intervals [25]. Without regular reviews and clarification, they may find it difficult to incorporate the dietary advice they are given.

**Self management of diabetes and difficulties encountered**

It has been shown that lack of awareness about lifestyle-associated factors increases the risk of diabetes. The results of the present study showed that in most cases participants’ lifestyles, in particular the cultural components of their lifestyles, were not considered in the management plan; instead, dietary options were simply imposed and hence found difficult to adhere to. These findings suggest that doctors and dieticians need to take more time to explain the causes and effects of the disease and how best to treat it, and, of course, to do so within an understanding of the specific social and dietary customs of the community.

An immigrant who does not speak the language in which his/her illness is explained can certainly never have a full understanding of the disease. Our results showed that participants had difficulties following the instructions given by their health care providers since these were in English. However, the effective management of diabetes requires substantial knowledge, self-management and ongoing interaction with the medical system. Patients with limited language proficiency and diabetes may thus be particularly vulnerable to the challenges posed by inadequate communication [22].

Among functionally independent patients with diabetes or heart failure, family support and family barriers were found to be significantly associated with patients’ self-management adherence [26]. In the Lebanese community, where language forms a barrier to information and thus understanding, the effect is two-fold: The person with diabetes frequently lacks a thorough understanding of the risks of the disease and the need for careful management and treatment, while their family, who are usually equally inadequately informed, lack the detailed understanding they would need to be supportive. Information needs to be made available to patients and family members in a language they understand and with suggestions that relate to the activities of their daily lives.

The results showed that for many participants the diet prescribed by the treating doctor was not compatible with their lifestyle and culture. People from other minority ethnic groups have been found to experience similar problems with diabetes dietary advice [27]. In terms of dietary advice, healthcare professionals rarely recognize and address barriers to healthier lifestyles in minority ethnic groups [28]. In a study of British Pakistanis and Indians, it was recognized that food has a specific value and significance among different ethnic minority groups [24]. If people are aware of healthier options within their traditional food choices, they may be more willing to compromise. Healthcare professionals need to talk to people about their eating habits, and reinforce this advice with leaflets suggesting healthier traditional food options. This could include healthier ways of cooking their favorite meals without compromising the taste [29].

**Impact of diabetes on quality of life**

The in-depth interviews showed that diabetes affected Lebanese immigrants’ physical, emotional and social life. Psychosocial distress has been found to impact negatively on patients with regard to initiating and maintaining recommended self-care [30]. This was confirmed by participants of the present study, who repeatedly cited the psychological and emotional stress they experienced as a result of diabetes as impeding their management and compliance with the treatment regime. A great majority of the study participants (80%) indicated emotional distress due to diabetes, experiencing feelings of depression, shame, anxiety, worry and/or fear with depression. Fear was common and a few participants indicated that they were ‘giving up’. The findings on the association between diabetes and depression are not conclusive and range from people with diabetes...
frequently attributing depressive mood to adversities and difficult life circumstances rather than the impact of the disease itself to depressive symptoms being associated with the deterioration of quality of life [31]. The current study supports the suggestion that individuals with both diabetes and depressive symptoms were less satisfied with their treatment, worried more about the impact of diabetes in the future and about the social and vocational impact of diabetes [32].

As Aitken and colleagues note, there may be pragmatic constraints on lifestyles imposed on by diet such that many individuals may feel disconnected [12]. Indeed, the social awkwardness posed by a restrictive diet in a culture where food and communal eating play such a significant part cannot be underestimated: For some participants the awkwardness was sufficient for them to avoid social gatherings altogether; others felt pressured to ignore their dietary restrictions and risk their health instead. Participants experienced feelings of being isolated and excluded and reported curtailing their social life for fear that people around them might not understand them and their problem.

The physical effects of diabetes – fatigue, easy exhaustion, the need to go to bed early, the need to urinate frequently and forgetfulness – are known to feel overwhelming to sufferers of the disease and to impact directly on their social life in the form of lost opportunities to interact socially or to compromise in the quality and frequency of such interactions. In a migrant community in which individuals are already alienated from the mainstream, the impact of such symptoms may actually become too much to bear.

The Lebanese participants in this study frequently felt that no one else understood their situation or experiences of living with and trying to manage their diabetes. In this regard, they may very well be correct. If a doctor does not ask a patient what his or her preferences are regarding diet, exercise, and taking or injecting medications, the patient will never feel that their treatment is specifically tailored to them and will continue to believe that the doctor simply ‘does not understand or care’.

It is known that changes in diet and increased physical activity can bring about changes in prevalence of diabetes. This at-risk community must be persuaded to align to the current Australian guideline of maintaining ‘healthy body weight by balancing food intake and regular physical activity’ [33]. To be able to do this awareness and diabetes education are the most pertinent steps. The best way to achieve this is through culturally and linguistically sensitive communication tools used by informed healthcare professionals [34]. Interpreters are already available to participate in the diabetes care delivery system, but the utilization of community leaders, and the dissemination of information and religiously sensitive dietary advice via Lebanese doctors and health care professionals, and via brochures and television and radio awareness programs in Lebanese may solve the problems of participation in diabetes awareness and management of the disease [35]. It has been indicated that focus group participation of the Lebanese community may address their problems more specifically, and that healthcare interventions designed in consultation with them may prove to be more readily accepted and demanding of interest from them [36].

Limitations of the Study

Since the qualitative study was based on a small sample (N=25), no reliable generalizations for the larger Lebanese community in Sydney or elsewhere or for other ethnic groups with similar characteristics can be extrapolated from the findings. However, these findings have suggested areas of relevance that should be investigated further among a larger sample.

The findings of the study suggest that the majority of the participants emphasized the negative impacts of diabetes on both their physical and emotional health, and that only one participant had effectively applied strategies to overcome these. This suggests that there may have been a selection bias in response to recruitment for the study, i.e. only those who were having significant problems with their diabetes were interested in participating. Further study with a larger sample from Lebanese communities and similar other ethnic groups may provide a better understanding of barriers to self management of diabetes and impacts of the disease in these communities.

The results show that the difficulties experienced by some of the participants in managing their diabetes may not be related to their migrant status but rather to their socio-economic status, frequently on the lower end of the spectrum. Further research is needed to explore this issue by comparing this group with English native-speaking Australians of a similar socio-economic background with diabetes.

More research is also needed to pinpoint problem areas and risk factors specific to diabetes in the Lebanese and other similar communities in Australia so that these groups may be more effectively included in the mainstream care delivery in the future.

Conclusions

The Lebanese population of Sydney with diabetes is no different from other groups with diabetes in regard to when their disease is diagnosed or what symptoms are prevalent. The majority of the participants were unaware of any symptoms of the disease, and were diagnosed ‘by accident’, or when receiving treatment for or investigating other health problems. However, there are stark differences between the cultural and social practices of this minority group compared to the majority living around them, and these differences have a significant impact on their experience of the disease.

The primary barrier preventing participants from fully understanding their disease and from discussing treatment options with their medical doctors was language. Such lack of understanding in turn prevents people with diabetes from explaining their disease to their family and others in the wider community, and communicating the seriousness of the disease and the implications any mismanagement. Communication between doctors and the study population was further impeded by what patients perceived as their doctors’ lack understanding of the cultural preferences and practices of their community. Without an understanding of the significance of certain foods in an ethnic diet, doctors may not be aware of the barriers to implementing their suggestions. Since a patient is unlikely to maintain a suddenly and drastically altered diet contrary to a lifetime’s eating habits, a valid food-frequency questionnaire could provide the best basis on which to develop pertinent but culturally compatible changes.

Information regarding the disease must be made easily and readily available to patients’ families, friends and their community. This will improve the community’s understanding and hence support of the needs of the person with diabetes. Given the poor literacy levels among the age cohort of this and potentially other migrant population groups, this could perhaps be achieved by operating a diabetes advice clinic to which newly diagnosed or struggling patients and their families can be referred. Empowerment is the most important measure that can build on community partnerships and collaborations between the healthcare
delivery system and the Lebanese population where interest can be generated automatically.

**Implications of Findings for Health Professionals in Health Care Delivery**

Participants repeatedly mentioned being told to change major aspects of their lives but not why. Until other services become available it must be assumed that patients are unable to inform themselves further or research details they have forgotten or are unsure about on their own, and that it is, instead, the duty of health practitioners to explain everything. Until they do, diabetes will continue to go under-treated and under-managed. Health care practitioners and nutritionist also need to consult the individual in order to establish healthier meal plans that will not culturally alienate members of a specific ethnic group. In regard to Lebanese people with diabetes, it is important that doctors understand that many of the changes they expect patients to make are made more difficult by virtue of the fact that their culture largely revolves around the very areas that need altering.

While cultural competency is important, health care providers should be aware that ‘there is something more basic and more crucial than cultural competency in understanding the life of the patient, and this is the moral meaning of suffering—that is, at stake for the patient; what the patient, at a deep level, stands to gain or lose’ [37]. Where no doctor with similar cultural and social background is available, it is vital that patients have access to a medical translator in order to decrease the feelings of separateness, isolation and confusion they are likely to experience.

For Lebanese and other ethnic populations to have more positive experiences involving their diabetes, services that cater specifically to these groups must be made available. Heath and colleagues [38] contend that this can be achieved through the development of partnerships and empowerment of the community group in question. Health care professionals and patients must work together to shape the treatment and management of the disease around patients’ lifestyles rather than trying to shape each patient’s life around treating the disease.

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