Experiences of diabetes self-management: a focus group study among Australians with type 2 diabetes

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Aims and objectives. The aim of this study was to explore the experiences and concerns of individuals with type 2 diabetes mellitus, in a predominantly low socio-economic setting.

Background. Currently, approximately 1 million Australians have diabetes and rates have more than doubled since 1989. Type 2 diabetes mellitus accounts for approximately 85% of diabetes cases. Risk factors include obesity, older age, low socio-economic status, sedentary lifestyle and ethnicity. Older individuals from low socio-economic backgrounds are particularly at risk of both developing and of mismanaging their condition.

Design. Exploratory qualitative design.

Methods. Focus groups were used to collect data from 22 individuals, aged 40 to more than 70 years, with type 2 diabetes mellitus, who were attending local health services for their diabetes care. Focus groups ranged in size from four to eight individuals and all were recorded, transcribed and analysed. Data were analysed using a thematic analysis approach.

Results. Participants described their experiences of managing their diabetes as emotionally, physically and socially challenging. Data analysis revealed four main themes including: (1) diabetes the silent disease; (2) a personal journey (3) the work of managing diabetes; and (4) access to resources and services. Throughout, participants highlighted the impact of diabetes on the family, and the importance of family members in providing support and encouragement to assist their self-management efforts.

Conclusions. Participants in this study were generally satisfied with their diabetes care but identified a need for clear simple instruction immediately post-diagnosis, followed by a need for additional informal information when they had gained some understanding of their condition.

Relevance to clinical practice. Findings reveal a number of unmet information and support needs for individuals with type 2 diabetes mellitus. In particular, it is important for healthcare professionals and family members to recognise the significant emotional burden that diabetes imposes, and the type and quantity of information individuals with diabetes prefer. It is also important to consider levels

What does this paper contribute to the wider global clinical community?

- This paper highlights the emotional burden of type 2 diabetes.
- It draws attention to unmet information needs of patients with low health literacy.
Introduction

Type 2 diabetes mellitus (T2DM) is one of the most prevalent chronic diseases in the developed world (Bays 2012, Khalil et al. 2012, Carolan-Olah et al. 2013), and this prevalence is now considered to have reached epidemic proportions (Zimmet et al. 2001). Risk factors include lifestyle factors such as sedentary lifestyle (Reeves et al. 2013), obesity and poor diet (Everson et al. 2002, Bays 2012), particularly excessive carbohydrate consumption (Gross et al. 2004) and low socio-economic circumstance (Everson et al. 2002). Ethnic characteristics also contribute and individuals from Polynesia, Asia, South Asia (Indian sub-continent) and Aboriginal heritage are considerably more likely to develop T2DM (AIHW: Australian Institute of Health & Welfare 2011).

Background

Type 2 diabetes mellitus rates have increased dramatically in the past two decades, in tandem with increasing population rates of obesity (Zimmet et al. 2001). This situation is a serious concern, as T2DM is strongly associated with severe health effects, caused principally by micro and macrovascular changes (Pagano et al. 2013). These changes give rise to a number of co-morbidities such as cardiovascular disease, renal disease, peripheral neuropathies, visual deterioration (Bays 2012, Khalil et al. 2012) and more recent evidence suggests a link between diabetes and cancer (Johnson et al. 2012). T2DM also contributes significantly to early and excess mortality from co-morbidities (AIHW: Australian Institute of Health & Welfare 2008).

In Australia, where this study was conducted, T2DM rates have increased dramatically in the past two decades (AIHW: Australian Institute of Health & Welfare 2011), and current estimates indicate that as many as 1.5 million individuals may be affected, many of whom are not yet diagnosed (Diabetes Australia 2012). Experts predict that this trend of increasing T2DM is likely to continue and most possibly escalate, due to rising rates of obesity (Atlantis et al. 2009, Khalia et al. 2012). At present, T2DM is considered to contribute 6% to the total disease burden annually in Australia (AIHW: Australian Institute of Health & Welfare 2008), which makes it one of the most urgent health challenges of the 21st century.

Although T2DM has very serious implications, when the condition is well managed, health outcomes are greatly improved (Siminerio et al. 2013). Self-management forms the basis of diabetes care and requires knowledge, skills and motivation as it requires modification of the diet, monitoring of blood glucose levels and an increase in exercise undertaken. Factors that inhibit self-management, and which have a deleterious effect on glycaemic control, include: limited education and poor health literacy; misunderstanding about the disease (Holmström & Rosenqvist 2005, Carolan et al. 2010); low socio-economic status (Abouzeid et al. 2013); and limited access to health services (Kim et al. 2007).

This project aims to explore the experience of diabetes care and access to resources and services, for individuals with T2DM in a socially and economically disadvantaged area, in Australian terms (ABS: Australian Bureau of Statistics 2011). The area in question is also one of the most culturally diverse regions in Victoria, with as many as 20% of the population having been born overseas and up to 36% speaking a language other than English at home (Department of Human Services 2002). High rates of T2DM and limited access to care compound the health dilemmas of this community. Focus groups were conducted in Vietnamese, Italian and English, reflecting the ethnic and cultural profile of the region. This paper reports on the English language focus groups. Vietnamese and Italian focus group findings have been reported earlier (reference withheld for blinding).

Methods

Data collection

Four focus groups of four to eight individuals were conducted in English using a number of open-ended questions (see Box 1) and this number of focus groups was chosen.
as likely to provide sufficient information on the phenomenon, and as congruent with other similar health studies using this method, where samples often range from 12–40 participants in three to six focus groups (Tammaru et al. 2010, Liamputtong 2011, Cooke & Thackray 2012, Komatsu & Yagasaki 2014, Liljeroos et al. 2014). This particular approach was chosen as an efficient means of accessing a number of individuals with T2DM, within a relatively short timeframe. Moreover, a key characteristic of this method is its social orientation, which promotes social interaction between group members, who share certain experiences, and we aimed to take advantage of this feature. In this study, all members had been diagnosed with T2DM and lived locally, and we therefore expected participants to be interested in each other’s experiences (Johnson et al. 2012, Currie et al. 2013) which should stimulate participants to collectively engage in a sense making endeavour. Similar findings of social interaction are reported in other health-related studies, using focus group methods (Bays 2012, Noto et al. 2012). Data were collected by external focus group facilitators and scribes, who were trained in sensitivity and in conducting focus groups. Focus groups opened with a general introduction of the facilitator and scribe and an overview of the purpose of the discussion. Initial questions were broad based and participants were encouraged to explore the concept of health and ‘feeling healthy’ prior to more targeted questions, such as the daily impact of diabetes. Focus groups were closed after all questions were answered and invitations for further comments and questions were exhausted. Participants were then thanked for their participation, the discussion concluded with a reminder that an overview of findings would be mailed to interested participants who wished to leave their contact details. Participants were then invited to partake in refreshments.

All focus groups and interviews were audio recorded and transcribed verbatim. Ethics approval was granted prior to study commencement and written consent was obtained at focus groups. Pseudonyms were used to protect participant confidentiality.

## Participant selection

Participants who met selection criteria were enrolled on a first-come first served basis. Selection criteria included: diagnosis of T2DM mellitus; living locally (defined local suburbs); English speaking; and, attending local services for diabetes care. The area in question is considered a low socio-economic area by Australian standards (ABS: Australian Bureau of Statistics 2011). Participants learned about the study through recruitment flyers which were posted at local community health centres, hospitals, general practitioner waiting rooms, local newspapers and social media. Administrative staff members were available to describe the project and to make researcher details available for contact. Interested individuals were also provided with an information sheet to take home and discuss with family members. Drop in sessions were organised for likely participants to ask questions and voice concerns, however, most participants contacted researchers directly for information. Participants who agreed to take part in focus group sessions, had their contact details forwarded to the research team, who convened the groups and coordinated attendance with the participants. All four focus groups were held at local community centres in July 2013. Each lasted approximately one hour. Participants were given a store gift voucher to

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### Box 1. Questions

| Question 1: | What does feeling healthy mean to you? | Why? | How has diabetes affected your health? |
| Question 2: | What was it that encouraged you to take action in managing your diabetes? | | |
| Question 3: | Who do you currently see/go to for your diabetes care? | | |
| Question 4: | How did you find out about services/information about diabetes? | What would make you look for more information? | |
| Question 5: | What daily impact does diabetes have for you? | What is most difficult about managing your diabetes? | |
| Question 6: | Some people are reluctant to access services, what do you think would assist these people to access diabetes care? | | |
| Question 7: | Whose job is it to inform the patient about all the service options (for multidisciplinary holistic care) which may be available to them? GP? Practice Nurse? Diabetes Educator? Specialist? | | |
| Question 8: | What do you expect of health service providers? | | |
| Question 9: | What are the barriers/what makes it difficult to accessing your local diabetes services? | | |
| Question 10: | What would help you access those services? | | |
| Question 11: | Have you ever received (or been offered) information in your own language? If so, types of information and where? | | |

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compensate them for their inconvenience, consistent with Liamputtong's (2011) suggestion that focus group participants should be compensated for their efforts, including travel and time.

Data analysis

Data were transcribed verbatim, de-identified and forwarded to research team members. Data Analysis was undertaken by hand using a qualitative framework, informed by Burnard’s thematic analysis (Burnard 1991) approach. Two researchers analysed the data independently. The following steps guided the process:

1 Reading and re-reading transcripts.
2 Writing up memos of emerging ideas.
3 Seeking out common concepts, ideas and perceptions.
4 Co-researchers independently undertook steps 1–3.
5 Meeting of co-researchers to critically discuss emerging themes.
6 Classification of concepts into themes.
7 Discussion continued until consensus was achieved.
8 Returning to the data to seek alternate meanings for themes (Burnard 1991, p. 462–463).

Results

Demographic data revealed a diverse sample in terms of age distribution, ethnic origin and time elapsed since diagnosis of T2DM. Participants were aged from 40 years to more than 70 years, with the majority (13/22) aged more than 60 years (Table 1). All spoke English, however, more than half (12/22) spoke another language at home. Ten participants were male (m) and twelve were female (f). Length of time since diagnosis ranged from less than six months to 40 years. The majority (19/22) had been diagnosed more than one year previously. Educational level was consistent with the area’s Socio-Economic Indexes for Areas (SEIFA) profile (ABS: Australian Bureau of Statistics 2011) and the majority of participants had attended some High School, and a very small number had attended university.

Themes

The experiences of living with T2DM and of accessing services were described in detail by participants in this study, many of whom had minimal knowledge of diabetes prior to diagnosis. A considerable number had been incidentally discovered to have high blood glucose levels during lifestyle screening procedures at shopping centres, or during a routine visit to their family doctor. These participants had then been referred for glucose tolerance testing and had subsequently received their diagnosis of T2DM. Many had never considered they were at risk of diabetes. Doris(f) explains:

I didn’t even know I had diabetes until I went … I did the prevention course because my husband… His doctor said to him, “If you don’t change your lifestyle … you could end up with type two diabetes.” … It was from that course that the dietician there… I came to know that I was a diabetic. I just thought diabetes was sugar. You check, you cut sugar and you’ll be all right. No. [not so simple]… Doris (f)

Overall, four main themes emerged from the data analysis, and together they shed some light on participants’ experiences of living with diabetes, managing their disease and of accessing resources, services and support. Themes include: (1) diabetes the silent disease; (2) a personal journey (3) the work of managing diabetes; and (4) access to

Table 1 Demographic characteristics

<table>
<thead>
<tr>
<th>Number of participants</th>
<th>Gender</th>
<th>Age</th>
<th>Time since diagnosis of type 2 diabetes</th>
<th>Home language spoken</th>
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<td>22 Participants</td>
<td>Male</td>
<td>10</td>
<td>40–49 years</td>
<td>&lt;6 months 2</td>
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<tr>
<td></td>
<td>Female</td>
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<td>50–59 years</td>
<td>&lt;1 year 1</td>
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<td>60–69 years</td>
<td>1–2 years 5</td>
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<td>2–5 years 5</td>
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<td>Mandarin/other 3</td>
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<td>Chinese language</td>
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<td>Eritrean 1</td>
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resources and services. Throughout, the role of the family, in motivating, supporting and encouraging participants, and occasionally in directing them to more healthy choices, was evident. These themes are described below.

Diabetes the silent disease
Participants, in this study, rated their experiences of living with diabetes as physically, emotionally and socially challenging. This included coping, on an emotional level, with the unseen but potentially deadly effects of diabetes, at the same time as making major lifestyle changes, in terms of food eaten and exercise undertaken. For a number of participants, the insidious progress and chronic nature of the disease made it burdensome emotionally, and some participants had difficulty coping:

When I start sugar diabetes sickness, all my strength slowly, slowly declines and the level [of illness] is always going up... so much damages, slowly, not straight away. Other sickness maybe kill people in one year, 6 month or heart attack they pass away. Diabetes, damage, damage, damage... Lee (m)

I thought it was a monster sitting on my back and not letting me do things with my Grandchildren... Violet (f)

Almost all participants had experienced some co-morbidities and were fearful of what additional complications they might face in the future. The unseen nature of complications gave rise to uncertainties and caused participants to refer to diabetes as a silent or invisible disease:

Diabetes in itself doesn’t have very physical symptoms, so it’s silently affecting different parts of your body... It’s not contained within itself... the eye, the nerves, the kidneys, the liver. Eventually it moves on to different parts of the body... Margaret (f)

Once you’re diagnosed with diabetes, the risk of heart attack and stroke, and all that, your kidneys, it affected everything. I’ve got friends that have lost both legs... Susan (f)

Living in fear of what is going to be next affected. At the moment, I’m having some nerve problems and that’s really concerning me. Violet (f)...

A personal journey
These features of diabetes made the experience a very personal one, and participants experienced a range of emotions, particularly in the early stages, before accepting their disease. Common reactions were distress, disbelief and a feeling of unfairness at a diagnosis they were not expecting:

You’re depressed sometimes. I can’t eat certain things... it’s always there... Milly (f)

That’s what I say to my husband. My husband is diabetic but his family all, they have it. My family no one got it, only me? I say [to God], why you give me the disease? Xiao (f)

Although participants continued to experience a range of emotions, these feelings had diminished over time and most realised they needed to accept their disease and to take responsibility for controlling their blood glucose levels. The majority understood clearly that the responsibility for managing their diabetes and reducing the likelihood of complications, rested with themselves, and whatever support they could garner, particularly from family:

I’ve realized... you don’t need to wallow in your misery. Get over it. You’ve got to accept it. Tom (m)

I’ve taken control of my life because you have to. You have to go in to bat for yourself, and I don’t wait for anyone to tell me when to have a blood test. I tell the doctor I want a blood test. I get a lot of referrals... Clementine (f)

This level of personal responsibility meant that having diabetes gave rise to feelings of loneliness and isolation as participants took on the tasks of managing their diabetes.

Some exemplars follow:
I was wallowing in misery for the first few months. You think you’re the only one... Tom (m)

I’ve got a son who’s just been diagnosed and his wife hands him his tablets, and I said to her, “You shouldn’t be doing that. That’s his journey. He’s got to do that.” No one can live your life once you’re a diabetic... Maria (f)

Although aware of the responsibility to self-manage their diabetes, a number of participants found it difficult to put into practice what they had learnt at diabetes classes and to find the personal motivation and resources to effect the significant behavioural modifications required, as below:

I think that the information is there, it’s just that we don’t actually want to accept [it]... We know what to have [eat]. Part of us just don’t [sic] want to accept this is what we need to do... Tom (m)

...I’ve put everything I can not to think about the negative issues and basically concentrate on doing what needs to be done to help myself and it’s not for anyone else except yourself. That’s probably the motivation that I guess everyone needs and it’s really hard if you don’t have enough resources or anywhere else to turn to... James (m)
On the other hand, a smaller number of participants indicated that they were grateful for having been diagnosed and viewed their diagnosis as an opportunity to learn about and to adopt measures to improve their health:

I guess I have to say I was thankful because it’s changed my life for the better. Julie(f)

I think the most important … in diabetes you can’t actually change the [disease] You can change the story. [Its] one of the few diseases where you can change the ending to your story by doing something about it… Paul(m)

Doing the exercises. I found it’s very, very healthy. It’s benefited me in a lot of ways and given me motivation to live a little longer. Violet(f)

Work of managing diabetes

Participants rated the work of diabetes self-management as difficult and raised a number of concerns, including a need to commit to a meal schedule and to have food prepared in advance. Some participants complained of a loss of enjoyment of food and suffered from cravings and feelings of deprivation. There were two sub-themes: the family, and difficulties with food, which included a loss of spontaneity.

The family

A number of participants raised concerns about the impact of their diabetes on the wider family and were keen not to be a burden on family members. Some felt their relationship with family members was impacted by the additional doctors’ and other appointments they must now attend and the extra work of managing their disease. These extra requirements had the effect of reducing the time they had available to assist sick or ageing parents and spouses, or to devote to their children or grandchildren:

She [wife] need my health…I am carry sometime my wife and she can’t go to long distance, wherever. She many operation, still get some operation, very big operation. I am so much tired. When she’s sick, my sugar level, diabetes low. After she sick, my sugar level rise…. Appointment time …waiting the doctor, too much queue. Before we go in the hospital and … waiting 10–15 minutes, see the doctor. Now two or three hours, I am waiting for the doctor…. Too much going on. Children, mother and father, always think for the children. Big impact…. It affects other family members too. Shei (m)

Nonetheless, despite the concerns, the family was also a motivating factor and participants were encouraged to adhere to diet and exercise regimes to minimise complications and to live longer. Some described spouses and children as motivating them to remain healthy, and this motivation took the form of support and encouragement and also of monitoring and commenting on their behaviour. Participants’ quests for health were also driven by the desire to be present and to fully participate in future family events, such as weddings:

… I don’t want my kids to see me struggling… Vince (m)

Your families have concern for you, your family members as well. You do not want to be a burden on them. We want to take care because we want to be, not to become blind or kidney failure, get gangrene. We don’t want all that so we take utmost care… Chen (f)

To be there when my son gets married, my oldest boy. I’ll be happy… Andre(m)

Difficulties with food

Participants described a number of difficulties with the food they ate and for some significant dietary changes were required, including regular scheduling of meals, and changing the amount and type of food eaten. For some participants, these changes resulted in cravings for carbohydrates and high calorie food, such as potato chips:

I’ve drastically changed my food, drastically … Doris(f)

Craving for food is a big, big issue of managing. It’s very hard to control the cravings… Maria (f)

I have a lot of trouble with carbs. I love my carb, I love my breads, I love my pasta… Jack(m)

In addition to controlling cravings and eating in a new and more regular way, participants spoke of the need to reduce the amount of food consumed, particularly at a single sitting and to distribute consumption throughout the day:

Any food like sandwich I take it half every two hours. Everything little… Alberto(m)

I was used to eating larger meals… Jack(m)

Also with the food, we can eat the same food as everyone else. Smaller portions… spread out [across the day]… Peter(m)

Others felt resentful of the relentless nature of food preparation and the time required to prepare and cook food that was appropriate for their dietary requirements. A number of participants felt deprived with the social and other
Access to services and resources

In this final theme, participants were generally satisfied with their access to services and felt their health needs were well met locally. Most felt they had a good relationship with their doctor and diabetes educator. Although satisfied with the care they received, participants complained about a number of inconveniences in accessing services, such as waiting for appointments, and logistical difficulties such as parking and transport. Nonetheless, many were philosophical about the shortcomings of the public system:

Well, I just know I’m going to wait so I take a book or something like that, you know, I could be doing other things. But he’s a good doctor, and I’m happy at how things are going… Susan(f)

Although the system generally functioned well, the occasional breakdown did occur and caused considerable anxiety, as Shei(m) explains:

My GP gave me prescription. I take them to chemist… chemist problem. My insulin is finish, no more stock. I am ordered, chemist say come tomorrow… I go next day… She say sorry, not come insulin today. I say… [in] one day I have no insulin. I am diabetes [sic], is important for me. I say to… what time come? She say, 10:00, 11:00 should be here. I am going fifth time, she say not come wherever… too much things. Coming definitely after 5:00 or 6:00. I am going again… I am not happy, go other chemist [next time]… Shei (m)

The occasional participant was also unhappy with the advice they received:

Two appointments with a dietician… very underwhelmed by that, because when you’ve been diagnosed with a complaint, you’re overweight anyway, and you go to some little Sheila [Australian colloquial term for woman] who’s eight and a half stone, and gives you this starvation diet… you just think, huh!… Andre(m)

The quantity, quality and user-friendliness of the diabetes-related information they received, was important to participants, and many felt overwhelmed by the quantity of instruction they received initially. Most favoured straightforward and specific information with clear and simple instructions. Some exemplars follow:

When you’re first diagnosed, you get so much information. It’s just… I know it’s all good. It does your head in. You just think… it’s all new to you, this big book and this book. You read through it once and you go, “Oh God.” Then you just fall down… it’s terrible… Terrie(f)

… when you got the nurses, they give you slight information but just enough for you not to confuse you. When you’re thrown all these books and charts at you, you say… what can I eat? Truth. Information. Straight out, no bugging around, just tell you what it is straight out… Andre(m)

Once participants had an opportunity to digest the information they received and to become acclimatised to managing their condition, many were proactive in seeking out additional information to improve the quality and variety of their diets:

Most of the advice, you get… it’s important to pick up what people say. If he said something, he said something, she said some-
Food, good old food. What to eat, what to have.... to get more information about what's sort of up-to-date, I guess? What sort of new foods [are] around... super-foods and things like that. One of the best resources I've found ever since was the magazine Diabetic Living... It's basically sort of a lifestyle magazine with up-to-date medication and food and everything else... Tom (m)

Participants were also concerned about the lack of promotion of healthy food and some were upset and confused by media reports of contemporary food fads, such as low carbohydrate diets. These new trends had little relevance in their lives but made it even more difficult socially and most participants felt there should be greater emphasis on healthy eating, in both the media and in the community:

And there's too much promotion of junk food... Tom(m)

More work in the prevention and the information should go out there to the community... Peter (m)

I think it's very hard in this country where the social media and all these wonderful chef shows and all this crap, they're all so... the mixed messages we're being given about, cut down on your carbohydrates, boost your proteins... I'm on insulin three times a day. There have[sic] to be a carbohydrate to burn it... Susan(f)

Discussion

The principal aim of this study was to explore the experiences and concerns of individuals with T2DM, in a predominantly low socio-economic setting, in a metropolitan area. That aim has been largely achieved and a number of areas for discussion have arisen from the study, and add to the current body of literature. Areas for discussion include:

- the uncertain nature of T2DM; food as a central issue; and meeting educational and information needs. These issues are discussed below.

The research approach, in the current study, is considered to have a number of advantages for both researchers and participants. For researchers, this approach is a low cost and efficient means of gathering data from a relatively large group of individuals of interest (Johnson et al. 2012, Currie et al. 2013), in this case, individuals with T2DM. Moreover, the shared experiences of participants usually help to create a synergy and to stimulate discussion. It also gives rise to the generation of interactive data, as participants clarify their experiences and perceptions (Wilkinson 1998, Kamberelis & Dimitriadias 2011). In this study, a considerable level of interaction was evident as participants typically finished off each other's comments and asked questions of each other. On a number of occasions, a topic raised by one participant was further clarified by another participant. The researcher can capitalise on this feature and draw out new insights, beyond data generated at interview. Kitzinger (1995) draws attention to an additional benefit, which is of relevance, in this study. The author suggests that individuals with poor literacy skills, or who are not well educated or feel they have little to say, may feel reluctant to participate in face to face interviews, but may be willing to participate in focus group discussions. Thus, the approach may permit access to an otherwise hard to reach group of individuals. Participants may benefit in having opportunities to raise their concerns and to learn from the experiences of others in the group. Nonetheless, despite these advantages, focus group methodologies also have a number of limitations and the discussion can be dominated by one or two forceful or talkative individuals. Data are also often difficult to analyse, due to cross-talking and difficulty in identifying individuals. For these reasons, it is very important that a skilled moderator conducts focus groups. In our case, in a bid to avoid some of the inherent difficulties, focus groups were conducted by professional focus group moderators, who were trained in sensitivity and who had experience of managing diverse focus groups. Limitations include the exclusion of participants without conversational English as it is very likely that non-English speaking local residents could contribute further insight. We aimed to address this deficit in focus groups that were conducted in Vietnamese and Italian in an earlier phase of the study.

The uncertain nature of T2DM

Participants in this study were troubled by the uncertainties they faced as individuals with T2DM, and this concern was related to the unseen and silent nature of the disease and the difficulty of knowing what the future held. Uncertainty also seemed to stem from the possibility of having to depend on others in the future and a possible loss of independence. Similar findings appear in earlier work in this field where a number of studies indicate that participants are fearful of future diabetes complications (Carolan-Olah et al. 2013, Park & Wenzel 2013), often in excess of the actual risk of those complications (Asimakopoulou et al. 2008). At the same time, other studies indicate that many participants feel unable to decipher the symptoms that they are experiencing, which causes concern and uncertainty about the future (Parry et al. 2006, Knecn et al. 2012, Middleton et al. 2012). Although this feeling of concern was commonly described in the literature, it was not a universal finding and Speight and Singh (2013), describe a
tendency among some individuals with T2DM to interpret a lack of identifiable symptoms as indication that their diabetes is a ‘mild’ case.

The notion of diabetes as a ‘silent killer’ was very evident in the current study, and functioned as an emotional burden. This exact concept was not found in the literature, however, the experience of diabetes as an emotional and psychological burden is very prevalent (Kokanovic & Manderson 2006, Manderson & Kokanovic 2009, Reeves et al. 2013). Manderson and Kokanovic (2009), for example, found that participants considered that their T2DM led to feelings of inadequacy and self-doubt and caused them to feel ‘worried all the time’ (p. 291) and Kokanovic and Manderson (2006) found that participants were distressed by their diabetes and struggled to find a balance between lifestyle changes and social engagement. Meanwhile, Li et al. (2013), revealed that women with T2DM expressed a range of emotions, including sadness, anger and a loss of independence, which threatened their self-identity. In each case, this emotional burden had an impact on diabetes self-management, and two common responses are described: anxiety and vigilance (Manderson & Kokanovic 2009), and a fatalistic acceptance of the disease, resulting in poor adherence to management guidelines (Bhattacharya 2012).

Food as a central issue

In this study, participants’ accounts were replete with discussions of their daily food struggles and the difficulties of extensive dietary change, as required by diabetes guidelines. As one participant poignantly noted it’s all about food, and participants in this study, reported a tendency to feel frustrated, depressed, socially isolated and pre-occupied with food preparation. Similar notions of dietary struggle and concern are commonly reported in other studies (Parry et al. 2006, Lippa & Klein 2008, Ahlin & Billhult 2012, Kneck et al. 2012, Mathew et al. 2012). Kneck et al. (2012), for example, discussed the trials of learning to read the body’s signals and the compromises involved in maintaining blood glucose control, while Ahlin and Billhult (2012), found that participants with T2DM described a continuous inner struggle and feelings of deprivation. These feelings resulted in some participants seeking out justifications for continuing with unhealthy dietary habits, rather than changing their diets (Ahlin & Billhult 2012). In particular, participants in Ahlin and Billhult’s (2012) study, described a cycle of inner conflict and overwhelming desire for certain foods, which one participant described as an ‘addiction’. This resulted in eating the desired food and later reasoning that everyone else was also eating this food. Mathew et al. (2012) who explored the experiences of Canadian men and women, with T2DM, also found that participants described diet struggles, and that their responses varied with gender. Women tended to restrict prohibited foods, whereas men were likely to reduce the quantity consumed, of prohibited foods, except during social outings. Although access to information is considered important in diabetes self-management (Onwudiehe et al. 2011), information alone does not affect meaningful change and Parry et al. (2006) and Lippa and Klein (2008), describe participants still struggling with glucose control, despite receiving support and information. Some of these difficulties relate to attitudes, health belief systems and financial resources (Nam et al. 2011). Throughout, all the studies that were reviewed, it became clear that extensive dietary change is experienced as very difficult, and finding the motivation to make lasting dietary change is a constant challenge. This is particularly the case when the earlier dietary habits were poor, making it necessary to completely change eating patterns (Murrock et al. 2013). In this event, requisite changes may be viewed as too difficult (Murrock et al. 2013), inappropriate or unworkable (Bhattacharya 2012, Shen et al. 2013).

Consistent with our study, the support of family is generally seen as important for individuals with T2DM, and useful in terms of providing information, and assisting and encouraging dietary change (Alam et al. 2012, Purcell & Cutchen 2013, Shen et al. 2013, Speight & Singh 2013). Alam et al. (2012), for example, who explored the experiences of British Bangladeshis with diabetes, found that family and friends were frequently used as information sources, especially where there were language difficulties. Shen et al. (2013) discuss family support and empathy as helpful, however study participants identified family expectations such as cooking and caring for the family as onerous, and left little time for self-care. Speight and Singh (2013) additionally caution that the overzealous family member can create additional difficulties for the person with T2DM.

Meeting educational and information needs

It is worth noting the participants in this study were largely satisfied with the services they accessed and the level of information and support that they received. They discussed various stages of adjustment and acceptance of their diabetes, and their information needs were linked to those stages. In the early stages, many felt overwhelmed by the changes required of them and the amount of information they received, and similar findings are reported in other studies. For example, Macdonald et al. (2013) who examined nurse
patient communication in diabetes management, found that patients felt overwhelmed by the volume of information they received, and this feeling was exacerbated by unmet patient expectations. Lippa and Klein (2008) additionally found that many patients were unable to grasp the implications of their disease, due principally to feeling overwhelmed by the volume of instruction and information they received, while Savoca et al. (2004) considered that feeling overwhelmed had a deleterious effect on self-management skill development among participants with T2DM.

In our study, participants' information needs tended to follow a common pathway and immediately following diagnosis, participants identified a need for clear, simple and specific instruction rather than the extensive information they received. Similar findings present elsewhere where individuals with T2DM declared a preference for simple practical instructions and advice (Parry et al. 2006, Shen et al. 2013, Speight & Singh 2013). This mismatch has important implications among low socio-economic and low literacy communities, where sophisticated or extensive literature is generally not accessed (ABS: Australian Bureau of Statistics 2006, Brinkley 2013). Indeed, a recent survey by the Australian Bureau of Statistics indicated that lower educational attainment and older age impact on health literacy, or the ability to read and process health-related material (ABS: Australian Bureau of Statistics 2006). It, therefore, seems likely that the provision of extensive or sophisticated diabetes-related information may compound, rather than assist, the adjustment difficulties of low socio economic and older individuals newly diagnosed with T2DM.

Once the initial shock and distress of diagnosis had abated, most participants, in this study, reached a degree of acceptance of their disease, and their information needs changed. At this stage, many participants described taking ownership of their diabetes and seeking out more in depth and/or specific information, on a range of topics, but largely related to food modification. Similar findings are explained by St Jean (2012), who studied the information-related behaviours of individuals with T2DM in the US. St Jean (2012) found that as their disease progressed, that information needs also changed in concordance with greater awareness of their condition. In our study, later information requirements went beyond the generic guidelines available and participants outlined a variety of ways in which they accessed additional information including: internet searching, evaluating information from others with T2DM, and information from magazines, that were aimed at a diabetic audience. The overall preference was for informal or practical information such as how to change recipes. This finding of not easily located in the literature, although

some examples of concordance are to be found (Whitford et al. 2013, Woodcock & Gillam 2013). Whitford et al. (2013), for example, trialled a series of patient generated FAQs (frequently asked questions) and answers to address the informal information needs of people with T2DM, and found that patients were very satisfied with this approach. Meanwhile, Woodcock and Gillam (2013) explored the information needs and preferences of older (>75 years) patients with T2DM in the US. They found that participants favoured face to face information, over written material, and learnt more in this medium.

Conclusion

In conclusion, participants in this study were generally satisfied with the care and instruction they received at local health services. Nonetheless, they were troubled by the uncertainties they will have to face in the future and felt they will benefit from counselling to discuss these fears. Two areas of information need were also identified: a need for clear simple instruction initially; followed by a need for more extensive but informal information at a later stage. This information should contain more explicit and practical information of a range of topics such as self-care and dietary substitutions.

Relevance to clinical practice

Findings from this study indicate a number of unmet needs and addressing these key areas may lead to an improvement in experience and self-management outcomes for individuals with T2DM. In the first instance, there is a clear need for emotional support as many participants describe their diabetes as a significant and ongoing emotional burden. In terms of information needs, many participants expressed a desire for informal and less complex information, and one way of offering both support and appropriate information may be to conduct group sessions with peers and an educator. This forum would provide opportunities for participants to ask questions and to clarify concerns, and would lessen the burden of seeking out additional written information. Such information searching may prove difficult for individuals from disadvantaged and low health literacy backgrounds. Additionally, as Whitford et al. (2013) have found that participants may benefit as much from the discussion generated from group sessions and from the expert responses as well (p. 105). The involvement of the family in such groups is also critically important, in terms of their own education on diabetes, and the provision of information on how best to support their family member with T2DM.
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Disclosure

The authors have confirmed that all authors meet the IC-MJE criteria for authorship credit (www.icmje.org/ethical_author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, and (3) final approval of the version to be published.

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