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# "Some say no, some say yes": Receiving inconsistent or insufficient information from healthcare professionals and consequences for diabetes self-management: A qualitative study in patients with Type 2 Diabetes

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ABSTRACT

*Aims:* To explore the information-seeking experiences of patients with Type 2 diabetes and how these influenced self-management behaviours.
*Methods:* We interviewed 18 patients with Type 2 Diabetes attending outpatient diabetes centers in South Western Sydney. Data were analyzed thematically.
*Results:* Patients described a number of challenges they faced when seeking information about diabetes self-management. One major challenge was receiving inconsistent and insufficient information from healthcare professionals, which consequently undermined patients' ability to self-manage diabetes. This became a disincentive in carrying out self-management tasks, and led to confusion and mistrust regarding the veracity of information received. Participants also described finding reliable information, and difficulty understanding and accessing relevant information as challenges. Medical jargon and lack of comprehensive explanations exacerbated knowledge deficits compounded by the complex maze of internet resources that some patients accessed. In response to what they perceived as confusing or inconsistent information, some patients followed "their own way" of managing their diabetes.

*Abbreviations:* T2D, Type 2 Diabetes; DSM, diabetes self-management; HCPs, healthcare professionals; GP, general practitioner

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*Conclusions:* Inconsistent information not tailored to the needs of patients adversely affects self-management. Taking time to provide simple explanations and assisting patients in navigating reliable web resources is becoming a vital role of healthcare professionals to reduce knowledge gaps in patients with low health literacy.


## 1. Background

Described as the '*silent pandemic*' [1], diabetes is one of the most common chronic diseases of our era, affecting 415 million people aged 20–79 years of age, and predicted to affect 642 million people by the year 2040 [2]. Diabetes self-management (DSM) is critical in achieving optimal diabetes outcomes, reduced diabetes complications and subsequent diabetes-related mortality [3]. As patients who are better equipped with diabetes knowledge and high self-efficacy are more likely to have better DSM behaviors [4], the onus then is upon healthcare professionals (HCP) to actively increase diabetes knowledge and promote DSM efficacy among patients with type 2 Diabetes (T2D). They play a crucial role in fostering patients' capacity by providing information and supporting patients' initiatives to make the necessary lifestyle changes [5,6]. HCPs' understanding of patients' personal circumstances [7], individualizing support and actively listening [8,9], providing accurate, relevant and consistent information and referring to credible sources of information [10], are all important enablers of DSM for patients with T2D. Adding to the complexity of information seeking, the number of HCPs that a patient may see when they attend a diabetes outpatient center (e.g. dietitian, exercise physiologist, diabetes educator and endocrinologist) increases the likelihood that inconsistent or conflicting information may be provided [11] if care is not well integrated with the patient's general practitioner (GP).

Receiving inconsistent information from HCPs who are seen as experts has been shown to result in negative consequences such as non-adherence to medications [12]; anxiety [13], and loss of confidence in self-management abilities [14]. Importantly, this inconsistency contributes to confusion as to the validity and trustworthiness of the information received and subsequently undermines patients' confidence regarding HCPs' abilities [15]. The lack of both coordination between health services (e.g. primary care and secondary care) and consensus among HCPs adds significantly to the information-seeking burden of patients with chronic disease [11]. This is particularly challenging among patients with low health literacy such as those from culturally and linguistically diverse (CALD) backgrounds, low socioeconomic status and the elderly [16].

Given that good diabetes outcomes are linked to adequate knowledge about the disease [16], and enhanced by effective patient-provider communications [17], the aim of this study was to explore the experiences of patients with T2D when seeking or being provided with information from HCPs. Further, the study also explored patients' experiences in locating, understanding and accessing information needed to engage in self-management behaviors.

## 2. Methods

### 2.1. Study design

This paper reports findings from the qualitative phase of a larger sequential mixed-methods study, which examined factors influencing diabetes self-management and the experiences of patients with T2D in South Western Sydney, Australia. Patient survey results from Phase 1 of the study have been previously reported and identified that the predictors of poor DSM were younger age, higher educational attainment, poor diabetes knowledge and depression [18]. Phase 2 sought to explore the experiences of these patients using semi-structured interviews.

### 2.2. Setting and participants

All patients who attended the diabetes outpatient clinics of two tertiary referral hospitals between May and December 2015 were eligible to participate in an interview. The study setting is one of significant cultural and linguistic diversity with more than half the residents speaking a language other than English at home and it is one of the districts identified as a low socioeconomic area in NSW, Australia [19]. Poor health and chronic disease rates are high with 56% of adults being overweight or obese and 11% of adults having diabetes [20].

While an a priori sample size calculation was undertaken for the larger mixed methods study [21], for pragmatic reasons, recruitment of participants in the qualitative phase of the study was achieved through convenience and purposive sampling using the patient lists of the two outpatient clinics as the sampling frame Fig. 1. As almost half (48.6%) of the residents in our study setting are from CALD backgrounds [22], we ensured that a similar percentage of the sample interviewed was from culturally and linguistically diverse populations. This was determined based on the language spoken at home recorded in the patient's medical record.

### 2.3. Data collection

One-on-one semi-structured interviews were conducted with patients with T2D, 18 years and older. Patients with type 1 diabetes and gestational diabetes were excluded. We contacted eligible participants by telephone before their scheduled appointment to explain the study, ascertain their English-language proficiency to participate in the interview

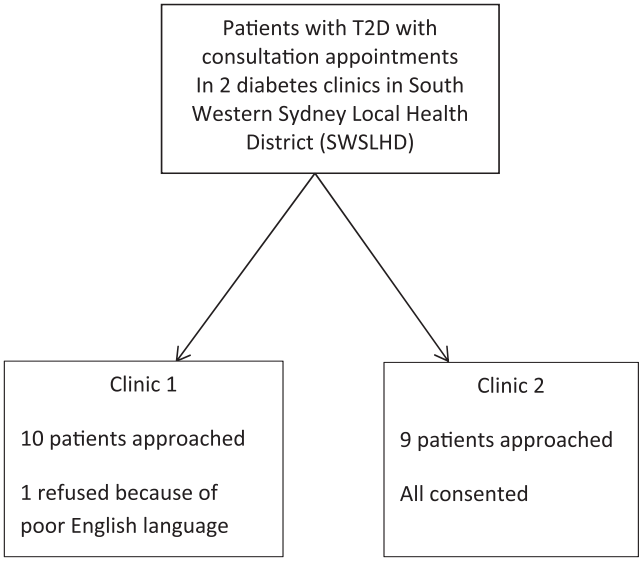


**Fig. 1 – Participant recruitment flowchart.**

without an interpreter, obtain their consent and set an appointment with them for the interview. Three members of the research team (DM, AS, DY) and a research assistant conducted the face-to-face interviews. To achieve consistency in data collection, the research team discussed the interview schedule prior to undertaking the interviews, which was further refined after the first two interviews. Interviews took between 30 and 45 min, and were undertaken in a private room either before or after patients' appointments with their HCP. The questions in the interview are included in Table 1. Interviews were digitally recorded and transcribed verbatim by a professional transcription service. The first author checked the transcripts against the audio-recordings for accuracy and removed direct identifiers (names of clinicians and hospitals). Pseudonyms were used to maintain participants' anonymity.

### 2.4. *Data analysis*

Three researchers (DM, VK & RW) independently analyzed the transcripts using an inductive analytic approach [23] to identify key themes and recurrent patterns in responses to the interview guide questions on participants' experiences of seeking and receiving diabetes-related information from HCPs. Initially, transcripts were coded based on words, phrases or sentences. Data segments were then gathered together into categories which were then merged into larger, overarching themes. Table 2 illustrates this process in relation to the interview question "Do you have problems talking/communicating with your healthcare providers?" Themes identified by each researcher were cross-referenced within the different coding categories that each researcher assigned. The entire team then reviewed the codes assigned, revised when necessary to gain consensus and finalized the themes. Familiarization with the data, whole of team discussions and review of the themes increased consensus. Any differences were resolved following team discussion. This process enhanced the coding consistency, helped to identify further themes, patterns and participants' explanatory model and increased our confidence in the veracity of the findings. Although data saturation was evident within the first 12 interviews, to ensure the sample included similar numbers of participants who spoke English and a language other than English at home, recruitment continued until 18 participants were interviewed.

In addition to demographic and clinical data, participants were asked to rate their knowledge about diabetes, confidence in and importance of DSM using a Visual Analogue Scale (VAS) where 1 was the lowest end of the scale and 10 the highest end. These scores were analysed using descriptive statistics (mean and standard deviation). Ethics approval was obtained from the South Western Sydney Local Health District (SWSLHD) Human Research Ethics Committee (HREC/14/Lpool/133).

## 3. Results

In total, 18 patients with T2D attending diabetes clinics participated in the qualitative phase of this study. The mean age of these participants was 69.6 years (*SD*: 9.6) with equal number of males and females. Just over half (56%) of the participants were born overseas with a mean duration of stay in Australia of 39 years. Two-thirds (67%) of the participants had been diagnosed with diabetes for more than 10 years, and only one participant had an HbA1c of less than the recommended 7% (53 mmol/mol) for people with T2D [24]. Table 3 details the demographic characteristics of the participants.

**Table 1 – Interview guide questions.**

| Interview guide |
|---|
| 1. On a day to day basis, what do you do to manage your diabetes? |
| 2. In managing your diabetes, what do you find easy to do? What do you find difficult to do? |
| 3. Do you get help from someone in managing your diabetes? How do they help you? |
| 4. Where do you get most of your information about diabetes and managing diabetes? |
| 5. What is your experience in looking for information about diabetes? What were the challenges that you encountered? How did you manage this? |
| 6. Do you have problems talking/communicating with your healthcare providers? (Nurse, specialist, GP) what were the problems you encountered, can you give me examples? How did you deal with this? |
| 7. On a scale of 1 to 10, how would you rate your knowledge about diabetes? 1 being no knowledge at all and 10 being very knowledgeable. |
| 8. On a scale of 1 to 10, how confident are you that you can manage your diabetes? |
| 9. On a scale of 1 to 10, how important is it that your diabetes is managed well? |

**Table 2 – Sample illustration of data coding.**

| Theme 1: "Some say no, some say yes": Mixed messages, inconsistent information | | |
|---|---|---|
| Textual data | Coding category | Theme |
| *"Some of the medical profession say no, insulin doesn't put on weight and others say, yes it does.* (Cheryl) | One HCP says one thing<br>Another HCP says another thing | Some say no, some say yes": Mixed messages, inconsistent information |
| "*Ah I talk about it [insulin dosing] with doctor* [GP] *and he said "This is your number [insulin dose] stick to this." And this lady* [diabetes educator]*, when I talk to her she said "Ask him* [GP] *for the sliding scale." And when I ask* [the GP]*, he said "There is no such thing as sliding scale," he said.* (Mark) | One HCP says one thing<br>Another HCP says another thing | |

The mean score for confidence in managing diabetes was 6.5 (*SD*: 2.7; range 1–10) and for knowledge about diabetes was 6.2 (*SD*: 2.9; range 1–10). Overall, participants rated the importance of managing their diabetes as high (mean 9.0, *SD*: 1.4, range 6–10).

Thematic analysis of the interview data showed that participants described a number of challenges associated with receiving information for DSM from HCPs (GPs and diabetes clinic staff), as well as barriers when engaging with HCPs in relation to T2D. The key challenges and barriers identified by patients included mixed messages and inconsistent information received from multiple HCPs, difficulty understanding information, and finding relevant information tailored to their individual circumstances. Details of these findings are presented below.

### 3.1. *Theme 1: "Some say no, some say yes": Mixed messages, inconsistent information*

A major theme revolved around participants receiving mixed messages and contradictory information, leading to confusion. In these situations, participants spoke of their challenge deciphering the inconsistent information. Cheryl, Mark, Angela and Thomas each described similar experiences with contradictory HCP messages. As Cheryl put it, there were conflicting messages about the role of insulin within the medical profession, which she viewed through the lens of her own experience as a patient.

> "Some of the medical profession say no, insulin doesn't put on weight and others say, yes it does. Same thing, if you do any research you get the conflicting views on whether it does or it doesn't. All I know is that my weight had been stable for a long time and then as soon as I was put on the insulin you could almost watch the weight go on." (Cheryl)

Similarly, Angela described conflicting advice about diet and the role of carbohydrates from her endocrinologist and her dietitian. Her response was to determine her own course based on her own experience.

> "Well, if I follow the specialist (the endocrinologist), which the dietitian said don't because I'd be starving and I'd end up on a hypo. Because he didn't want me to have any carbohydrates or anything. Because I live by myself, I can't take chances like that. So I just limit what I take. I know what I can eat, and I do break it at times. But doesn't seem to affect it very much." (Angela)

Mark related a similar experience about vague information regarding insulin dosing, sliding scale and "number" that the GP and the diabetes educator instructed him to follow.

> "Ah I talk about it with doctor [GP] and he said this is your number stick to this. [. . .] And this lady [diabetes educator], when I talk to her she said ask him for the sliding scale. [. . .] And when I ask, he said there is no such thing as sliding scale, he said what I told you this is according to your numbers before yeah" (Mark)

Participants also stated that receiving inconsistent advice from HCPs made it confusing to determine which source to follow, prompting their decision to ignore the conflicting advice, and instead independently formulate their own plan for self-management. Thomas described his response to mixed messages when he put it this way:

> "Somebody say one thing, somebody say different thing, I don't care what the people say; I eat what I want to." (Thomas)

### 3.2. *Theme 2: "I don't understand, it's very confusing": Understanding information from HCPs*

While the first theme described the challenges of being provided with conflicting information about diabetes management, the second theme acknowledged the difficulties of some participants in that even when they obtained consistent information, they had difficulty understanding it.

Participants identified several reasons regarding their difficulty understanding this information. First, instead of using simple English, HCPs commonly communicated using medical jargon. This was reported not only in the outpatient clinic, but also when participants attempted to seek their own information online. One participant pointed out that his effort to find information on the internet had not helped him to man-

age his diabetes because of difficulty understanding medical language: "*yeah [I] go on the internet. It's a bit hard. Because if you don't pick the right places it's too medical*" *(Andrew)*. This difficulty with technical language was also evident in another participant's response, who mentioned that medical jargon was being used during consultations which he did not understand: *"I think I hear the things, I don't know anything about it [. . .] they are talking medical expressions [. . .] medical things [that I don't understand]* " (Mark).

The second reason for difficulty understanding information was the lack of clarity and inadequate explanation provided by the HCP. Tools such as blood sugar level charts, diagrams and food lists given by HCPs that were intended to help patients with their self-management were not explained clearly, consequently these confused rather than clarified, leaving them frustrated and unable to manage their diabetes effectively.

> John: Everything [all the information and help] is pretty good except I think probably this plan, this book.
> Interviewer: How to Test Your Sugar Level.
> John: I don't know how to fill it in. The diagram, I don't understand. It's very confusing.

When Anthony discussed what he found difficult about self-managing diabetes, he mentioned having trouble understanding the food chart and feeling frustrated about looking for expert advice.

> "I don't know what to eat and they say, oh, you follow the chart. What is this bloody chart? You don't explain to me. How am I going to understand? That's why I'm looking for the dietitian who can explain to me. This side, it says good meat, this side, bad meat. Who going to eat the bad meat? We're going to go for good meat. For example, hey? So that's why I'm looking for a dietitian." (Anthony)

All participants stated in the interviews that they had no difficulty understanding English and could communicate adequately with their HCPs. Nevertheless, it seemed likely that language barriers played a role in hampering their communication and understanding of the information provided, as illustrated in Thomas' comment that he could understand his HCP when he spoke English but "*..slowly. We* (referring to wife), *manage.*"(Thomas).

### 3.3. *Theme 3: "You don't know what to ask": Finding information about managing diabetes*

Participants discussed having difficulty locating information about diabetes management. As Andrew noted, before he came to the clinic getting information was *"hard"*, while Michael explained that he *"never got any information about diabetes"* despite having had the disease for thirty years.

The reasons for lacking information usually took one of two different forms for participants: a) not knowing what to ask; or b) difficulties getting information from HCPs. In the first scenario, participants acknowledged a challenge in knowing how to begin finding information. Mark and Peter each described their lack of knowledge as 'not knowing what to ask' because they were not even aware of the extent of their knowledge limitations:

> "I didn't know who to ask, and where to go" (Mark)
> "Don't know what you have to ask, because you don't know what you don't know" (Peter)

In the second scenario, participants described problems getting information from their HCPs. They explained that they felt that their HCPs or GPs were not providing them with adequate information or were not listening to their issues of concern during consultations and therefore, did not address these issues:

> "GP doesn't talk about much, more like what you eat or don't put weight on. What the GP says, I'm not very much interested because I already know that. [. . .] They test me everything. But what makes me angry, why you keep me there if you don't tell me nothing. They didn't tell me if they found anything - my liver, my kidney, my this, my that. [. . .] Oh, thank you very much. Now I know exactly like before, nothing." (Jessica)
> "I think he's [GP] been a bit slack [. . . ] Well, he didn't offer [any information]. He didn't offer anything." (Peter)

In some cases, their GP did not offer information that would help them improve their diabetes management, but instead reiterated that there is *"nothing that can be done"* (Jessica).

Regardless of why they lacked information, participants described feeling frustrated. This led to reflections that they were partly responsible for their ignorance and 'should' have been more proactive:

> "I'm using my normal diet at home, but no educator teach me or show or tell me anything. That's why I'm looking for the education - I mean, the teacher to explain me all food, what I am supposed to eat and what not to eat" (Anthony)
> "I blame my GP before because he will ask me to have blood tests. [. . .] Then he don't tell me anything. [. . .] it's also my fault. I should ask more what's going on" (James)

For some participants, the difficulty was not just finding information, but applying what was felt to be generic information to their specific circumstances. James explained his experience of seeing a nutritionist to get advice on diet, but finding it too general to be useful:

> "No, I can understand it, but it's very hard to follow. Because for example, you just need - for example - about this calorie, this only food, but the list is very long. I think it's better if they just more specific" (James)

Participants also described their struggle to obtain information specific to their needs; nowhere was this more apparent than in the management of co-morbidities. Several participants mentioned a range of physical and mental health conditions that they described as obstacles to maintaining an exercise regimen: injuries, dizziness, osteoarthritis, joint

**Table 3 – Demographic characteristics of participants.**

| Pseudonym | Age (years) | Country of birth | Employment status | Duration of diabetes (Years) | Therapy | HbA1c(%) | BMI | Confidence[#] in managing diabetes | Knowledge[#] about diabetes | Importance[#] Of diabetes self-management |
|---|---|---|---|---|---|---|---|---|---|---|
| Diane | 68 | Macedonia | retired | 11 | Mono (insulin) | NA | 33.67 | 7 | 7 | NA |
| Michael | 65 | Australia | retired | 40 | Mono (tablet) | 8.4 | 40.28 | 6 | 1 | 6 |
| Andrew | 66 | Australia | retired | 21 | Dual[*] | 8.5 | 30.80 | 8 | 9 | 10 |
| Julie | 85 | Italy | retired | 6 | Dual[*] | 9.3 | 20.44 | 10 | NA | 10 |
| Anthony | 72 | Fiji | retired | 20 | Mono (tablet) | 9.4 | 32.35 | 3 | 10 | 10 |
| Angela | 80 | Australia | retired | 9 | Mono (insulin) | 14.1 | 31.84 | 10 | NA | 10 |
| Matthew | 68 | Australia | retired | 16 | Mono (insulin) | 9.1 | 32.15 | 5 | 8 | 8 |
| Rachel | 76 | Australia | retired | 23 | Dual[*] | 11.0 | 35.70 | 1 | 3 | 8 |
| Peter | 67 | Australia | retired | 3 | Mono (insulin) | 8.7 | 23.36 | NA | 4 | NA |
| Mark | 72 | Yugoslavia | retired | 22 | Dual[*] | 7.6 | 36.55 | 6 | 5 | 9 |
| Sarah | 64 | Australia | retired | 2 | Dual[*] | 11.3 | 56.57 | 9 | 7 | 10 |
| Cheryl | 69 | Australia | retired | 16 | Mono (insulin) | 9.8 | 43.41 | 7 | NA | 8 |
| Karen | 67 | El Salvador | retired | 18 | Dual[*] | 11.9 | 28.97 | 7 | 7 | 7 |
| Thomas | 86 | Italy | retired | 20 | Dual[*] | 7.1 | 31.25 | 8 | 10 | NA |
| John | 54 | Paraguay | unemployed | 2 | Mono (insulin) | 9.9 | 36.77 | 5 | 2 | 10 |
| Alicia | 48 | Samoa | unemployed | 15 | Mono (tablet) | 8.5 | 51.67 | 10 | 9 | 10 |
| James | 66 | Philippines | retired | 2 | Dual[*] | 6.6 | 27.25 | 7 | 7 | 10 |
| Jessica | 79 | Italy | retired | 12 | Dual[*] | 11.4 | 33.25 | 2 | 4 | NA |
| MEAN (SD) | 69.6 (9.6) | | | 14.3 (9.8) | | 9.5% (1.9) | 34.8 (8.9) | 6.5 (2.7) | 6.2 (2.9) | 9.0 (1.4) |

NA no answer obtained.

[*] Insulin and Tablet.

[#] Participants were asked to rate their confidence in managing their diabetes, their knowledge about diabetes, and their perception of the importance of diabetes self-management, in a scale of 1 to 10 (1 being the lowest and 10 being the highest).

problems, depression, hearing problems. For example, James explained how he was unable to exercise because of a breathing problem and Angela described how she suffered from osteoarthritis:

> "No, it's because I cannot exercise long because I have a hard time breathing." (James)
> "The arthritis in my knees became too bad and then I found I couldn't walk at all. I ended up having bi-lateral knee replacements, total knee replacements." (Angela)

Participants explained these conditions as the reasons for not exercising, and said that they did not receive assistance from HCPs on how they could adapt an exercise program around their condition. Overall, participants appeared to be well aware of the general importance of exercise in managing their diabetes, but not of any strategies on how to apply the general advice to their situation, and this left them feeling disempowered and frustrated:

> "I would like to improve it, but I asked the doctor and he said, [de-identified] can't improve nothing, you stay on that, every three months [doctor says] the same. So, there is no hope. There's no future for diabetes" (Jessica)

## 4. Discussion

A key concern of a number of participants in this study was a gap in their knowledge about diabetes, which they recognised as a hindrance in managing their diabetes. This is consistent with findings in the literature that report lack of knowledge as the most frequently cited barrier to optimal self-management [25]. Few studies, however, have specifically shown what patients really mean when they say "lack of knowledge" as a barrier. This study unpacked how patients defined "lack of knowledge" in diabetes and DSM, which they described in three main areas: (a) inconsistent information (b) understanding information (confusing language and the way it was presented); and (c); difficulties in finding reliable information ("what, who and where to ask").

Despite recognising the importance of and the need to self-manage their diabetes, participants struggled to engage in self-management behaviours when faced with inconsistent information or, information that they found difficult to understand or locate. This struggle was reflected in generally low self-rated VAS scores for confidence and knowledge about diabetes management among participants in this study. Patients with diabetes must establish a complicated regimen of self-management tasks and incorporate this into their daily life to effectively maintain good diabetes control and prevent complications. Lack of knowledge about these tasks cultivates uncertainty and lack of confidence and consequently non-adherence to DSM.

Of particular concern is the negative impact of inconsistent information on patients which has been shown to generate mistrust of information obtained from HCPs [26] or, reliance on less trustworthy information sources [10]. In the current study, one response to these conflicting messages was the participant resorting to taking her own course of action, which was not necessarily beneficial for good self-management practice.

The experience of obtaining inconsistent and unreliable information was accentuated when patients sourced information from the internet. In a study to evaluate the reliability of different websites providing diabetes information, only 17% met all their reliability criteria, and only five of 43 sites were considered user-friendly [27]. Thakurdesai et al. [28] found high levels of variability in the presentation of core diabetes concepts, and many of these websites were not endorsed by a credentialed body [26]. Participants in this study further noted that searching the internet for information was challenging; even when information was found, the materials were often difficult to understand, underscoring the importance of tailoring the readability of online education materials to within the recommended reading capacity of seventh grade [29]. The lack of understanding and confidence about the veracity of web-based information as well as the lack of skills needed to navigate the internet further overwhelm those seeking to use this as a source of information [30,31].

An additional issue identified by participants in this study that contributed to their confusion was the use of medical expressions and terminologies they did not understand. This made engaging in self-management strategies even more taxing, preventing them from participating in more involved processes, like goal-setting and shared decision-making, as recommended by the Chronic Care Model [32,33], compounded among those with functional English language skills but lack the capacity to understand English used in a clinical settings [21].

Underlying all these factors is the emotional response to disempowering words that some HCPs inadvertently use when communicating with patients. In a qualitative study conducted by Dickinson [41], patients stated that many of the words used by HCPs in delivering diabetes education were judgmental evoking feelings of fear, anxiety and disempowerment. This was exemplified by one of the patients interviewed in this study who shared that the GP did not offer information but instead stated that "*nothing can be done*" about diabetes, which promoted feelings of hopelessness and a response of "*so why manage if nothing can be done anyway,*" provoking abandonment of self-management. In response, the American Diabetes Association (ADA) has endorsed guidelines for HCPs to use more empowering and encouraging words and rejecting words that are negative and judgmental such as diabetic, obese, fat, poorly-controlled, non-compliant [34]. These words discount the self-management efforts of patients and lower their motivation to improve their condition.

It is unsettling that participants in this study who had long-standing T2D and were already accessing the diabetes services and attending consultations with HCPs reported inadequate diabetes knowledge. Many of these participants had characteristics typified by those with low health literacy such as being older, from a non-English speaking background and living in suburbs associated with low socioeconomic status [35]. There seemed to be a lack of awareness of HCPs to verify the level of health literacy of patients and to tailor their

information to this level. What seems to be an often overlooked component of DSM education is the lack of practical strategies to enable patients to translate knowledge obtained into practice that will facilitate daily DSM [36].

This study reveals potential consequences for patients with T2D who receive conflicting information from HCPs. The multiple tasks of daily self-management are challenging as they are, without the added burden of having to decide which information is reliable. Taking time to address the uncertainties of patients regarding inconsistent information and diabetes self-management could lead to improved patient-HCP relationships, good decision-making about diabetes self-management, enable patients to develop positive self-management plans and cope with distress that may be a consequent of lifetime DSM. The use of patient decision aids (PtDAs) could also be considered given that they have been demonstrated to improve knowledge transfer in patients with T2D with more active involvement in their clinical care through participation in decision-making [37].

As the trend of diabetes management increasingly veers towards multidisciplinary and multicomponent care, it is more important to have a well-integrated system where members of the team communicate and provide synchronous information to patients [38]. This study also highlighted the need for HCPs to clearly define their role in the clinical care of people with diabetes so patients have a point of reference for clarification. In addition, culturally congruent community health care workers who are formally trained and compensated to support community health education, is an important strategy to increase engagement and health literacy [39].

With the explosion of web-based information that is easily accessible to patients, overlooking the internet as a source of information for patients is a missed opportunity. It is important that HCPs take on the role of directing patients when searching for information in cyberspace and teaching them how to evaluate the trustworthiness and quality of information. Offering virtual consultation chatrooms in between face-to-face consultations, where people can be provided with information or immediate feedback about their self-management dilemmas could be a good way of demonstrating patient support, thus, encouraging and upholding self-management behaviours. This will reinforce the recommendations of the 2017 National Standards for Diabetes Self-Management Education and Support with the benefit of providing patients with a feedback loop for ongoing management support [40].

While this study captured many of the issues faced by patients with T2D in acquiring information about their disease and management, participants were from a particular cohort who were already accessing the diabetes services and attending the diabetes clinics. The experiences of participants in this study may not reflect the experiences of those who fail to attend or do not access the diabetes services at all. Further, whilst variation in duration of diabetes was evident in this sample, only one participant had an HbA1c reflecting good control of diabetes hence, the experiences of these participants may not reflect those of people with good glycaemic control. In addition, because of the high socioeconomic and cultural diversity of the populations in South Western Sydney, our sample population may not be representative of population groups that are more homogenous. Future research is needed to increase understanding about the experiences of barriers to self-management in a broader patient population.

## 5. Conclusion

While patients with T2D need to be responsible for self-management, persistent failure to equip them with the necessary information, support and positive reinforcements for self-management continues to be a barrier. There is an urgent need to provide consistent and relevant information that patients understand, pitched and contextualized to meet the needs of these patients but at the same time bolster their self-confidence to manage their condition. In this context, HCPs have an expanded role in diabetes self-management, including directing patients to reliable sources of web-based information.

## Authors' contribution

DM, YS, BE, CA and DY contributed to the conceptualisation, design and planning of the study. DM, DY and CA contacted potential participants, set the appointments and conducted the interviews. DM, VK and RW independently analysed the data, which were reviewed and verified by CA, DY, BE and YS. All authors participated in the team discussions to consolidate the analysis until consensus was reached. All authors contributed to writing drafts of the manuscript. YS and BE made critical revisions to the paper. All authors contributed to the revisions of the manuscript. Finally, all authors read and approved the final manuscript.

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## Declaration of Competing Interest

The authors declare no competing or conflict of interest.

## Funding

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## Ethics approval

This research was performed in accordance with the Declaration of Helsinki. Ethics approval was obtained from South Western Sydney Local Health District (SWSLHD) Human Research Ethics Committee (HREC/14/Lpool/133). Participants signed a consent form before the interview and agreed for the interview to be audio-recorded.

## Consent to publish

Participants signed a consent form agreeing to the publication of the results of the study provided that they are not identified in any publication.

## Availability of data and materials

Data in the form of verbatim quotes from participants are contained within the manuscript. Full interview transcripts generated in this study are not publicly available to maintain the privacy of participants, but are accessible from the corresponding author on reasonable request.

## Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.diabres.2019.107830.

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