Understanding the nutrition care needs of patients newly diagnosed with Type 2 Diabetes; a need for open communication and patient-focused consultations

ABSTRACT

Patients who are newly diagnosed with Type 2 Diabetes Mellitus (T2DM) commonly attempt to modify their dietary intake after receiving nutrition care from primary health professionals. Yet, adherence to dietary recommendations is rarely sustained and factors influencing adherence are poorly understood. This study explored T2DM patients’ experiences of dietary change and their views on how primary health professionals can best support long-term maintenance of dietary change. A purposive sample of 10 individuals recently diagnosed with T2DM participated in three individual semi-structured qualitative telephone interviews: at baseline, then at 3 and 6 months after recruitment. Interview questions were modified from the initial interview in order to investigate emerging findings. A two-step data analysis process occurred through content analysis of individual interviews and meta-synthesis of findings over time. Participants initially made wide ranging attempts to improve dietary behaviours, but most experienced negative emotions from the restraint required to maintain a healthy diet. Participants felt confused by the conflicting advice received from health professionals and other sources such as friends, family, internet and diabetes organisations. Participants frequently reported feeling rushed and not heard in consultations, resulting in limited ongoing engagement with primary health care services. These findings suggest there is opportunity for primary health professionals to enhance the dietary support provided to patients by acknowledging the challenges of sustained improvements in dietary intake, open communication, and investing in patient relationships through more patient-focused consultations.

Keywords: general practice, primary care, nutritional management, nutrition therapy, chronic disease.
What is known about the topic?

- Patients who are newly diagnosed with Type 2 Diabetes commonly attempt to modify their dietary intake after receiving nutrition care from primary health professionals. Adherence to dietary recommendations is rarely sustained and factors influencing dietary adherence are poorly understood.

What does this paper add?

- The results suggest there is opportunity to enhance the dietary support provided to patients by investing in patient relationships through more patient-focused consultations and open communication.
Introduction

Type 2 Diabetes Mellitus (T2DM) is a lifestyle-related chronic disease and leading cause of morbidity and mortality in Australia (Australian Institute of Health and Welfare, 2007). Over 5% of the Australian population have been diagnosed with T2DM, and an additional 0.9% are predicted to be diagnosed annually (Australian Bureau of Statistics (ABS), 2012). T2DM is typically diagnosed and managed in the primary health care setting, and patients with T2DM receive health care from a variety of primary health professionals (Diabetes Australia, 2012). Importantly, the health outcomes of patients with T2DM are influenced by their dietary intake (Coppell et al., 2010). Therefore, facilitating patients to have a healthy dietary intake is a key component of T2DM management (Diabetes Australia & Royal Australian College of General Practitioners (RACGP), 2008; National Health and Hospitals Reform Commission, 2009).

Patients who are newly diagnosed with T2DM commonly attempt to modify their dietary intake after receiving nutrition care from primary health professionals (Castro-Sanchez & Avila-Ortiz, 2013). In the first 6 months after diagnosis, patients often experience changes to their enjoyment of food whilst trying to follow a recommended diet, and most report only temporarily adherence to dietary recommendations (Castro-Sanchez & Avila-Ortiz, 2013). The United Kingdom Prospective Diabetes Study was the largest clinical research study into diabetes management (n=3867 participants), and has shown that establishing short-term optimal glycaemic control in the early stages after diagnosis reduces the risk of macro- and micro-vascular complications, as well as all-cause mortality 10-years after diagnosis (Murray et al., 2010). Given the influence of dietary intake on glycaemic control of patients with T2DM, investigating ways to further support patients to maintain healthy dietary behaviours in the early stages after diagnosis is important.
Exploring patients’ experiences and perceptions is crucial to understanding how to provide patient-centred care. Patient-centred care is an approach to healthcare that meets the specific needs, values and beliefs of patients (McMillan et al., 2013) and is regarded as imperative to the optimal management of chronic disease, including T2DM (Holman & Lorig, 2000). Many primary health professionals, such as General Practitioners, Practice Nurses, and Dietitians report providing “nutrition care” to patients, which refers to any practice conducted to support patients to improve their dietary intake (Ball et al., 2012; Ball et al., 2010). Recent investigations into the nutrition care provided by primary health professionals highlights that patient-centred care is not always achieved, and may be hindering the efficacy of nutrition care for chronic disease management (Ball et al., 2012; Ball et al., 2013). Given the importance of optimal dietary intake in T2DM self-management, it is necessary for primary health professionals to better understand the experiences, challenges and needs of patients attempting to improve their dietary behaviours in order to provide effective patient-centred nutrition care.

The aim of this study was to examine the perceptions of patients who have been recently diagnosed with T2DM regarding nutrition care provided by primary health care professionals. Specifically, the study explored patients’ experience of dietary change and their views on how primary health professionals could best support long-term maintenance of dietary change. This understanding can be used to facilitate health professionals to provide nutrition care that addresses the needs and experiences of patients.
Methods

This study utilised a longitudinal, qualitative design to describe the perceptions and experiences of patients who have recently been diagnosed with T2DM. The study was approved by the Griffith University Human Research Ethics Committee (reference number PBH/09/14/HREC).

Participant Recruitment

A purposive sample of individuals with T2DM (<4 months since diagnosis) was recruited via e-newsletters and social media pages of Diabetes Australia, and state branches of Diabetes New South Wales, Diabetes Queensland, Diabetes South Australia and Diabetes Tasmania. The sampling strategy aimed to recruit a combination of male and female, young and old, employed and unemployed/retired participants. Potential participants who contacted the research team were provided with a plain language information sheet, prior to providing consent and arranging an initial interview.

Data Collection

Each participant was involved in three individual semi-structured telephone interviews; at baseline, and then at 3 and 6 months after recruitment into the study. A semi-structured interview guide was developed for each round of interviews. Interviews included questions such as “how has your recent diagnosis influenced your feelings about food?”, “describe your interactions with health professionals regarding food and healthy eating” and “at this moment, how could health professionals be most helpful in supporting you in healthy eating?”. Elaboration probing, clarification probing and attention probing were utilised to gain a deeper understanding of the participants’ perceptions (Liamputtong, 2010). Interview questions were modified from the initial interview in order to investigate emerging findings (Thomson & Holland, 2003).
All interviews were conducted by one investigator (RD), were 30-60 minutes in length and were digitally recorded and transcribed verbatim. Immediately after each interview, an entry was made in a reflective journal that outlined the impressions of the interview. Data collection and analysis were conducted concurrently, whereby recruitment and data collection continued until data saturation was considered to have been achieved. In practical terms, saturation was considered to have been reached when no new responses and subsequent preliminary categories were detected as interviews progressed (Strauss & Corbin, 2007).

**Data Analysis**

A two-step data analysis process occurred for this study. First, content analysis was used to analyse the verbatim transcripts as it allows an in-depth understanding of the participants’ nutrition care needs (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Analysis of verbatim transcripts involved an iterative process of reading the transcripts to become familiar with the data, generating initial sub-categories, searching for categories, reviewing the categories and finally labelling the categories (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Triangular analysis was conducted by two investigators (LB and RD) by independently generating initial sub-categories, and then comparing and discussing to reach agreement. Second, a meta-synthesis approach was undertaken to synthesise and interpret the data across the three time points (Sandelowski & Barroso, 2007). The process involved extracting the sub-categories and interpreting them in order to identify higher order categories that transcend findings from each time period. Regular meetings were held with the whole research team whereby emerging findings were critically reviewed, and this ensured that the identified and defined sub-categories accurately reflected the data for transferability and credibility.
Results

Ten individuals participated in the study, each completing three interviews. The participants included 3 males and 7 females, and their ages ranged from 27-74 years. A summary of the three categories and their sub-categories that emerged from the analysis are displayed in Table 1.

INSERT TABLE ONE ABOUT HERE

Adjusting to Diagnosis

The first category encompassed the impact of being diagnosed with T2DM on participants’ perceptions about the food they eat and their broader dietary intake. The adjustment process involved considerable emotional adaptation, which occurred at different rates amongst participants. Initially, participants reported feeling shocked and surprised at being diagnosed with T2DM. Most considered their usual dietary intake to be healthy, and this added to the challenge of coming to terms with having a long-term health condition.

“I’ve always considered [that] we ate healthy… it never entered my mind that I would have sugar diabetes.” (Participant 7, Interview 1)

The diagnosis of T2DM appeared to have an immediate negative impact on participants’ views about dietary intake in general, particularly in social situations when others reacted to the news.

“All the sad faces, they say ‘Oh you’ve got diabetes’. People are now scared to cook for me. It’s actually intimidated them to think they can’t actually cook normal food.” (Participant 8, Interview 1)
Three and six months after the initial interview, participants began to adapt to the diagnosis of T2DM, generally moving on from the initial shock, and feeling more in control, as the following statements from the same participant in successive interviews demonstrate:

“I keep saying to myself ‘I’m not depressed, I’m not allowed to be depressed’. I got so depressed when I was diagnosed of course, and I don’t feel quite as black as that but I don’t feel that I’m in control of myself at the moment either” (Participant 7, Interview 2)

“I’ve accepted it now, and just have a little swear and curse every now and then. It’s been a little bit easier lately, I’m handling it better.” (Participant 7, Interview 3)

After adjusting to the diagnosis, participants wanted continued improvement in their management of T2DM, even beyond the goals suggested by their supporting health professionals.

“The doctor said she was really happy with my BGL at 6.5, but I think maybe below 6 is better. I know it’s quite difficult, but I want to try anyway.” (Participant 5, Interview 3)

**Modifying Dietary Behaviours**

The second category related to participants’ experiences of modifying their dietary behaviours in order to improve their blood glucose management and other health outcomes. These experiences ranged from logistical considerations of food preparation, to broad emotional adaptation to having different dietary behaviours compared to before diagnosis.

Initially, wide ranging attempts to improve dietary behaviours were undertaken by participants. Participants experienced an emotional impact of restricting their diet, as well as managing ongoing changes.
“I’ve made some wholesale changes to the way I view eating, what I eat and particular attention, like stuff like food labels…making sure I eat three meals a day and don’t skip meals.” (Participant 2, Interview 1)

As time progressed, participants had differing experiences of sustaining dietary changes, with some finding that monitoring blood sugar levels provided useful feedback on food choices.

“I’ve got to the stage now where I don’t think too much about the diet because…you’re just in the habit of eating healthy meals so I know now what I should be eating, and what are sometimes foods.” (Participant 2, Interview 2)

“You know you’ve eaten the right thing, because the [blood sugar] reading is lower” (Participant 6, Interview 2)

However, for many participants, maintaining a healthy dietary intake continued to be a challenge as time progressed, mostly because it felt restrictive.

“It’s a challenge…I’ve been putting a bit more on my plate, having a second serve of something…it’s the old habits…it’s not something I could maintain.” (Participant 3, Interview 2)

“I’m getting to the point where I’m cheesed off with always having to have diabetic biscuits and other things, you get bored with them. I’m feeling I’m having to make a sacrifice that other people don’t have to.” (Participant 9, Interview 3)

Despite the challenge of maintaining a healthy dietary intake, some participants reported feeling aware of the consequences of not eating healthy foods.

“I can’t see myself drifting back to eating the same way as I was, because I know what the consequences are.” (Participant 2, Interview 3)
Receiving Support from Health Professionals

The third category related to participants’ experiences of receiving nutrition care from health professionals. Participants perceptions extended beyond the content of advice provided by health professionals, to broader experiences of support and communication in health care consultations.

When participants were initially diagnosed with T2DM, they received an overwhelming amount of conflicting nutrition information. The information came from health professionals, as well as dietary advice from friends, family, online sources and T2DM organisations.

“I kept finding so much controversy it made my head spin…they say you have protein, you have carbs, and you have your veggies and stuff. Well, then you read no meat, no animal protein, no none of this, ...who is right and who is wrong? I found it confusing”

(Participant 2, Interview 1)

Participants found their initial interactions with dietitians to be challenging, due to the direct, instructional nature of the nutrition care provided.

“A few days after I was diagnosed I went to a dietitian and she laid it all out…I wasn’t impressed. This woman was just there to purposefully lay down a diet…to put me in line and show me that this, that and that.” (Participant 1, Interview 1)

“I’d had a nice lead in with the educator and then all of a sudden I saw the dietitian and she was laying down the law and I was thinking “this is a bit of a turn around!”

(Participant 2, Interview 2)

Participants found that aside from the support provided by dietitians, other health professionals, as well as family/friends and online support were helpful on occasions.
“The diabetes educator...she handled me very well and I felt different when I came out of there...they put it in perspective, which is sort of what I needed.” (Participant 2, Interview 1)

“There’s one lady at work, her husband has type 2 diabetes and she tells me what she does with him, so yeah, that is really good.” (Participant 3, Interview 2)

Overall, participants had limited ongoing engagement with primary health care services. This appeared to be a result of limited understanding about how the primary care system operated, and the role of different health professionals, as well as limited value on the services provided in this setting.

“The GP gave me one of those ‘go and see 5 people a year’ diabetes plans but I haven’t organised any of it...it’s not a big deal, it’s just something I probably need to tick off to keep everybody happy and then I can relax again for another year.” (Participant 8, Interview 2)

“I didn’t quite understand what diabetes educators did or the dietitians,” (Participant 2, Interview 2)

Most participants thought that the support provided by primary health professionals had considerable room for improvement, because they felt rushed and not heard in consultations, and because open communication was not always achieved.

“They get you in there, they tell you you’ve got type 2 and you’ve got to make these changes, and it always feels like a rush to finish with you and get you out the back door and start with a new case.” (Participant 2, Interview 3)

“You’re talking to someone and they go ‘your half hours up, I have got another patient waiting’. Nobody has got the time to sit and take the time to talk. I find that very
frustrating and annoying. You just start to say something and then you’ve got to leave.”

(Participant 1, Interview 3)

Differences in Accommodating New Dietary Behaviours

The collective experiences of participants over time suggest that individuals have different experiences in accommodating new dietary behaviours after being diagnosed with T2DM. The experiences of participants in this study appeared to be influenced by contextual conditions such as immediate family support and responsibilities, confidence in existing food knowledge, and familiarity with health professionals and the health care system.

Three archetypical experiences were apparent in this study. First, some individuals appeared to take a factual and directive approach to adjusting to their diagnosis and modifying their dietary behaviours. In order to achieve this, they preferred clear instructions from health professionals and felt most comfortable eating in accordance with a pre-determined plan. Positive feedback from continued healthy eating (such as improved blood glucose management and weight loss) outweighed the negative emotions felt from being restricted in their food choices, and this motivated continued adherence to the point of sustained improvement in dietary behaviours.

Second, some individuals appeared to take an adaptive approach to adjusting to their diagnosis, modifying their dietary behaviours, and seeking support from health professionals. The initial shock of diagnosis reduced their confidence in making dietary choices, and they placed considerable importance on guidance from health professionals and other sources of dietary information (such as family, friends, internet, diabetes organisations). Early improvements in dietary intake were not considered sustainable due to the negative emotional impact this had on their quality of life. However, over time, adjustments to dietary intake that
were considered to be reasonable and achievable were made. These individuals perceived themselves as having made general improvements in their dietary behaviours that had positive impacts on blood glucose management and other health outcomes. However, these individuals also experienced regular occasions of making food choices that were not viewed as ideal, and risked having a poor dietary intake over time.

Third, some individuals experienced persistent negative emotions after diagnosis, and did not make meaningful adaptations to their dietary behaviours over time. These individuals felt overwhelmed from the conflicting information received from health professionals and other sources of dietary information, which caused them to withdraw from the experience of making dietary choices and receiving support. Improvements in blood glucose management and other health outcomes appeared to be a result of undereating and avoiding social eating situations, which was not identified in consultations with health professionals. These individuals perceived themselves as requiring considerably more support than what they felt was available, and were frustrated by the lack of immediate success when following guidelines provided by primary health professionals.
Discussion

This study contributes new information on patients’ experiences of dietary change after being diagnosed with T2DM and their views on how primary health professionals can best support long-term maintenance of dietary change. Participants’ insights resulted in three categories being generated, including adjusting to diagnosis, modifying dietary behaviours, and receiving support from health professionals. This information is important due to the relationship that exists between health care experiences, chronic disease self-management practices (including dietary behaviours) and health care outcomes (Sequist et al., 2012).

Participants in this study experienced challenges in adjusting to their recent diagnosis of T2DM, which had a direct negative impact on their views about their dietary intake. Being diagnosed with T2DM is recognised as a particularly alarming and emotional time for patients, because it is viewed as a transformation point from a healthy person to one who is aware, frightened and sometimes embarrassed by having a long-term health condition (Histock et al., 2001; Hilson 2014). The impact of the diagnosis on participants’ attitude to food was considerable, including reduced confidence in what to eat, reduced enjoyment of eating, and feeling uncomfortable eating with others, including family, peers and friends. These factors have the potential to impact on the effectiveness of nutrition care provided by primary health professionals, and health professionals should be aware of this impact when providing nutrition care to patients.

Previous studies investigating dietary changes after diagnosis with T2DM report that following initial dietary changes, patients often move into an accommodation-adaptation phase regarding their dietary intake (Castro-Sanchez & Avila-Ortiz, 2013). However, this finding was not apparent in all participants in the current study, even six months following recruitment into the study (up to 10 months after diagnosis). While some participants did
report positive perceptions about their dietary intake as time progressed, many participants continued to experience negative emotions from the restraint required to maintain a healthy diet, and the conflict between diet-related social activities and necessary self-management behaviours. The three archetypical experiences apparent in this study and the individual timelines in which participants adjusted to changes in dietary intake highlight the importance of flexible and tailored support for patients in the months after diagnosis.

Participants in this study reported that they have received an overwhelming amount of contradictory nutrition information from health professionals and other sources. A recent survey of Australian adults who self-identified as needing to improve their dietary behaviours suggested that nutrition information sources perceived as most trustworthy, credible and effective included Dietitians, Nutritionists and GPs, but the most frequently utilised sources were the internet, friends, family and magazines (Cash et al., 2014). The use of family as a source of information aligns with Family Systems Theory, which conceptualises families as a system of interrelated parts, which influence each other and contributes to the growth or detriment of others (Bowen, 1966). Furthermore, the participants in the current study reported limited ongoing engagement with health professionals such as Dietitians and GPs, despite being described in the recent survey as most trusted, credible and effective (Cash et al., 2014). Clearly, further understanding about how patients decide which nutrition information sources to use appear warranted.

The support provided by primary health professionals to the participants in this study was generally reported as requiring significant improvement. Interestingly, the factors that were most influential to patients’ experiences of receiving nutrition care appeared to be open communication, not feeling rushed, and being genuinely supported, rather than any specific nutrition advice or approach. This appeared to be important for all participants, particularly
those who experienced persistent negative emotions after diagnosis. Open communication and genuine support are considered critical for building relationships with patients with T2DM, and the way this is displayed is influenced by a health professional’s own personality and the emotions they are experiencing (Kowitt et al., 2015). Similar factors that influence patients’ experiences of health care have been identified in other Australian population groups, such as new mothers, where their perceptions of their health care quality were reduced when they felt unsupported and hurried in consultations (Corr et al., 2015). Collectively, this suggests that primary health professionals could enhance the delivery of their care by investing in patient relationships through longer, more patient-focused consultations and open communication.

Participants described situations where health professionals provided nutrition care that did not meet their needs. Facilitating Australian primary health care professionals to provide nutrition care in a patient-centred manner is important to optimise self-management of T2DM and reduced risk of complications. Compassion fatigue amongst GPs and other primary health professionals has been suggested to occur in Australia, where there is a gradual lessening of compassion over time as a result of being regularly exposed to patients’ problems (Shrestha & Joyce, 2011). This lack of empathy from health professionals has been associated with significantly increased metabolic complications in patients with T2DM (Canale et al., 2012). Given this association, strategies to reduce compassion fatigue and subsequently enhance patient-centred care appear to warrant investigation, and may improve the self-management of patients with T2DM, including improved dietary intake and subsequent health outcomes (Lawson & Flocke, 2009). Furthermore, the findings of this study provide additional support for the use of emerging workforce models in Australia to meet the challenges of chronic disease prevention and management. Recommendations for improvements to Australian primary care include greater self-management support through
enrolment of patients with primary care teams, expansion of workforce capacity through greater training, and new categories of health workers such as health assistants who may receive special training to assist those in the community (Harris et al., 2008).

Participants had limited ongoing engagement with primary care services, reportedly due to limited understanding about how the system operated and the role of different health professionals. Interestingly, a recent study has shown that patients with T2DM rarely attend all Medicare-subsidised dietetic appointments they have access to, despite an association of modestly greater reductions in weight and waist circumference observed in patients who attended more consultations (Spencer et al., 2013). Given that insufficient health care support is likely to impact on patients’ health outcomes (Diabetes Australia & RACGP, 2008), greater support for patients to ‘navigate’ the system and maintain engagement appears warranted. This has been identified by the Australian Government as a priority for primary health care, however the implementation of actions is yet to undergo evaluation (Australian Government, 2013).

Despite the general negative emotions felt with their experiences of dietary change and health care, a limitation of this study is that the actual changes to dietary intake were not investigated, and therefore remains unclear in this population group. While many participants reported improved dietary intakes after diagnosis, confirmation of the usual changes in nutrient intakes warrants further investigation. This information will identify common areas that patients may benefit from further support from primary health professionals in order to promote sustained healthy dietary behaviours. Furthermore, this study explored participants’ experiences over a 6-month period following diagnosis with T2DM. The long term experiences of dietary change and nutrition care has not been explored, and warrants consideration.
In conclusion, this study explored patients’ experiences of dietary change and their views on how primary health professionals can best support long-term maintenance of dietary change. Three archetypical experiences of accommodating new dietary behaviours were apparent in this study. Most participants felt confused by the conflicting advice received from health professionals and other sources such as friends, family, internet and diabetes organisations. Participants frequently reported feeling rushed and not heard in consultations, resulting in limited ongoing engagement with primary care services. These results suggest there is opportunity for primary health professionals to enhance the dietary support provided to patients by acknowledging the challenges of sustained improvements in dietary intake, investing in patient relationships through more patient-focused consultations and open communication.
Conflicts of Interest: None declared.

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References


### Table 1: Categories and sub-categories emerging from the interviews.

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<tr>
<th>Categories</th>
<th>Definition</th>
<th>Sub-categories</th>
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| Adjusting to Diagnosis              | Impact of being diagnosed with T2DM on perceptions about food and dietary intake | • Shocked and surprised at being diagnosed with T2DM  
• Immediate negative views about dietary intake  
• Beginning to moving on from the initial shock of diagnosis  
• Wanting continued improvement beyond suggested goals |
| Modifying Dietary Behaviours        | Experiences of modifying their dietary behaviours in the attempt to improve the management of the blood glucose levels and other health outcomes, ranging from logistical considerations of food preparation, to broad emotional adaptation to eating differently than before diagnosis. | • Wide ranging attempts to improve dietary behaviours  
• Emotional impact of restricting diet and managing ongoing changes  
• Differing experiences of sustaining dietary changes  
• Maintaining a healthy dietary intake continues to be a challenge  
• Monitoring blood sugar levels provides useful feedback on food choices  
• Feeling aware of the consequences of not eating healthy foods |
| Receiving Support from Health Professionals | Experiences of interacting with health professionals and discussing food and dietary intake | • Receiving overwhelming, conflicting nutrition information  
• Receiving initial directives from dietitians is challenging  
• Ongoing engagement with primary care services is limited and not highly valued  
• Feeling rushed and not heard in consultations |