

This is the peer reviewed version of the following article: Crowe M., Whitehead L., Bugge C., Carlyle D., Carter J. & Maskill V. (2017) Living with sub-optimal glycaemic control: the experiences of Type 2 diabetes diagnosis and education. *Journal of Advanced Nursing* 73(3), 612–621, which has been published in final form at <https://doi.org/10.1111/jan.13145>. This article may be used for non-commercial purposes in accordance With Wiley Terms and Conditions for self-archiving.

Received Date : 22-Mar-2016

Revised Date : 19-Jul-2016

Accepted Date : 31-Jul-2016

Article type : Original Research: Empirical research - qualitative

**Living with sub-optimal glycaemic control: the experiences of Type 2 diabetes
diagnosis and education**

Prof Marie CROWE Professor RN PhD^{1,5}

Prof Lisa WHITEHEAD Professor RN PhD⁴

Dr Carol BUGGE Senior Lecturer RN PhD²

Dr Dave CARLYLE Senior Lecturer RN PhD¹

Associate Prof Janet CARTER DipClinPsych PhD³

Ms Virginia MASKILL Lecturer RN MHSc⁵

¹ Department of Psychological Medicine, University of Otago, Christchurch, New Zealand

² School of Health Sciences, University of Stirling, Scotland, United Kingdom

³ Department of Psychology, University of Canterbury, Christchurch, New Zealand

⁴ School of Nursing and Midwifery, Edith Cowan University, Perth, Australia

⁵ Centre for Postgraduate Nursing Studies, University of Otago, Christchurch, New Zealand

Funding

This study was funded by the NZ Tertiary Education Commission STAR fund.

Conflict of interest

No conflict of interest has been declared by the authors

Corresponding author:

Marie Crowe
Department of Psychological Medicine
University of Otago, Christchurch

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jan.13145

This article is protected by copyright. All rights reserved.

PO Box 4345
Christchurch, New Zealand
Tel: +64 3 3720400
Fax: +64 3 3720407
Email: marie.crowe@otago.ac.nz
URL <http://www.otago.ac.nz/christchurch/index.html>

Running Heading: Living with T2DM

Abstract

Aim: To explore the experiences of diagnosis and education for people living with Type 2 diabetes who have sub-optimal glycaemic control.

Background: The increasing prevalence of Type 2 diabetes is a global concern. Many people have difficulty maintaining optimal glycaemic control with up to 50% having HbA1c levels higher than recommended. A range of factors have been suggested as possibly contributing to this, however, little is known about how their experience of diagnosis, education and support to attempt to understand the context of their self-management practices.

Design: A qualitative thematic analysis of interviews conducted with people with sub-optimal glycaemic control prior to their participation in an intervention study.

Method: Thirty participants taking part in a psychosocial/educational intervention for people with sub-optimal glycaemic control were interviewed in 2012 before the intervention commenced. These interviews explored each participant's experience of the diagnosis and associated education. The interviews were transcribed and a thematic analysis was conducted.

Findings: Almost all the participants had been shocked at receiving the diagnosis and felt it had been a moral indictment on their lifestyle. Many had been given the impression that they had a mild form of diabetes and most had been given very little information on self-management that they had found useful.

Conclusion: The findings suggest that for the participants there was a considerable gap between the rhetoric of person-centered services and the reality of the experiences of diagnosis and education for the self-management of Type 2 diabetes.

Key words: diabetes, qualitative research, self-management, type 2 diabetes, patient education, nurse, nursing

Summary statement

Why is this research needed?

- It is well-recognised that Type 2 diabetes is a growing global problem with serious health and economic consequences if optimal glycaemic control is not attained and maintained.
- Up to 50% of people with Type 2 diabetes do not maintain optimal HbA1c levels and there has been relatively little research into the context where this occurs.

What are the key findings?

- Four themes were identified from the participants' interviews: the wake-up call, a moral indictment, it's only Type 2 and no one tells me.
- Participants described feeling shocked and ashamed at receiving the diagnosis and receiving inadequate information and support to manage the condition.

How should these findings be used to influence policy/practice/research/education?

- Because people are often shocked and ashamed when they receive a diagnosis of Type 2 diabetes particular attention should be given to how and when they are given information to manage the condition.

- Generic health information on Type 2 diabetes may not be particularly helpful but a more individualised approach that identifies how people can make changes in the context of their particular life may be more effective for improving glycemic control.

Introduction

Effective management of diabetes is a fast-growing global problem. It is estimated that 285 million people worldwide have diabetes mellitus (Shaw *et al.* 2010), 90% of whom have type 2 diabetes mellitus (T2DM) (Zimmet *et al.* 2001). Self-management is the usual treatment approach for this group and this usually requires lifestyle changes that include reducing refined carbohydrate and saturated fat intake, increased physical activity, weight loss, medication management and blood glucose monitoring (Henderson *et al.* 2014).

In reality, many people living with diabetes are unable to maintain glycemic control within the recommended levels (4-7% / 20-53 mmol/mol) (Peyrot *et al.* 2005). Strategies to address this pressing health care issue have been developed at global, national, local and practice level (Shaw *et al.* 2010) yet rates of sub-optimal glycemic control continue to increase (Hoerger *et al.* 2008). It has been estimated that 13% of adults in the United States are unable to maintain glycemic control within the recommended levels (Ali *et al.* 2012) and only 35% have optimal glycemic control (Koro *et al.* 2004). A European study of people over 40 years with T2DM found that 37.4% had HbA1c levels $\geq 7\%$ (de Pablos-Velasco *et al.* 2014).

These suboptimal levels can lead to higher levels of glycated hemoglobin and have been associated with increased rates of diabetic retinopathy, chronic kidney disease and cardiovascular disease (Ali *et al.* 2012). Understanding what is happening for

people with sub-optimal glycemic control is important if future strategies and clinical interventions are to have any effect.

Background

The levels of inadequate glycemic control are concerning given the physical and economic costs this has for patients, their families and health services. Managing diabetes is both time-consuming and burdensome and many people feel unable to successfully manage their T2DM because they feel overwhelmed by what they are expected to do and the time required to do this (Chlebowy *et al.* 2010). The contemporary approach of promoting self-management practices places a large and sometimes onerous health care responsibility on those with the diagnosis and their families. Lifestyle change is the primary self-management strategy for managing T2DM yet many people find this difficult and may not understand why it is required (Inzucchi *et al.* 2012). There is no well-established explanation for why some people have sub-optimal control although clinical inertia (Khunti *et al.* 2013); lack of family support (Mayberry & Osborn 2012); limited access to healthcare (Benoit *et al.* 2005); poor coping skills and perseverance (Savoca *et al.* 2004) and lifestyle choices (Schellenberg *et al.* 2013); have all been identified as possible contributing factors.

Daly *et al* (2009) have identified that both inadequacies in self-care behaviours and medical management contribute to sub-optimal control. Their study identified that the main barriers across most self-care behaviours were the cost of accessing health care and depression; in addition, these two variables were highly correlated. Better glycemic control was found to be associated with better physician-patient communication. Despite the impact of suboptimal glycemic control few studies have focused exclusively on the experiences of those with sub-optimal glycemic control to better understand this in the context of their diagnosis and education.

Qualitative research provides the opportunity to identify and examine the issues people with sub-optimal glycemic control experience when they are managing T2DM but there is a relative paucity of studies in this area. Some studies have examined the barriers and facilitators to management of Type 2 diabetes but have not targeted those with sub-optimal glycemic control specifically (Fort *et al.* 2013, Park & Wenzel 2013, Jones *et al.* 2014). Understanding experiences, beliefs, attitudes and behaviours is crucial to clinical care because these areas have a profound effect on health-seeking behavior and adherence to treatment (Ritholz *et al.* 2011).

The study

Aim

To explore the experiences of diagnosis and education for people living with Type 2 diabetes who have sub-optimal glycemic control.

Design

This qualitative study was embedded in a randomized controlled trial (RCT) and used semi-structured interviews to focus on the context of sub-optimal glycemic control from the experiences of people with T2DM. The RCT was a three-arm intervention study: an education intervention, an education plus Acceptance and Commitment Therapy intervention or usual care. The primary outcome of the RCT was improvement in glycemic control as measured by HbA1c. By interviewing participants after screening and prior to randomization we hoped to identify what they knew about T2DM and what experiences might provide the context to their sub-optimal glycemic control. The interviews were conducted throughout 2012.

Participants

Three hundred and three people responded to advertisements for the intervention study and were assessed for eligibility. Inclusion criteria were that participants were

aged 18 years or over with a confirmed diagnosis of T2DM and HbA1c outside of the recommended range (4-7%, 20-53 mmol/mol) for 12 months or more. Persistent, suboptimal glycaemic control was defined as having at least two records of HbA1c > 7%, 53mmol/mol, in the past 12-18 months, including HbA1c >7%, 53mmol/mol on recruitment. Exclusion criteria were minimal but included participation in psychotherapy or participation in a diabetes education programme.

One hundred and seventy-two people met eligibility criteria with HbA1c levels that were confirmed through clinical and laboratory records. One hundred and eighteen participants completed baseline data collection. This qualitative study thematically analysed the data from the interviews of the first 10 participants randomized to each group (n=30). Whilst it is generally agreed that saturation is the usual determinate of sample size in qualitative research, there were pragmatic reasons associated with the requirement to identify a pre-determined sample size for both funding and ethics application requirements. This has been recognized by other authors, for example Glaser (1998).

Data collection

Data were collected with semi-structured interviews that were all conducted by one author (VM by phone). The interviews were digitally recorded and then transcribed by an experienced audio-typist who had signed confidentiality agreements as per the Ethics protocol.

A semi-structured interview format was used by the interviewer:

- Tell me about when you were first diagnosed with T2DM.
- What was your response to the diagnosis?
- What do you know about T2DM?
- How has diabetes impacted on your life?

- How do you manage your condition?

The interviews lasted between 30 and 45 minutes with the interviewer encouraging each participant to explore each question/prompt in depth.

Ethical considerations

The research protocol was approved by the institutional research ethics committee where the study took place.

Data analysis

The thematic analysis was conducted according to the framework described by Braun and Clark (2006). One author (MC) conducted the close reading of the transcripts, generated the codes and clustered these into categories. These categories were then integrated into themes following discussion with the research team members. Once the themes were identified they were named, defined and described. This was followed by a process of illustrating each theme with relevant excerpts from the transcripts. A process of thematic verification involved another author (LW) examining the audit trail of codes, categories and themes in relation to the transcribed interview.

The final phase was a synthesis of themes. This involved exploring the relationship of the themes to each other and to the socio-cultural context where they emerged (Crowe *et al.* 2015). It is at this point that the presentation of that the process shifted from a descriptive process to an interpretive process to identify meanings embedded across the data and what Braun & Clarke (2006) describe as making an argument in relation to the research question. See Table 1 for process of theme development.

Rigour

Processes for ensuring rigour were based on those described by Crowe, Inder & Porter (2015): credibility, transferability and dependability. Credibility relates to the

way data were interpreted. Although qualitative research is an interpretive process, the interpretations may need to be substantiated and in this case the interpretations were discussed with the full research team to ensure there was evidence to support the interpretations made. Transferability involves providing the reader with sufficient information for them to assess similarities or differences between the context where the study was conducted and their own clinical practice setting. In these interviews, the participants who were taking part in an intervention to improve glycemc control and their sub-optimal control had been validated with HbA1c blood tests. They were recruited from a range of sources but all had had recent GP contact for the blood tests to be processed. Their willingness to take part in the study suggests that they were reasonably motivated to make lifestyle changes. The context of data collection provides the reader with a context that would have influenced these particular findings. Dependability involves providing sufficient information on both the data collection and data analysis processes to enable the decision-making trail to be followed. In this case we have provided a table that illustrates theme development and provided quotes from participants to illustrate the theme.

Findings

The participants consisted of 19 males and 11 females with an age range of 44- 65 years (mean age 58 years). The mean years since diagnosis was 8.9 years and the mean HbA1c was 8.1 (range 7.01-12.2). The thematic analysis identified four themes:

1) the wake-up call 2) moral indictment 3) its only Type 2 and 4) no one tells me.

These themes identify personal, social and health care influences on their management of T2DM. The wake-up call described the participants' responses to the initial diagnosis; the moral indictment reflects how participants experienced the social/cultural response to the diagnosis; its only Type 2 describes the way the

diagnosis was minimized by the participants' general practitioners; and no one tells me describes the lack of support provided by primary care and other services. The sense of personal and social blame coupled with minimization of the diagnosis and a perceived lack of support/information from primary care providers suggests a fertile context for the development of sub-optimal glycemetic control. The numbers attached to each quote are the research identifiers for each participant.

The wake-up call

This theme describes participants' responses to learning of their diagnosis of T2DM. It encompasses the participants' feelings of shock and the identification of the diagnosis as another burden to bear. Most participants described a feeling of shock that they had experienced when they received the diagnosis:

Well I started having episodes where I was extremely thirsty just feeling lethargic, generally unwell and it sort of went on for a wee while ... so I went to my GP and they did the 24 hour glucose tolerance test ... to be honest it was a bit of a shock ... I thought 'no' at first. It takes a bit to sink in and then you think 'oh this is a bit of a worry'. #63

The shock was often associated with a sense of the seriousness of having diabetes:

I said 'S*' to myself 'this is quite serious I really should listen to what they're actually saying' ... it was a wakeup call to tell you the truth. #163

The shock that participants described was often associated with a sense that they had no idea that they were at risk of getting diabetes:

[I was] pretty stunned really, I you know, I'm probably like a lot of people just thought that it won't really happen to me. #94

Some participants cited examples of other people they knew who had T2DM and had suffered serious physical complications:

I wasn't very chuffed because you know it's quite a difficult thing to control, then it has serious impact if you don't control it, you know loss of limbs, blindness and all those sorts of things ... it's stressful, you try not to worry about it, but you know when I've got friends of mine that have diabetes and one has just lost his leg and another one has just died and they were only Type 2 as well ... #45

For others knowing other people with the diagnosis provided a resource or example of how they could cope with the diagnosis:

Oh I was devastated at the time I thought 'oh my god' you know, but it's not as bad as I thought. My daughter's coped with it really well so you know I just thought well I can too. #15

For most the shock was associated with their perception of diabetes as a disease associated with aging or another burden to bear.

- Oh [I was] shocked, relieved to have an answer to why I was so tired. ... You know it was just another burden to bear. #126
- I thought well most of the people I know who have got diabetes are huge, they either get their limbs cut off somewhere along the line so I was really worried. #210
- [It was] a bit of a kick in the guts really you know, I suppose you think of say it's an old person's disease as it were and you know something else that you had to go through life worrying about. #128
- I actually thought it was serious, like something that you get as you get older and you put on weight or something like that, but I've never been really overweight anyway. #15

The sense of shock that most participants experienced was generally associated with their preconceptions of the risk factors associated with T2DM and the type of people who were likely to have the disease.

Moral indictment

The ‘moral indictment’ theme was associated with the participants’ preconceptions of people who have diabetes. When they received the diagnosis they experienced it as a sense of blame related to their lifestyles – that they had lived a lifestyle that produced T2DM. Many participants associated the diagnosis with obesity, poor self-care or laziness:

Diabetes means to me fat, negligent, slack that’s what it means or the other side of it you’re ill.... it could be deemed to be self-inflicted.... that means a flaw on your character. #99

Others associated the diagnosis with poor dietary choices:

I thought fat people or you know people that were consistently eating rubbish would get diabetes. #105

The following quote captures the essence of this theme – that if you have been diagnosed with T2DM you have not lived the right sort of life:

[I felt] totally gutted because I thought that I’d lived the right sort of life and that it shouldn’t happen. But then I related it to maybe how I used to live a few years ago and thought ‘oh hang on I haven’t really helped this’ I felt this is not good. I’ve got it but it’s probably not going to kill me so I’m going to do the best I can to keep it under control. #99

The diagnosis was regarded by some as a judgment on the type of life they had lived and that there was a 'right' and 'healthy' way to live:

This is going to teach me to live healthily anyway because all it is is living how we should be living. #105

Another participant expressed frustration and helplessness that even if you lived the right sort of lifestyle it was still possible to get T2DM:

You know he had nothing, he ate properly, he walked every day, he did everything the doctor said and he still got type 2 diabetes. ... I felt there wasn't really much I could do [if it affected others who lead healthy lifestyle]. #107

Although many participants' perceptions of T2DM were frequently associated with self-blame for the life they had lived, some did recognise that living the 'right' lifestyle was not a guarantee against receiving the diagnosis.

It's only Type 2

The next theme 'It's only Type 2' reflected how most participants had downplayed the diagnosis. Most seemed to have based this on the information they received from their GPs:

The doctor said to me that we will test you and see how you are getting on and he came back and said 'well it looks like you have got a very mild case of diabetes'. #123

Other participants seemed to have inferred that it was not serious from their GPs' responses:

Just a few months ago he got stuck into me about it all but prior to that he really hadn't been taking a hell of a lot of interest in it ... it's fairly mild and

type 2 and I thought oh well I've only got type 2 you know what I mean it's not that bad and I really didn't take a hell of a lot of notice. #163

Some participants described that by thinking of it as mild or only Type 2 it helped them cope with the diagnosis:

- I can think I have diabetes which I'm not that comfortable with, or I am a Type 2 diabetic which I am better with, I don't know why I think like that. #99
- Because it was only type 2 diabetes so I wasn't really worrying about it that much. ... Oh it hasn't really affected my life at all really, yeah just that I've got to take medication for it that's all. #91

This theme minimised T2DM and was used by both GPs and participants to downplay the gravity of the diagnosis. It reflected both misinformation and a coping mechanism used by participants.

No one tells me

This theme describes the lack of information and support perceived by the participants. It captures the sense of being at a loss about what to do in relation to managing their T2DM. Most participants described inadequate information and support provided by the primary care services available to them. Some participants thought the problem lay with GPs not having adequate knowledge:

I personally don't think people in the medical profession understand. Not all of them understand it. #153

Others described how difficult it was to access the services that were available to them:

I had some terrible problems getting in there [Specialist diabetes service].

Initially it was because of my work hours. I'm not just able to drop what I'm doing and rush away to things and they kept insisted on giving me

appointments during the day even though I had tried to explain to them that really my appointments needed to be later in the afternoon and they really couldn't accommodate me. ... I mean unfortunately diabetes is a 24 hour day 7 day a week illness and here you have a professional body who is there to help people with this disease who are only open basically from 9 to 5 sort of thing and in fact they actually close a little bit earlier than that. #94

Most participants were reliant on their GP to signal what was happening with their diabetes but many did not get that signal:

I don't know because I've had testings before, you know where they do that sugar testing and stuff and obviously you know I think I must of been alright, well they've never called me back or whatever so I think I've probably been up and down and up and down quite a lot without even knowing it. #174

It was also common that participants did not know how to talk about their diabetes with their GP:

I mean the diabetes never comes up [when I go to GP]. I mean we just look at my medications. He asks me if there is there any problem or anything like that you know and there hasn't been ... I don't know what to say to him because I don't know enough about the diabetes to know how severe it is. #103

The lack of information provided to them concerned many participants

Yeah but the trouble with [going to GP] is I don't know what I should be eating, I don't know what I should be eating anyway, I mean I know I should be probably exercising a wee bit more, running and all that Absolutely nothing, I know nothing about what I should be doing and what I shouldn't be doing you know. #125

Others found the information provided was not personalised and was not useful in the context of their lives:

I don't go to a GP. To me they're reasonably impersonal but I think if there was someone who gave me like a regime on, a realistic regime on eating and exercising I think that would help. I think what was discouraging was from day one that they were sort of telling me 'oh you only have you know sort of eat one sandwich at lunchtime' and all that. I had a hard physical job so that was nowhere near enough to sustain me and I found it was unrealistic to be able to have you know a couple pieces of lettuce and tomato and that would be it for lunch. #106

One participant described how the only information they had received was via pamphlets but this was not helpful:

No he [GP] has not talked about it. He's been giving me pamphlets but you read one, you read them all. #188

This theme highlights a significant shortfall in the availability of information and support provided to the participants by GPs and other primary care services. This is not to say that information was not provided but it suggests it was not information that participants remembered, found relevant to their lives or were able to integrate into their lives. Most participants wanted information and this was the reason they wanted to participate in the study.

Discussion

The participants in this qualitative study were mostly middle-aged men (63%) a group not easily accessed for clinical studies. From our findings it appears that the experiences of diagnosis and education for T2DM for these participants with sub-optimal glycaemic control was influenced by personal, social and primary care

Accepted Article

responses to the diagnosis of T2DM. We found that most participants had experienced shock at receiving the diagnosis and many found it was a moral indictment on their lifestyle. Almost all of the participants were unaware of the potential physical impact of T2DM and most had minimized the diagnosis as a 'mild' form of diabetes. It was notable throughout all the interviews that their GPs had played a main role in minimizing the seriousness of T2DM and had provided participants with very little useful information. Participants found generic information unhelpful and difficult to apply to their management of diabetes.

There has been very little research into the context of sub-optimal glycaemic control and our study has contributed knowledge about how people who go on to have sub-optimal glycaemic control experience diagnosis and education. The exploration of these experiences gives some context to why people with T2DM may not be managing their glycaemic levels and suggests there may be clinical factors associated with the process of diagnosis and education that may be contributing to this..

The sense of shock that our participants experienced on receiving a diagnosis of T2DM has also been reported by Beeny *et al.* (1996) who found that over half of respondents (the level of glycaemic control was unknown) that they surveyed reported strong emotional reactions at the time of diagnosis, including anxiety, shock and anger. Other studies have identified that people with T2DM frequently experience difficulties making lifestyle changes which has been attributed to a lack of recognition of the risks associated with diabetes (Henderson *et al.* 2014). Dietrich (1996) found that the doctor's attitude at the time of diagnosis was critical in patients' attitudes about the seriousness of diabetes and subsequent self-management behaviour. If the doctor downplayed the seriousness of T2DM it was perceived as less serious by the patient. This may be a contributing factor to the 'It's only Type 2' theme. Many

Accepted Article

participants remembered being told by the GP that they had a mild form of diabetes or that T2DM was a mild form of diabetes. The consequence of this may be that if participants think it is 'mild' they may see less need to make lifestyle changes. This in combination with a lack of adequate support/information may have been an important contributor to their sub-optimal glycaemic control. It has been well-documented that poor patient-provider communication is associated with poor treatment adherence (Ciechanowski *et al.* 2001, Aikens *et al.* 2005, Matthews *et al.* 2009, Nam *et al.* 2011).

The stigma associated with T2DM described by our participants has also been highlighted by other authors. Browne *et al.* (2013), identified that health professionals and the media were involved in promoting fear, blame and disgust related to negative stereotypes of people with T2DM as being unhealthy, fat, lacking control, lazy, dirty and a drain on societal resources. These stigmatising attributes are promoted by a construction of T2DM where the individual is regarded as solely responsible for their disease because of an unhealthy lifestyle (Browne *et al.* 2011). Because our sample was mostly men there may also have been the associated self-stigma of diabetes as a sign of weakness. Mathew *et al.* (2012) have identified that men may perceive diabetes as a threat to their masculine identity and tend to be reluctant to let people know about it. As a consequence of keeping it private they were less likely to observe nutrition recommendations in social settings. Self-stigma occurs when people agree with and internalize negative stereotypes. Beverly *et al.* (2012) found that many patients with T2DM feel responsible and guilty and blamed themselves for sub-optimal glycaemic control. This self-blame can serve as a barrier to effective access of health-care services.

The need for information that was relevant to the participant's life was the most pervasive theme identified in the participants' transcripts. This is probably not surprising as these were people who had agreed to take part in psychosocial and educational interventions for T2DM. However it has been well-established in a systematic review of studies examining the factors that influence the ability to self-manage diabetes (Wilkinson *et al.* 2014) that individuals and their significant others require appropriate, consistent, understandable and specific education to facilitate self-care. This needed to be supported with continuity of care from someone who knew them, sufficient time to discuss issues and person-centred rather than paternalistic treatment. These conditions that promote effective self-management of T2DM were not apparent from our participants' experiences.

Nagelkerk *et al* (2006) identified that the most effective strategy for facilitating improved self-management was the development of a collaborative relationship with the healthcare provider. A collaborative relationship alongside educational and support resources may be an effective response to one of the major difficulties in self-management identified by patients – changing lifestyle habits that are well-established and integrating new habits into their lifestyle (Booth *et al.* 2013). The National Standards for Diabetes Self-management Education and Support (Haas *et al.* 2013) have identified that for people with T2DM to successfully self-manage their condition they need to be provided with information on core topics that have demonstrated successful outcomes, education and support needs to be individualized to each participant's needs, individualized on-going support needs to be provided and their needs to be regular evaluation of achievement of goals.

Limitations

This qualitative study involved participants with sub-optimal glycemic control who had chosen to take part in an intervention to improve this. They may be different to other groups of people with sub-optimal control. Our participants were predominantly male which may have provided a gender bias in responses. Many qualitative study participants are predominantly female so this study did provide an opportunity for males to voice their experiences. The mean age was 58 years and the years since diagnosis 8.9 so it was a predominantly middle-aged group who may have had different experiences to other age groups.

While it is common practice to conduct face to face interviews for qualitative research and there may be some limitations to the data collected, there is evidence that telephone interviews are of similar quality (Sturges & Hanrahan 2004). The qualitative study was conducted in one city in New Zealand in 2012, the year after a significant earthquake. The timing and geographical location of this study may have introduced a specific context to the study although participants' sub-optimal glycemic control had been identified prior to the earthquake.

Conclusion

The findings suggest that for the participants there was a considerable gap between the rhetoric of person-centered services and the reality of the experiences of diagnosis and education for for Type 2 diabetes. The self-management practices of people with T2DM are shaped by a public health construction of T2DM as a lifestyle disease for which the person is wholly responsible and a lack of meaningful information and support from primary care.

In the New Zealand context to this study the Ministry of Health (responsible for funding and delivery of primary care services for T2DM) advocates the need for

people-centred services, achieving effective self-management, improving the quality of care, providing integrated care and providing healthcare informed by evidence (Ministry of Health 2015). This is a laudable policy that needs to be resourced in practice settings. Primary care practices need to evaluate their current processes for diagnosis and education regarding T2DM to ensure they are people-centred. This needs to be supported by research into the best way of achieving person-centred care and models of care delivery that best meet the needs for education that is relevant to the person's lifestyle. For the participants in this study the primary health care services available to them were inadequate and could be regarded as contributing to their problems with glycaemic control.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

* <http://www.icmje.org/recommendations/>

References

- Aikens J.E., Bingham R. & Piette J.D. (2005) Patient-provider communication and self-care behavior among type 2 diabetes patients. *Diabetes Educator* **31**(5), 681-690.
- Ali M.K., Bullard K., Imperatore G., Barker L. & Gregg E. 2012. Characteristics associated with poor glycaemic control among adults with self-reported

diabetes- National health and nutrition examination Survey, United States 2007-10. *Morbidity and Mortality Weekly Report*. Centre for Disease Control and Prevention.

Beeney L., Bakry A. & Dunn S. (1996) Patient psychological and information needs when the diagnosis is diabetes. *Patient Education and Counseling* **29**(1), 109-116.

Benoit S.R., Fleming R., Philis-Tsimikas A. & Ji M. (2005) Predictors of glycemic control among patients with Type 2 diabetes: A longitudinal study. *BMC Public Health* **5**(1), 36.

Beverly E.A., Ritholz M.D., Brooks K.M., Hultgren B.A., Lee Y., Abrahamson M.J. & Weinger K. (2012) A Qualitative Study of Perceived Responsibility and Self-Blame in Type 2 Diabetes: Reflections of Physicians and Patients. *Journal of General Internal Medicine* **27**(9), 1180-1187.

Booth A.O., Lowis C., Dean M., Hunter S.J. & McKinley M.C. (2013) Diet and physical activity in the self-management of type 2 diabetes: barriers and facilitators identified by patients and health professionals. *Primary Health Care Research & Development* **14**(3), 293-306.

Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**(2), 77-101.

Browne J., Zimmet P. & Speight J. (2011) Individual responsibility for reducing obesity: the unintended consequences of well intended messages. *Medical Journal of Australia* **195**(7), 386.

Browne J.L., Ventura A., Mosely K. & Speight J. (2013) 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open* **3**(11), e003384.

- Chlebowy D.O., Hood S. & LaJoie A.S. (2010) Facilitators and barriers to self-management of type 2 diabetes among urban African American adults: focus group findings. *Diabetes Educ* **36**(6), 897-905.
- Ciechanowski P.S., Katon W.J., Russo J.E. & Walker E.A. (2001) The patient-provider relationship: Attachment theory and adherence to treatment in diabetes. *American Journal of Psychiatry* **158**(1), 29-35.
- Crowe M., Inder M. & Porter R. (2015) Conducting qualitative research in mental health: Thematic and content analyses. *Australian and New Zealand Journal of Psychiatry* **49**(7), 616-23.
- Daly J.M., Hartz A.J., Xu Y., Levy B.T., James P.A., Merchant M.L. & Garrett R.E. (2009) An assessment of attitudes, behaviors and outcomes of patients with type 2 diabetes. *J Am Board Fam Med* **22**(3), 280-90.
- de Pablos-Velasco P., Parhofer K., Bradley C., Eschwege E., Gonder-Frederick L., Maheux P., Wood I. & Simon D. (2014) Current level of glycaemic control and its associated factors in patients with type 2 diabetes across Europe: data from the PANORAMA study. *Clinical Endocrinology* **80**(1), 47-56.
- Dietrich U.C. (1996) Factors influencing the attitudes held by women with type II diabetes: A qualitative study. *Patient Education and Counseling* **29**(1), 13-23.
- Fort M.P., Alvarado-Molina N., Pena L., Montano C.M., Murrillo S. & Martinez H. (2013) Barriers and facilitating factors for disease self-management: a qualitative analysis of perceptions of patients receiving care for type 2 diabetes and/or hypertension in San Jose, Costa Rica and Tuxtla Gutierrez, Mexico. *BMC Family Practice* **14**(Sept), 131.
- Glaser B. 1998. *Doing grounded theory: Issues and discussions*, Mill Valley, CA, Sociology Press.

- Haas L., Maryniuk M., Beck J., Cox C.E., Duker P., Edwards L., Fisher E.B., Hanson L., Kent D., Kolb L., McLaughlin S., Orzeck E., Piette J.D., Rhinehart A.S., Rothman R., Sklaroff S., Tomky D., Youssef G. & Standards Revision Task F. (2013) National standards for diabetes self-management education and support. *Diabetes Care* **36 Suppl 1S**100-8.
- Henderson J., Wilson C., Roberts L., Munt R. & Crotty M. (2014) Social barriers to Type 2 diabetes self-management: the role of capital. *Nursing Inquiry* **21**(4), 336-345.
- Hoerger T.J., Gregg E.W., Segel J.E. & Saaddine J.B. (2008) Is glycemic control improving in US adults? *Diabetes Care* **31**(1), 81-86.
- Inzucchi S.E., Bergenstal R.M., Buse J.B., Diamant M., Ferrannini E., Nauck M., Peters A.L., Tsapas A., Wender R. & Matthews D.R. (2012) Management of hyperglycaemia in type 2 diabetes: a patient-centered approach. Position statement of the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). *Diabetologia* **55**(6), 1577-96.
- Jones L., Crabb S., Turnbull D. & Oxlad M. (2014) Barriers and facilitators to effective type 2 diabetes management in a rural context: A qualitative study with diabetic patients and health professionals. *Journal of Health Psychology* **19**(3), 441-453.
- Khunti K., Wolden M.L., Thorsted B.L. andersen M. & Davies M.J. (2013) Clinical Inertia in People With Type 2 Diabetes A retrospective cohort study of more than 80,000 people. *Diabetes Care* **36**(11), 3411-3417.
- Koro C.E., Bowlin S.J., Bourgeois N. & Fedder D.O. (2004) Glycemic control from 1988 to 2000 among U.S. adults diagnosed with type 2 diabetes: a preliminary report. *Diabetes Care* **27**(1), 17-20.

- Mathew R., Gucciardi E., De Melo M. & Barata P. (2012) Self-management experiences among men and women with type 2 diabetes mellitus: a qualitative analysis. *Bmc Family Practice* **13**(Dec), 122.
- Matthews S.M., Peden A.R. & Rowles G.D. (2009) Patient-provider communication: understanding diabetes management among adult females. *Patient Educ Couns* **76**(1), 31-7.
- Mayberry L.S. & Osborn C.Y. (2012) Family Support, Medication Adherence and Glycemic Control Among Adults With Type 2 Diabetes. *Diabetes Care* **35**(6), 1239-1245.
- Ministry of Health. (2015) Living well with diabetes: A plan for people at high risk of or living with diabetes 2015–2020. Ministry of Health. Wellington.
- Nagelkerk J., Reick K. & Meengs L. (2006) Perceived barriers and effective strategies to diabetes self-management. *Journal of Advanced Nursing* **54**(2), 151-8.
- Nam S., Chesla C., Stotts N.A., Kroon L. & Janson S.L. (2011) Barriers to diabetes management: Patient and provider factors. *Diabetes Research and Clinical Practice* **93**(1), 1-9.
- Park H. & Wenzel J. (2013) Experience of social role strain in Korean women with type 2 diabetes. *Journal of Advanced Nursing* **69**(6), 1400-1409.
- Peyrot M., Rubin R.R., Lauritzen T., Snoek F.J., Matthews D.R., Skovlund S.E. & Panel I.D.A. (2005) Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabetic Medicine* **22**(10), 1379-1385.
- Ritholz M.D., Beverly E.A. & Weinger K. (2011) Digging deeper: the role of qualitative research in behavioral diabetes. *Current Diabetes Reports* **11**(6), 494-502.

- Savoca M.R., Miller C.K. & Quandt S.A. (2004) Profiles of people with type 2 diabetes mellitus: the extremes of glycemic control. *Social Science & Medicine* **58**(12), 2655-2666.
- Schellenberg E.S., Dryden D.M., Vandermeer B., Ha C. & Korownyk C. (2013) Lifestyle Interventions for Patients With and at Risk for Type 2 Diabetes A Systematic Review and Meta-analysis. *Annals of Internal Medicine* **159**(8), 543-+.
- Shaw J.E., Sicree R.A. & Zimmet P.Z. (2010) Global estimates of the prevalence of diabetes for 2010 and 2030. *Diabetes Research and Clinical Practice* **87**(1), 4-14.
- Sturges J.E. & Hanrahan K.J. (2004) Comparing telephone and face-to-face qualitative interviewing. *Qualitative Research in Psychology* **4**107-118.
- Wilkinson A., Whitehead L. & Ritchie L. (2014) Factors influencing the ability to self-manage diabetes for adults living with type 1 or 2 diabetes. *International Journal of Nursing Studies* **51**(1), 111-22.
- Zimmet P., Alberti K.G.M.M. & Shaw J. (2001) Global and societal implications of the diabetes epidemic. *Nature* **414**(6865), 782-787.

Table 1 Coding process

Codes	Categories	Themes
Stunned shocked		The wakeup call
Gutted Bit of a worry Kick in the guts	Shock	
Nothing you can do about it Another burden to bear	Another burden to bear	
Something else to worry about		
I thought I'd lived the right sort of life Living how I should be living Fat negligent slack Sign of weakness Character flaw	Lifestyle choices	Moral indictment
It's fairly mild Its only Type 2 It hasn't affected me	Denial	Only Type 2
Self-discipline Complacence Doing the same old Take it in my stride	Self-management	
Codes	Categories	Themes
Need to know more		No one tells me
Need more time/support Accessibility of services Not individualised Don't like being dictated to Sock tactics	Need more health care support	