Is diagnosis of type 2 diabetes a “teachable moment”? A qualitative study

Dr Elena Dimcheva Dimova1, Dr Vivien Swanson2 and Dr Josie M.M. Evans1

1 Faculty of Health Sciences and Sport, University of Stirling, FK9 4LA, Scotland
2 Faculty of Natural Sciences, University of Stirling, FK9 4LA, Scotland

Corresponding author: Dr Elena D. Dimova, elena.dimova@gcu.ac.uk, School of Health & Life Sciences, George Moore Building, Glasgow Caledonian University, Cowcaddens Road, Glasgow, Scotland

Declarations of interest: none

Funding: This work was supported by the Economic and Social Research Council (ESRC) as part of a PhD project.

Abstract

Aims
To explore the potential of a type 2 diabetes diagnosis to be a “teachable moment”.

Methods
Semi-structured interviews were conducted with 23 participants (10 people with type 2 diabetes, 13 relatives of people with type 2 diabetes) in Scotland, UK. They explored cognitive, emotional and behavioural changes following diagnosis of type 2 diabetes in oneself or in a relative. Data were analysed using Framework approach.

Results
Strong emotional responses are not always related to the occurrence of a teachable moment. Risk perception and outcome expectancy were found to be teachable moment factors for patients with type 2 diabetes and their offspring, but not their partners. Change in self-concept increases the likelihood of type 2 diabetes diagnosis to be a teachable moment for patients but not for relatives. In some cases, type 2 diabetes is perceived as incompatible with current roles thus hindering diabetes self-management. Relatives often engage in caring for patients and “policing” their behaviour but did not report perceived changes in social roles.

Conclusions
The study suggests that diagnosis of type 2 diabetes is a teachable moment for some patients and their relatives. These findings have implications for interventions to address diabetes self-management in patients and primary prevention in their relatives.

Keywords
Type 2 diabetes; teachable moment; patients; relatives; interviews
Introduction

Diagnosis of illness can be a teachable moment when people adopt spontaneous behaviour change. The teachable moment construct is underpinned by existing conceptual models [1-3] and suggests that naturally occurring health events (e.g. illness diagnosis) increase people’s motivation to respond positively to educational messages and adopt new behaviours. McBride et al. [4] propose a model suggesting for a health event to be a teachable moment it needs to i) increase peoples’ perceptions of personal risk and outcome expectancy ii) prompt an emotional response and iii) produce a redefinition of social role or self-concept (although it may not have to fulfil all three conditions).

However, this model was developed in cancer and smoking cessation and the majority of empirical work on teachable moments has been in cancer, a potentially terminal condition [5-7]. In addition, previous work in cancer suggests that illness diagnosis may also trigger behaviour change in the patient’s relatives [8-11]. However, it remains unclear whether the teachable moment criteria suggested by McBride et al. [4] are applicable to other long-term health conditions.

The current study applies the concept of the teachable moment to type 2 diabetes. Previous research shows that people may perceive diabetes to be less serious than cancer [12]. Although some studies suggest that diagnosis of type 2 diabetes may prompt behaviour change [13-15], no previous studies have directly explored the potential of the diagnosis to be a teachable moment for patients or their relatives. The patients’ relatives represent a group at increased risk of type 2 diabetes due to shared genetics in first-degree relatives [16] or shared lifestyle in partners [17]. One recent study applied the teachable moment construct to gestational diabetes, but perceived risk may be greater in this context, as it also relates to the baby’s health and well-being [18].

This study explores the relevance of McBride et al.’s [4] model to people with type 2 diabetes and their relatives. More specifically, it aims to identify whether people experience increase in perceived risk and outcome expectancy, strong affective response and redefinition of social role or self-concept in response to diagnosis of type 2 diabetes in oneself or a relative.

Methods

Study design

Ethical approval for this study was granted by the University of Stirling, School of Health Sciences ethics committee (7th Oct. 2015, SREC 15/16, Paper No. 37, version 1).

This was a qualitative study, conducted in Scotland (UK) that explored people’s cognitive, emotional and behavioural responses to diagnosis of type 2 diabetes.

Study information is reported according to COREQ guidelines [19].

Recruitment
This study used non-probability convenience sampling [20]. Recruitment was carried out through community outreach in Forth Valley, Scotland. Posters and flyers explaining the study were placed in 109 community locations, such as community centres, libraries, charity shops, bowling and golf clubs, post office branches and the University of Stirling. Diabetes UK advertised the study on their website, newsletter and social media pages. The study was also advertised by word of mouth.

Interested participants were invited to contact the researcher. They were screened for eligibility based on the following criteria: 1) over the age of 18 years; 2) able to speak and write in English; 3) a recent diagnosis of type 2 diabetes in oneself or a relative. The word “relative(s)” in this article is used to refer to any first-degree family member or partner (whether married or not) of someone with type 2 diabetes. Time since diagnosis was not specified in the inclusion criteria as type 2 diabetes is a chronic condition and people’s perception of what constitutes a recent diagnosis may differ. If a participant was eligible to take part, they were asked to nominate one or more non-diabetic relatives who might be willing to take part in the study (or nominate the relative with diabetes if it was the relative who got in touch). The participant was then asked to provide their family member with the study flyer and the researcher’s contact details.

Data collection

Interviews were deemed to be the most appropriate data collection method to explore people’s experiences, views and motivations [21]. Semi-structured face to face or phone interviews were conducted with people with type 2 diabetes and/or their relatives. Before the interview, participants completed a demographic questionnaire. The interview schedule was developed based on previous literature [4, 22]. The full interview schedule is displayed in Box 1.

Members of the same family were not always interviewed together, due to participants’ availability. In some cases, only one member of a family was able/willing to take part. It was decided not to exclude people whose family members were unable to take part because the study did not aim to explore discrepancies in the views of people from the same family. Participants were given £10 as reimbursement for their participation. The interviews were conducted by a female researcher (EDD) with training and experience in collecting qualitative data. Data collection continued until data saturation was reached in terms of sampling criteria and perceived depth and relevance of information collected. In order to avoid data redundancy, saturation was deemed to have been achieved when no new data emerged.

Data analysis
The interviews were audio-recorded, transcribed verbatim and checked against the recordings for accuracy. Field notes were not used as part of data analysis. All information was anonymised and participants were given study numbers. Data were analysed using Framework Approach, which requires the researcher to stay close to the original data in order to “capture, portray and explain the social worlds of the people under study” (p.279) [23]. This provides systematic and clear stages to the analytic process [24]. Such transparency ensures trustworthiness of data as it allows others to see how the final themes were developed and explore their relevance to other contexts. Analysis followed Spencer et al.’s [23] steps, which include familiarisation, constructing an initial framework, indexing and sorting, reviewing data extracts, data summaries, developing categories, mapping linkages, and providing explanations and interpretations. The interview questions were initially used to guide data analysis, after which data analysis adopted a more inductive approach. Data analysis was conducted by using Microsoft Excel.

Analysis was conducted by the primary author. Another author with extensive experience in qualitative research (VS) reviewed the data analysis stages to ensure that the final themes emerged from the data.

In order to provide participants with feedback on the outcome of the study they have contributed to, a lay summary of findings was disseminated to all people who took part in the interviews.

Insert Table 1 about here

Results

Participants

Forty two people showed interest in the study and 23 took part in 17 semi-structured interviews (10 patients, 13 relatives: 7 offspring, 1 mother, 5 partners) between November 2015 and March 2016. Thirteen of the interviews were individual and four included the patient and their relative(s). Relationships included two families (father, mother, two daughters; father, mother, daughter); a mother-daughter dyad; and three couples. The remainder were either a patient or a relative whose family member with diabetes was unable to take part. Interviews lasted between 25 and 85 minutes and took place in participants’ homes (N=6), private rooms at University of Stirling (N=6), a local hotel (N=1), a local library (N=1), a private office at a participant’s workplace (N=1), and over the phone with the researcher in a private room (N=2).

The characteristics of participants are presented in Table 1.

Interview findings
During the developing categories stage of data analysis, two groups of patients emerged: patients who adopted behaviour change immediately after the diagnosis of type 2 diabetes and patients who took time to adjust to the diagnosis. People were placed in the first group if they talked about specific changes in their behaviour. People were placed in the second group if they talked about needing time to come to terms with the diagnosis, struggling to accept what it meant and relying on others for diabetes management. We made the assumption that diagnosis was, by definition, a teachable moment for those patients who attempted to change their behaviour immediately after diagnosis but not for those who needed time to adjust. The comparison of perceptions and behaviour changes between these two groups enabled the exploration of McBride et al.’s [4] suggestion about necessary attributes of a teachable moment.

Two groups of relatives also emerged: people who adopted behaviours believed to prevent type 2 diabetes and people who did not adopt such behaviours. People were placed in the first group if they reported specific changes they had made to their behaviour. Again, we made the assumption that diagnosis was, by definition, a teachable moment for these relatives. People were placed in the second group if they reported no change in behaviours, known to prevent type 2 diabetes, thus suggesting the diagnosis was not a teachable moment for them. By comparing the perception and behaviour changes between these two groups we were able to explore McBride et al.’s [4] teachable moment factors.

Affective response

Diagnosis of type 2 diabetes often provoked an emotional response. All participants, both patients and relatives, talked about experiencing strong emotions including shock, relief, anger, sadness, disappointment or fear, although there were differences in the way people responded to their emotions. In some patients the surprise at diagnosis receipt evoked fear:

“In the first month of thinking I had this and then being diagnosed around that time, I did struggle to sleep on three or four occasions, thinking about dying and having this kind of strange intrusive thoughts, which is odd. I’ve never had that before in my life.” I3P2, patient

The surprise in other patients acted as a main motivator for behaviour:

“A bit sort of shocked really, but surprised, you know, that was all really...and then to just find out more about it. That was it...just to see what I could do and what I couldn’t do” I2P1, patient

Some patients, who had symptoms of type 2 diabetes, expected the diagnosis and felt relief because the diagnosis provided an explanation for previous poor health and allowed them to “know their enemy” and make changes to control their condition:
“I suppose initially I actually felt quite relieved ‘cause I thought: well, I’ve not been well and I thought there is something I can do about this” I13P7, patient

Some relatives also felt relieved because they did not perceive type 2 diabetes to be a very serious condition:

“I wasn’t entirely surprised. I was relieved that it wasn’t anything, and when I say more serious, I mean that it’s controllable and stuff like that.” I6R13, partner

It appeared that the people who adopted behaviour change immediately after the diagnosis and those who needed time to adjust experienced similar emotions.

Perceived risk and outcome expectancy

Patients, who adopted behaviour change in response to diagnosis, said they had always been aware of the potential complications that can result from type 2 diabetes. However, the diagnosis made these complications personally relevant and increased their perception of diabetes severity:

“I already knew about certain complications, but it brings it more home to you when you’ve actually been diagnosed and you have to be wary of certain situations” I14P8, patient

The increased perception of severity and relevance of complications prompted some people to consider the worst possible outcome of the current situation and consider type 2 diabetes as a potentially fatal condition. This increased motivation to change behaviour:

“I guess I was a little bit frightened but it was more the idea that if I didn’t sort it out then I wouldn’t get, I have a little boy who is 2 and a half now, and I wouldn’t get to see him go to school unless I did something.” I15P9, patient

These patients adopted behaviours they believed would reduce negative type 2 diabetes consequences (i.e. outcome expectancy). They talked about increasing physical activity, reducing carbohydrate and sugar intake, decreasing portion size and caring for their feet.

However, in the group of people who needed time to adjust and did not immediately make behaviour changes, perception of risk was increased but it was often associated with a period of denial and inability to make changes:

“And I presume it’s fairly common if not, close to 100% common that there is any kind of bereavement process, there is a period of denial in the beginning, isn’t it? None of this can be happening to me, not really being able to process what’s going on…” I3P2, patient
Some of these patients also talked about relying on their relatives for diabetes management:

“...if I do something that's gonna make it worse, I'd hope somebody either the doctor or a nurse or [wife] would point out that I was doing it...” I6P4, patient

Similar to the patients, relatives considered the potential severity and impact of type 2 diabetes after it became personally relevant to them. However, offspring of patients appeared more likely to experience increase in perception of personal risk of type 2 diabetes and adopt risk-reducing behaviours. The use of words, indicating necessity (e.g. need, made), was apparent in offspring’s accounts of behaviour change:

“...before then [diagnosis] I was thinking: I’m fine, I don’t need to worry about my life; but as soon as that happened [father got diagnosed] it was like: wait, what about if I am gonna get diagnosed, how’s that gonna affect me in the future?; It’s made me think sort of well ahead of what I should be. It’s made me think: right, I need to do this, I need to do all this to stop myself from getting into that position. So it’s kind of gave me a wake-up call as to stop myself from ever reaching that position” I5R6, offspring

“...bloody hell, everything seems to be mounting up that I’ve got a good chance of getting this..., so I need to make sure that I do as much as I can not to bring it on myself” I12R11, offspring

Some relatives whose parent had type 2 diabetes acknowledged the fact that they might not be able to prevent type 2 diabetes. However, they chose to adopt protective behaviours to minimise the potential impact diabetes could have on their lives:

“There is a risk that no matter how healthy we are, we can get it later on in life maybe at the same age dad got it so that, maybe you couldn’t prevent it, but can certainly try and have a healthy lifestyle so when it does happen you have already got better controls already in place to deal with it if it does happen but if people are just unhealthy generally, I suppose you could prevent it by being healthier and not getting it in the first place.” I2R2, offspring

Partners did not appear to have experienced increased perception of diabetes risk. Many of them compared their behaviours to those of the patient and did not believe their own behaviour would lead to type 2 diabetes:

“...Well, I watch what you eat, you know...there are so many things that I wouldn’t do from, you know, you put half an inch of what I think...and I can’t eat, I couldn’t eat a sandwich that you made without you taking the butter off it because you put on...you put more butter on a
sandwich than I put cheese on it, you know...you have cream, custard and ice cream all together on your pudding and I would never do...I would want to vomit before I do that, so I think we are just brought up with very different attitudes to eating.” I3R5, partner

Self-concept and social role

Patients who adopted behaviour change immediately after diagnosis, talked about changes in the way they perceive themselves (i.e. self-concept). They made a comparison between their behaviour before and after the diagnosis and evaluated their self-concept based on that:

“I am extremely tired all the time whereas I was a woman before who wouldn’t think twice of, just constantly being on the go, would never sit down. But now I am so tired, when I finish a day’s work I am exhausted which is not like me at all. I’ve become somebody else” I14P8, patient

Some of these people adopted specific behaviours they believed would help them maintain their pre-diabetes identity. The person below described falling asleep on the sofa as a “diabetic” behaviour, which they did not want to engage in:

“I am having to go dog walking with my fantasy dog. To stop that falling asleep on the sofa ’cause I think that’s diabetic as well. I don’t know if it is, but in my head it is.” I10P6, patient

In other cases, type 2 diabetes was an opportunity to redefine one’s identity. Below is a quote from a patient who reported frequent overeating, which he believed contributed to the development of type 2 diabetes:

“...To what extent is eating, especially now that I know the consequences, to what extent is that self-harm, you know...(...)it’s deliberately destructive (...) there’s a lot of questions like: How do I see myself and what is it about? And I think the diet...working out my identity with food, working out my relationship there, is part of a big thing for me in terms of how I see myself and the diabetes has definitely changed and I might be opening myself up to some unpleasant things about destructive behaviours and how I can duck relationships…” I15P9, patient

Patients, who adopted behaviour change, also constructed their new identity by differentiating themselves from other people with type 2 diabetes. Some patients talked about the “good diabetic” versus the “bad diabetic” where the “bad diabetic” is a person who is overweight and who displays poor self-management:
“But you see that with maybe some people with diabetes, when you look at it, it’s a stereotyping again, obviously quite fat and maybe they don’t look after themselves right either but they get the type 2 diabetes and I think maybe they’re expecting some miracle medication to cure it and then something will happen to their feet....” I2P1, patient

In comparison, sometimes there was a struggle to accept the need to engage in diabetes-related behaviours, such as checking insulin levels, in the group of patients who did not make immediate changes:

“I think I’ve been on a bit of an emotional rollercoaster as well in terms of...being numb, avoiding it for a bit and trying to let it sink in and trying to work out how to manage the fact that...I was used to feeling fine and now I prick myself...getting into some kind of a routine...” I3P2, patient

In some cases, diabetes was believed to be incompatible with patients’ social roles, primarily due to perceived stigma around type 2 diabetes:

“I have a very high profile, high power job, leading people and...that stigma, I know, it will be in their mind...so I need to carefully think about that and manage that in the appropriate time” I3P2, patient

This in turn presented difficulties in the management of the condition:

“Can I do that [check insulin level] in the car in the car park or to drive down the road, can I do it in the gents’ toilet, do I do it on my desk, all that kind of stuff” I3P2, patient

“If I went out for a meal with friends who don’t really know I am diabetic then I will just eat normally and adjust and take more insulin to cope with that” I14P8, patient

With regard to relatives who adopted risk-reducing behaviours, there was no evidence that they experienced changes in their self-concept or social role. However, all relatives talked about changes in their responsibilities in terms of caring for the patient, cooking food that complies with the diabetes regimen and policing the patient’s behaviour. In spousal relationships, this sometimes led to changes in relationship balance:

“I think probably the balance in our relationship has changed. I would probably see me having more of a caring role than I had before [diagnosis]” I6R7, partner

In parent-offspring relationships, role reversal was observed where daughters adopted caring roles:
“He’s [father with type 2 diabetes] doing okay, he struggles from time to time, I think he eats sweet packets so that gives me a reason to shout at him for it” I5R6, offspring

However, there were partners, who did not believe to be at increased risk of type 2 diabetes, and who made a clear distinction between themselves and the person with diabetes. These people’s role in the house did not appear to have changed:

“I mean I understand that, you know, what [wife]’s got, you know, I am quite happy to go along with it and if I need to pig out or something, I’m probably gonna do it.” I13R12, partner

Discussion

This study explored the relevance of McBride et al.’s [4] teachable moment model to type 2 diabetes. The study focused not only on people with type 2 diabetes but also on relatives of people with type 2 diabetes. Given that first-degree relatives and partners of people with type 2 diabetes may be at increased risk of developing the condition [16, 17], the study expands the teachable moment construct into primary prevention. Each of McBride et al.’s [4] teachable moment factors is discussed below in relation to the current study and previous research.

Affective response

The current study did not provide support for McBride et al.’s [4] suggestion that events that elicit strong emotional responses increase the likelihood of illness diagnosis to be a teachable moment. This is because almost every participant (patient or relative) reported experiencing strong emotions but these emotions evoked different responses. In some people emotions, such as shock and surprise, motivated them to adopt behaviour change. In others they led to denial and avoidance. Negative emotions, such as fear, have been shown to discourage behaviour change, especially when people are not convinced of their self-efficacy or the effectiveness of specific behaviours [25, 26]. However, this finding is promising because it shows that diagnosis of type 2 diabetes triggers an emotional response and clinicians and researchers need to be aware of this when delivering interventions.

Risk perception and outcome expectancies

Patients whose perception of diabetes severity and susceptibility to negative diabetes-related consequences increased after diagnosis, were more likely to adopt behaviour change and were thus assumed to have experienced a teachable moment. This provides support for McBride et al.’s [4] model and previous models that suggest perceived risk increases the likelihood of adopting health-related behaviours (Health Belief Model [1], Common-sense model [22]). Outcome expectancy was
also a facilitator for behaviour change as these patients adopted specific behaviours to offset negative diabetes outcomes (e.g. reducing sugar intake and portion size). This supports McBride et al.’s [4] model and previous research showing that beliefs that specific behaviours would lead to specific illness-related outcomes are associated with changes in self-management [27-29].

With regard to relatives, diagnosis of type 2 diabetes appeared to increase risk perception mostly in the offspring, rather than partners, of patients with this condition, suggesting that type 2 diabetes diagnosis is more likely to be a teachable moment for this group. This supports previous research showing that first-degree relatives of people with type 2 diabetes may believe they are at higher risk of getting type 2 diabetes, compared to the general population [30, 31]. One explanation for this could be that offspring are aware of their genetic predisposition to type 2 diabetes while partners place greater emphasis on lifestyle factors and perceive their behaviour to be different from that of the patient. Previous research in type 2 diabetes and heart attack shows that although some people believe the illness runs in their family, they perceive their lifestyle to be different from that of the affected relatives [32, 33]. Offspring reported a perceived need to change behaviour and adopted specific behaviours to reduce their risk of type 2 diabetes (e.g. reducing sugar intake). This suggests that outcome expectancy may be a teachable moment factor for the offspring of patients.

**Social role and self-concept**

This study provides mixed support for McBride et al. [4] who suggest that changes in self-concept or social roles contribute to the potential of illness diagnosis to be a teachable moment. Patients, who changed their behaviour in response to the diagnosis thus suggesting diagnosis was a teachable moment for them, evaluated their self-concept and were either motivated to adopt strategies that would allow them to keep their previous self-concept or they welcomed the identity changes as an opportunity for the situation to improve. Disruption in identity and potential identity transformation following a chronic illness diagnosis have been demonstrated before [34-36]. In type 2 diabetes, Knec et al. [37] found that newly diagnosed patients with type 2 diabetes evaluated their pre-diagnosis behaviours in order to decide which behaviours could be continued and which had to be changed. Many patients in the current study also wanted to avoid being perceived as a “bad diabetic”, which motivated them to adopt behaviour change and comply with diabetes management guidelines. However, in some cases type 2 diabetes was perceived to be incompatible with current social roles. McBride et al. [4] suggest that people with lung cancer who smoke may have a sense of obligation to stop smoking to avoid stigma of non-compliance. However, in the case of type 2 diabetes, there is perceived stigma that people are to be “blamed” for their condition [38]. This was
a barrier for self-management for some patients in this sample as they were reluctant to disclose their condition to friends.

Relatives in this study did not report changes in self-concept. Although many relatives supported the patient by changing existing responsibilities or adopting new ones, change in social role did not appear to be related to the experience of a teachable moment. Offspring talked about telling parents what to do suggesting a potential role reversal while partners expressed a need to “police” and care for the patient suggesting a shift in relationship balance. Similar changes in family roles following diagnosis of diabetes have been observed before, showing that women are more likely to adopt multi-caregiving roles [39].

Implications

The current findings have implications for management of type 2 diabetes in patients and prevention in their relatives. The suggested teachable moment factors can be incorporated into a brief diabetes intervention, delivered by healthcare professionals, such as diabetes nurse specialists (DNS). Nurse-led brief interventions have been shown to be effective for smoking cessation [40] and alcohol [41]. This could be facilitated by using the teachable moment communication process model (TMCP), which teaches clinicians how to capitalise on teachable moments in practice [42]. Routine diabetes appointments present an excellent opportunity for such interventions and also for prompting family communication about diabetes. Family communication around the teachable moments factors is key for optimising the potential of type 2 diabetes diagnosis to prompt behaviour change. Research has already indicated that adult offspring of patients with diabetes generally seem receptive to being informed via the family system about reducing their diabetes risk [43, 44].

Additionally, the majority of patients recognise the necessity of disseminating risk and preventive messages in their family [30, 44, 45]. Whitford et al. [44] show that people who have spoken with their relatives with diabetes about diabetes risk were more likely to see themselves at risk of type 2 diabetes, worry about diabetes and see diabetes as serious.Patients can be encouraged to bring a relative to their appointment with the DNS. The DNS can prompt communication about emotions and how they influence behaviour. In patients, particular focus should be placed on diabetes severity, as this can be an important teachable moment factor. Relatives would benefit from discussion around risk perception and this may be particularly important for partners who often do not view themselves at increased risk of type 2 diabetes. Families can discuss behaviours they can adopt together (e.g. changes in diet) in order to offset negative diabetes-related outcomes, thus addressing outcome expectancy as a teachable moment factor. Social roles, especially where these are incompatible with diabetes, need to be addressed so they do not present a barrier to self-
management. Similarly, discussion around adopting caring roles in relatives and the perceived need to “police” the patient, could provide a platform for further family communication about the needs of the patient and their relatives.

Limitations

The current study has several limitations. First, the convenience sampling did not allow for strategic recruitment where there is a good variety and sample members differ in terms of key characteristics [20]. Second, recruitment was carried out in one health board in Scotland. Regional differences in healthcare experience may exist and can influence psychological outcomes [46, 47]. Finally, the study did not consider psychosocial characteristics and ethnic, racial and socioeconomic background, which have been shown to affect behaviour change [6, 8, 48-50].

Summary

The current study provides support for the idea that diagnosis of type 2 diabetes is a teachable moment. It shows that McBride et al.’s [4] factors (i.e. affective response, risk perception and outcome expectancy, self-concept and social role) are relevant to patients with type 2 diabetes and their relatives, thus expanding the teachable moment construct into primary prevention. Interventions need to be tailored to address individualised experience of potential teachable moment factors and encourage family communication around these factors.

References


### Box 1. Interview schedule

#### Setting the context

Explain aim of the study and my role as a primary researcher

To the patient: We can start with you telling me how you got diagnosed with type 2 diabetes? (Prompts may include: How did you feel when you found out?; How long after that did you tell your family?; What about your friends?)

To the relative: Do you remember how you found out? How did you feel?

To both: Do you openly talk about type 2 diabetes in your family?

#### Changes in perceptions

- **Cause**: What do you think causes type 2 diabetes? (Explore any changes in knowledge of causes since diagnosis)

- **Identity**: What do you think are the symptoms of type 2 diabetes? (Explore any changes in knowledge of symptoms since diagnosis)

- **Severity**: Tell me about what you think about the seriousness of type 2 diabetes? (Explore any changes in perceived diabetes severity since diagnosis)

- **Consequences**: What do you think are the consequences of type 2 diabetes? (Explore whether the patient has experienced any consequences and whether there are changes in perceived diabetes consequences since diagnosis)

- **Timeline**: How long do you think your type 2 diabetes will last? (Explore any changes in knowledge of diabetes duration since diagnosis)
• Control: To patient: What do you think about your ability to control type 2 diabetes? To relative: What do you think about prevention of type 2 diabetes? (Explore any changes in perceived diabetes control since diagnosis)

• Illness coherence: Do you feel like you understand type 2 diabetes? (Explore any changes in understanding since diagnosis)

To the relative: What do you think about your chances of developing type 2 diabetes? (Explore whether their perception of risk has changed since diagnosis in their relative); Are you worried about developing type 2 diabetes in the future?

Changes in behaviour
To the patient: Tell me more about your behaviour since diagnosis. Have you made any changes to your behaviour since you got diagnosed? (Prompt about specific changes in diet, exercise, lifestyle). Has it been easy? (Prompt around barriers to making changes)

To the relative: Have you made any changes to your own behaviour? (Prompt about specific changes in diet, exercise, lifestyle). Has it been easy? (Prompt around barriers to making changes)

To both: Can you tell me more about the ways the diagnosis has affected the way you see yourself and your social role? (Prompt around perceptions of oneself; accepted norms of behaviour; stigma; roles within the house and at work); How has T2D affected your relationship with your relatives?

To both: Do you think that diagnosis is a good time to speak with the patient’s relatives and tell them more about their risk of type 2 diabetes and the ways it can be prevented? (Prompt about why they think it would be a good time, or not).

Table 1 Participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>Patients (n=10)</th>
<th>Relatives (n=13)</th>
</tr>
</thead>
</table>

533

534
| Duration of type 2 diabetes | Range: 3 weeks – 18 months  
Mean: 7.9 months  
Median: 6.5 months | Duration of diabetes in their relative with the condition:  
Range: 6 weeks – 11 months  
Mean: 6.8 months  
Median: 8 months |
|----------------------------|-------------------------------------------------|
| **Route to diagnosis**     | 5 presenting GP with symptoms  
3 periodic screening  
1 visit GP for other reasons  
1 after gestational diabetes | **Route to diagnosis for their relative with type 2 diabetes:**  
2 presenting GP with symptoms  
1 usual check up |
| **Relationships with patient** | Not applicable | 6 daughters  
3 wives  
2 husbands  
1 son  
1 mother.  
6 share genetics but live apart from patient  
2 share genetics and live together  
5 do not share genetics and live together |
| **Gender**                 | 5 male  
5 female | 10 female  
3 male |
| **Age**                    | Range: 37-71 years  
Mean: 53.6 years  
Median: 51 years | Range: 18-68 years  
Mean: 41.17 years  
Median: 45.5 years |
| **SIMD (Scottish Index of Multiple Deprivation)** | Range: 2-10  
Mean: 5.7  
Median: 6 | Range: 2-10  
Mean: 6.92  
Median: 6 |
<p>| <strong>Education</strong>              | 9 had education after high school (2 PhD, 1 MSc, 2 BAs/BSc, 1 one year at | 9 had education after high school (3 PhD, 1 MSc, 2 BAs/BSc, 2 college, 1 HND, 3 current students) |</p>
<table>
<thead>
<tr>
<th></th>
<th>university, 1 Diploma, 1 Police promotion exam, 1 HNC&lt;sup&gt;5&lt;/sup&gt;, 2 current students)</th>
<th>1 – high school education</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment</strong></td>
<td>4 full-time</td>
<td>4 full-time</td>
</tr>
<tr>
<td></td>
<td>3 retired</td>
<td>4 part-time</td>
</tr>
<tr>
<td></td>
<td>2 unemployed</td>
<td>2 unemployed</td>
</tr>
<tr>
<td></td>
<td>1 part-time</td>
<td>1 self-employed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 retired</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 other</td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td>8 in a relationship</td>
<td>12 in a relationship</td>
</tr>
<tr>
<td></td>
<td>2 single</td>
<td>1 single</td>
</tr>
<tr>
<td><strong>Family history of diabetes</strong></td>
<td>5 yes</td>
<td>8 yes</td>
</tr>
<tr>
<td></td>
<td>5 no</td>
<td>5 no</td>
</tr>
<tr>
<td></td>
<td>Number of relatives with diabetes: 1-4</td>
<td>Number of relatives with</td>
</tr>
<tr>
<td></td>
<td></td>
<td>diabetes: 1-4</td>
</tr>
<tr>
<td><strong>How they heard about the study</strong></td>
<td>5 word of mouth (relative who took part or someone who saw advert)</td>
<td>7 word of mouth (through patient who took part or someone who saw advert)</td>
</tr>
<tr>
<td></td>
<td>2 University of Stirling portal</td>
<td>2 University of Stirling email</td>
</tr>
<tr>
<td></td>
<td>1 Diabetes UK newsletter</td>
<td>2 University of Stirling portal</td>
</tr>
<tr>
<td></td>
<td>1 Falkirk Sensory centre</td>
<td>2 Stirling council intranet</td>
</tr>
<tr>
<td></td>
<td>1 West Lothian Diabetes support group social media page</td>
<td></td>
</tr>
</tbody>
</table>

<sup>1</sup>Scottish Index of Multiple Deprivation (SIMD): SIMD is used to identify areas of multiple deprivation in Scotland. It ranks small areas from most deprived (ranked 1) to least deprived (ranked 10) ([http://www.gov.scot/Topics/Statistics/SIMD](http://www.gov.scot/Topics/Statistics/SIMD)).

<sup>2</sup>PhD – Doctor of Philosophy

<sup>3</sup>MSc – Master of Science

<sup>4</sup>BA/BSc – Bachelor of Arts/Bachelor of Science
542  5 HNC - Higher National Certificate
543  6 HND - Higher National Diploma