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A Qualitative Exploration of Experiences of Diagnosis Amongst People Living with Type 2 Diabetes

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1. Abstract

1.1. Background: Previous research h¬as found that experiences of being diagnosed with Type 2 Diabetes (T2D) shape how people regard their condition, which can later have an impact on self-management. This research examines experiences of diagnosis reported by people living with T2D.

1.2. Methods: Using semi-structured interviews (N = 25), focus groups (3 x N = 12 participants) and open-ended questionnaires (N = 6), people living with T2D were recruited from a community-based T2D participation group. Data were analysed thematically using a framework analysis.

1.3. Results: Patients' accounts of diagnosis yielded 3 main themes: (1) Routes to diagnosis; (2) Symptom status during diagnosis experience; and (3) Responses to T2D diagnosis. It was found that participants' routes to diagnosis and their experiences of symptoms prior to, and during, the diagnosis process presented varying barriers and facilitators to receiving, understanding and/or acting on, the ramifications of their condition. This, in turn, shaped how participants' responded to their diagnosis.

1.4. Conclusion: The paper concludes that positive experiences of diagnosis may be possible if barriers to receiving a T2D diagnosis are removed through health promotion measures. Equally, healthcare professionals should seek to resolve the uncertainties that people experience around the time of diagnosis. It is recommended that the latter could be achieved by tailoring patient information and support according to 1) routes to diagnosis, and 2) the stage of the condition has reached at the time of diagnosis.

2. Keywords

Type 2 Diabetes; Qualitative; Diagnosis; Patient perspectives; Patient experiences

3. Background

Type 2 Diabetes (T2D) is a long term condition requiring lifestyle changes, such as dietary changes, increased physical activity as well as medication-taking. These measures are known collectively as self-management which aims to control diabetes and avoid the life-threatening complications of the condition. It has long been argued that delivery of diagnosis can be a key factor shaping self-management [1,2]. For example, Polonsky et al [1] investigated the levels of distress that patients experienced at the time of diagnosis, then measured levels of distress alongside clinical indicators of self-management 1-5 years later. It was found that where patients reported that healthcare professionals offered reassurance and

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a clear care plan at the time of diagnosis, that less distress and better self-management outcomes were evident in these patients 1-5 years later.

A body of, predominantly qualitative, research exists looking at people living with diabetes' experiences of diagnosis. The work of Hiscock et al [2] and Peel et al [3] has described how 'routes' to T2D diagnosis have causal relationships with emotional reactions to diagnosis, as well as people's ability to absorb educational information at this time. Hiscock et al [2] suggested that people initially experienced a period of reacting to the diagnosis, rather than responding to the implications of the diagnosis. As such, Hiscock et al [2] recommended that too much information at the time of diagnosis was not considered appropriate or helpful by patients. However, in Hiscock et al [ibid.] study there was a notable bias in recruitment of patients from a diabetes helpline, i.e. these people were actively seeking information on T2D self-management when recruited. Seeking information may have been a result of this group experiencing their diagnosis as a shock, rather than T2D diagnosis being a shock in all diagnoses. Conversely, Peel et al [3] found that this assertion of a global 'shock' period post-diagnosis was presumptuous. They found three routes to diagnosis: the 'suspected diabetes' route; 'illness' route; and 'routine' route. The different routes to diagnosis shaped people's emotional responses, and reactions to diagnosis were more complex and diverse than just a 'shock' scenario. The study [3] also found that patients' requests for information at the time of diagnosis were frequently unrelated to 'emotion'. In the case of a 'routine testing' diagnosis, the 'seriousness' of the illness was often determined by the amount and type of information and services that patients were offered at this time. Indeed, Parry et al[4]. found that diagnosis is a crucial (under-used) point of learning in T2D self-management, and that issues of clarity, timing and authority of the diagnosis, i.e. how diagnosis was delivered by healthcare professionals, shaped patients' emotional responses.

Eborall et al [5] argue that qualitative work has shown that people diagnosed through screening take T2D less seriously than those diagnosed as a result of, for example, hospital admission. Eborall et al [ibid]. study showed that perceptions of the illness changed over the process of diagnosis, and that it was possible to facilitate psychological adjustment through having clear information at the time of T2D screening and/or diagnosis, as well as follow up information for patients. However, the opt-in nature of research and of screening processes (i.e. that characterize Eborall et al study sample) may affect the transferability of this research. This is because the sample may be comprised largely of participants who wanted clarity about, or had an interest in, their current health status and would thus respond positively to information-giving.

Lawton et al [6].found that, following diagnosis, patients felt that they lacked the confidence and knowledge to manage T2D, and often wanted quick access to services. Troughton et al [7] looked at patients with a diagnosis of 'pre-diabetes' and found that their experiences were characterised by uncertainties about their diagnosis, which related to the physical consequences of the condition and how to manage them. The study [7] also found that patients sought certainty by reading into healthcare professionals' responses in clinical encounters as a gauge of how serious the condition was - e.g. how diagnosis was delivered by the health professional. Troughton et al [7] also note that the process of screening itself demonstrates to (asymptomatic) patients that changes that have occurred in their body. However, Weinger et al [8] found that patients described a 'backburner' phase following diagnosis where they felt well, and didn't prioritize diabetes over other issues in their life. However, Lawton et al [6], Troughton et al [7] and Weinger et al[8] studies focus on the experiences of asymptomatic, newly-diagnosed T2D patients usually diagnosed through screening. Hence, these studies tend to preclude the experiences of those diagnosed through other routes, e.g. hospitalisation or where the patient suspects an illness.

In overview, looking at responses to diagnosis from the patient's perspective it would appear that although there may be a period of shock to diagnosis, and this may not be the norm. Rather, routes to, and delivery of, the diagnosis and how information is given at the time of diagnosis are influential factors in patients' perceptions, understanding and experiences of diagnosis albeit frequently demonstrated solely in newly-diagnosed asymptomatic patients. Routes to diagnosis have been shown to influence how patients initially respond to diagnosis in the short-term, and that this has an association with future self-management outcomes. Less is known about how the different mechanisms work in different routes to diagnosis. It is also clear that patients experience uncertainty at the time of diagnosis which influences the type of information and services they would like to receive. This uncertainty can also lead to patients looking for external cues in professional attitudes and actions to assess the significance of T2D for their lives. However, there are gaps in understanding how progression of the illness at the time of diagnosis impacts on people's experiences of diagnosis as homogenous samples are largely used, drawn from those recently diagnosed by diabetes screening.

Hence, the aim of this study was to explore factors shaping patients'

experiences of T2D diagnosis. The objectives in support of this aim sought to:

i. Examine the pathways to diagnosis that people living with T2D experience;

ii. Explore how progression of the condition at the time of diagnosis shaped participants' experiences;

iii. Describe the barriers and enablers people living with T2D perceive and experience during of diagnosis;

iv. Explore how people living with T2D responded to their T2D diagnosis (in light of objectives 1, 2 & 3).

4. Methods

Participants were recruited from a Diabetes Patient and Public Involvement Group a peer-support group for people living with T2D sponsored by a local health provider. A theoretical framework and epistemology/ontology informed by critical realism was adopted which viewed people's experiences as subjective experiences of their objective circumstances. Using a case study approach, members were drawn from one inner London borough with diverse socio-demographic population including both high levels of deprivation and some of the wealthiest areas in the country. A group-based, purposive maximum variation sampling approach was taken to capture the naturally occurring diversity of people living with T2D, and to ensure participants had different routes to, and time since, their diagnosis. Qualitative data were collected using three separate methods of data collection to maximize: 1) Participation in the study and participant diversity; 2) Recruitment of irregular attendees of the group and 3) The possibility of triangulation between methods. Participants could choose to take part in focus groups, and/or one-to-one semi-structured interviews and/or filling out open-ended questionnaire. In total thirty-seven (n=37) participants were recruited (from a potential sample of n=166 participation group members). Twenty-five (n=25) one-to-one interviews were conducted, 6 questionnaires and 11 people attended 3 focus groups (n=3,3,5 attendees). Only five (n=5) participants participated in more than one method; i.e. a questionnaire participant also did a one-to-one interview, and 4 focus group participants also went on to do one-to-one interviews. Participants were asked questions such as 'How were you diagnosed with Type 2 Diabetes' and 'How did you respond to your diagnosis'. Data collection continued until saturation point was reached. Saturation point occurs where adding participants to the existing sample is unlikely to generate any new ideas this is estimated to occur anywhere from the 12th [9] to around 25th interview [10] or around the third to fifth focus group [11].

All data collected were transcribed verbatim and analysed thematically using a data driven, framework analysis approach [12]. To ensure rigour, transcripts were also read by two researchers (SS, PN) and the thematic framework was developed keeping to the agreed themes that emerged, as well as negotiating new themes (or sub-themes) where there was disagreement [13]. Using framework analysis, quotes from the transcripts were then assigned to the themes [14], hence the illustrative quotes given in the findings are examples selected from, but representative of, all comments in a given theme. Demographic data were also collected from participants using a questionnaire to ensure participants had diverse characteristics.

Although small from a quantitative, experimental paradigm, using qualitative samples of this size have been shown to be robust strategy to obtain data which explores patients' understanding and identifies emerging themes using in-depth semi-structured designs which often pave the way for further quantitative research [14-19]. Ethical clearance was gained from Kings College NHS Hospital Research Ethics Committee and signed informed consent, anonymity, confidentiality and right to withdraw were attained throughout the study.

5. Findings

The participants who took part in the study were asked to recall as clearly as possible their experiences of diagnosis, and to discuss the impact that T2D diagnosis on had their day-to-day lives at the time. Participants discussed diagnosis as a process where T2D was detected, and subsequently diagnosed. The findings below are split into four parts. The first section (section 3.1.) outlines some of the socio-demographic characteristics of the sample. The remaining sections present the main themes found in the data: Section 3.2. presents the 'Routes to diagnosis' theme; Section 3.3. presents the 'Symptom status during diagnosis' theme; and in Section 3.4., the 'Responses to T2D diagnosis' theme is presented. As stated above, in the findings presented, quotes will be used throughout to illustrate themes. The quotes are followed by the abbreviations denoting participant number (PT#) and data collection method (interview = I, focus group = FG, questionnaire =Qu) e.g. PTI#, PTFG# and PTQn#. A page (P.) and line (L.) numbers are also given for all quotes. This allows quotes to be traced back to the original transcript e.g. PTI #2, P.1:L1. Gender is also given, i.e. (m) or (f), to allow the reader to develop a mental image of the participants.

5.1.Sample profile

The majority of those taking part were female (57%, N=21) and aged 60+ (86%, N=32), the latter being commensurate with the onset of T2D amongst older people. Sixty-five per cent (65%; n=24) of participants were white with the remaining participants self-reporting being black African or black Caribbean. Reflecting the deprived nature of the area, only N=6 (16%) participants were living in a household with an above average household income. Income status tallied with having a higher educational status - as the six wealthiest participants were the only ones educated to degree level or higher. In contrast, N=7 (22%) of participants lived in households with an income which fell below £8,000 per annum (p.a.) and these participants were most likely to have education to primary school level only.

5.2. **Routes to Diagnosis**

The first theme of route to diagnosis had four distinct sub-themes reflecting different routes to T2D detection and diagnosis, these were:

i. Symptom onset and self-referral diagnoses route;

ii. Screening diagnoses route;

iii. Acute onset/hospitalisation diagnoses route;

iv. Monitoring of a pre-existing condition or a dual diagnoses route.

v. These are discussed in turn below.

5.2.1 Symptom Onset and Self-Referral Diagnoses Route: Of the participants who took part in the study, twelve (n=12) received a diagnosis as a result of symptom onset and self-referral to health services. The symptoms participants detected, prompted self-referral and eventual diagnosis."I was not feeling myself, always knackered. So I went to the doctor and she did some tests and when they came back she said: 'You've got diabetes'" PTI#11 (f): P.2; L.22.

Symptoms followed the classic form of frequent urination, excessive thirst and tiredness. Some participants also reported prolonged sweats and feet pain as triggers to self-referral. Four 'self-referring' participants also 'self-diagnosed' prior to attending the doctor for a formal diagnosis. "I was a psychiatric nurse and I went to work and I didn't feel well. To be honest I used to skip breakfast so I thought it was that. I should have noticed the symptoms, I had spoken to the doctor before but it was overlooked […] I just realised I had diabetes, so I checked [...] All the doctor did was confirm it." PTI#20 (f) - P.1; L.10.

Two of these patients were able to self-diagnose (through working in the health service and/or being able to self-test blood and urine), another patient participant's daughter was a nurse who helped to diagnose T2D, and the remaining participant reported that he remembered the symptoms from caring for his mother with diabetes. As we can see, the participant above had also received an early misdiagnosis which acted as a barrier to diagnosis. Conversely, her knowledge of T2D, and access to testing equipment, facilitated and enabled eventual diagnosis.

5.2.2. Screening Diagnoses Route: A further eleven (n=11) participants were informed of their diagnosis as a result of screening or 'M.O.T.s', as participants frequently referred to the screening process. Where symptoms were reported prior to screening these were often framed as having known something 'wasn't right' but not having known what, or not having recognised the symptoms as 'diabetes'. As such symptoms were retrospectively realised. The latter was common where T2D was reported as 'in the family' suggesting that, in some cases, patients were still able to explain away symptoms despite having a familial experience of diabetes.

"I should have spotted it really, my mother had it. But I'd put the weight and light-headed feeling down to age. But, of course, it was diabetes. I should have seen that." PTI#13 (m) - P.1; L.18.

Hence, one barrier to diagnosis within the screening route occurred where patients reported that they may have had symptoms before screening, but that they explained away these symptoms as they were so benign. This is why for some participants, the process of screening demonstrated to them the effects of T2D when symptoms were largely absent.

"I knew that something was wrong with me but I didn't know what it was. When I went to the hospital for some tests, I had to do blood and some liquid, and blow into something and when they got the results they explained to me I had diabetes and what it is all about. The diabetes was happening in my body but I didn't know." PTI#15(m) - P.1; L.16.

The process of screening itself facilitated these patients' understanding of changes to their bodies which had led to their diagnosis, thus facilitating an understanding of their diagnosis. But other participants diagnosed through screening reported that the delivery of their diagnosis acted as a barrier to understanding their diagnosis as diagnosis was delivered inappropriately and with insufficient information:

"There wasn't really any symptoms. I just went to have a check-up and blood pressure and all that lot. [...] I got back the results,

the lady from the surgery called me: 'You have to come to see the doctor you've got diabetes.' I don't know her, is she a doctor? No. This isn't right, can they do this? It's my personal information." PTFG#2(f) - P.6; L.9.

This clearly shows that, in this case, mismanagement of the diagnosis delivery by health services had an impact on this participant's experiences at the time of diagnosis.

5.2.3. Acute Onset and Hospitalisation Diagnoses Route: In this third sub-theme, participants reported being diagnosed as the result of the sudden onset of T2D complications and hospitalisation (n=5). Two of these participants reported that diagnosis was given when they were admitted to hospital with an ailment that was then discovered to be a diabetic complication, e.g. gout.

"I was taken to hospital. It was very sudden, I didn't know, it was just about two weeks, I started drinking a lot but I was in Kenya and Kenya was very hot, so I don't take it very seriously. I just thought it was because of the heat and I was running around and I was planning to come to visit my children, so I thought I was overdoing it, you know. And then finally I started going in and out of consciousness and I was taken to the hospital, and I was put in intensive care in Nairobi." PTI#3 (f) - P.1; L.16.

As we can see, although the participant had some awareness of signs of illness and changes to her body these signs were dismissed in light of other things happening in her life. Again this route, reinforced a key barrier to T2D diagnosis that the symptoms of T2D can be readily explained away in the day-to-day context of people's lives, e.g. symptoms are explained away due to hot weather or 'overdoing it'.

5.2.4. Monitoring of a Pre-Existing Condition or a Dual Diagnoses Route: The final sub-theme of 'route to diagnosis' comprised of people who received a dual diagnosis, or were diagnosed as a result of monitoring another illness (n=8). Illnesses reported included lupus, AIDS, hepatitis B, arthritis and cancer. These participants frequently had no experience of T2D symptoms, or had only experienced T2D symptoms alongside symptoms of other conditions. For example, in discussing the onset of symptoms the participant below described how the symptoms of T2D were clustered together with HIV status:

"I knew I was ill but it wasn't what I associated with diabetes and I should have recognised it but I just thought it was a type of flu. I knew after a week it wasn't flu but you would have thought the health professionals would have spotted it. But I got through it. [...] I am a diabetic because of the drugs given me for HIV, it turned me into a diabetic, that turned me into a person with high blood pressure, that gave me problems with cholesterol and now I have got angina." PTI#10 (m): P.1; L.20 / P.1; L.50.

Conversely, some participants who reported a comorbidity at the time of diagnosis combined their understanding of T2D with the co-occurring illness in a way that made the two indistinguishable. As this newly-diagnosed patient participant described:

"I was having a lot of problems, which eventually got diagnosed mostly as prostate cancer, they included needing to pee fairly urgently, feeling rough, therefore eventually I did the un-male thing and went to the doctor [...] And first of all blood samples a couple of months later I got on to the alternate propositions and confirmed as having both. The cancer and the diabetes. [...] A bloody nuisance but that so, basically as far as I can work out the symptoms are very much the same for both things. So I can't really complain too much about diabetes. I'm not sure if it is that!" PTI#2 (m) - P.1; L.8.

Hence, we can see in this route to diagnosis also involved barriers to interpreting symptoms where patient participants had to tease out the symptoms of T2D from the effects of the co-occurring condition.

5.2.5. Overview of Routes to Diagnosis Theme: In overview, when describing diagnosis in terms of their 'route to diagnosis', showed that aspects of their experiences informed barriers to, and facilitators of, T2D diagnosis. One patient reported misdiagnosis which acted as a healthcare professional-related barrier to a formal diagnosis of T2D, but this barrier is possible across all routes to diagnosis. Other barriers reported were specific to patients' routes to diagnosis. Patient participants with co-occurring conditions reported one barrier to T2D management relating to being unable to tease out symptoms specific to T2D. Another barrier, common in routes where symptoms were present, was the seemingly benign nature of T2D symptoms making it easy to explain some symptoms away, which delayed interpretation and self-referral.

Some patients with previous experience of T2D in their family saw experience of T2D as facilitating identification of symptoms, subsequent self-referral and therefore enabling T2D diagnosis. Equally, access to diagnostic equipment facilitated self-diagnosis which later led to formal diagnosis. Finally, it was found that some patients felt their diagnosis had been un/successfully managed, as some participants who received a diagnosis through screening described diagnosis as being poorly delivered. Hence it is clear that, for some participants, the route to diagnosis had implications for the barriers and enablers that participants experienced at the time of diagnosis.

5.3.Symptom Status During Diagnosis

In the second theme of symptom status during diagnosis, patients' awareness and experiences of managing symptoms at the time of diagnosis are presented. Six sub-themes of symptom status were found based on the participants' experiences of symptoms and the role the patient played in eventually being diagnosed by a healthcare professional:

i. Asymptomatic
ii. Awareness of symptoms and self-diagnosis
iii. Awareness of symptoms and self-referral at onset
iv. Uncertain of symptoms and delayed self-referral
v. Apprehensive of symptoms and delayed self-referral
vi. Severe symptoms

Routes to diagnosis engendered different experiences of symptoms, purely in terms of how the condition had progressed prior to detection or diagnosis. These ranged from asymptomatic, to mild, to some patients' experiencing severe complications. Patients were either screened, hospitalised or referred themselves to health professionals for diagnosis based on their assessments of the symptoms, or for an existing condition.

5.3.1. Asymptomatic: This sub-theme incorporated patients who described themselves as asymptomatic at the time of diagnosis, as they were diagnosed with T2D through screening. As such, no self-referral to health services occurred and patients had little experience of symptoms during diagnosis.

"I went to the clinic for some tests, the annual tests where they test blood and so forth and it came out that I was diabetic, which was a surprise, as I had no previous symptoms." PTI#5(m) - P.1; L.15.

These patient participants often reported the process of screening itself as demonstrating to them that T2D had 'occurred in the body', as the quote above stated:"The diabetes was happening in my body but I didn't know." PTI#15(m) - P.1; L.19.

As noted in the previous section, many of these participants also retrospectively said that they felt that something was wrong.

5.3.2. Awareness of Symptoms and Self-Diagnosis: Patients described themselves as aware of their symptoms prior to diagnosis, but were not formally diagnosed with T2D, but were briefly self-diagnosed.

"I had spoken to the doctor before but it was overlooked. [...] I just realised I had diabetes, so I checked [...] All the doctor did was confirm it." PTI#20 (f) - P.1; L.12.

As noted in the previous section, this participant reported having had symptoms and suspected they related to T2D. She had acknowledged these symptoms by self-referring to a healthcare professional.

5.3.3. Awareness of Symptoms and Self-referral at Onset: Some participants described themselves as aware of symptoms prior to diagnosis, and were later diagnosed with T2D through self-referral to a healthcare professional. These participants described having symptoms prior to diagnosis but did not suspect T2D.

I kept getting really tired, just tired and a bit thirsty. So I went to the doctor and they did some tests and there it was'You've got diabetes' PTI#11 (f): P.1; L.10.

Almost straight away, they acknowledged these symptoms by self-referral to a healthcare professional, after which they had received a diagnosis of T2D.

5.3.4. Uncertain of Symptoms and Delayed Self-Referral: Patient participants described themselves as aware of physical changes (signs and symptoms) prior to diagnosis, but uncertain whether to ascribe these sensations the status of symptoms. These symptoms were easy to explain away, therefore, there were delays in self-referral and eventual T2D diagnosis.

"...I just thought it was a type of flu..." PTI#10 (m): P.1; L.2.

In this manner, symptoms were also interpreted by patient participants as 'not too serious' or not prioritised.

"I just thought it was because I was overdoing at work, you know?" PTI#5 (f) - P.1; L.21.

Following a visit to the doctor, a diagnosis was made at a later point. It is likely that in severe cases, this accelerated to diagnosis by hospitalisation.

5.3.5. Apprehensive of Symptoms and Delayed Self-Referral: A few patient participants described themselves as aware of physical changes, but feared potentially negative outcomes and therefore delayed self-referral and T2D eventual diagnosis. The symptoms were viewed as a potentially serious illness, or the effect/complications of another pre-existing condition. The actual existence and/or effects of the symptoms were then disavowed or assigned to a different pre-existing condition or event by the patient participant in fear of potentially negative outcomes.

"Sometimes, the way I felt, I probably think I should have gone and told the doctor that I'm feeling quite bad […] But usually it just goes by itself, comes and goes, and I just couldn't think tablets or injections not really up for that." PTI#9 (f) - P.1; L.38.

The above participant was newly diagnosed with T2D and was living with Lupus.

5.3.6. Severe Symptoms: One patient described her symptoms as being so severe at the point of diagnosis that she was no longer able to respond as the symptoms had affected her judgement. She was diagnosed through hospitalisation:

"I had a kind of thing in my brain that somebody wanted to kill me, maybe it was the many books I read, you know. And I became very uncooperative. And finally, well finally... they managed to put me under control and treat me because for the first few days they could not come near me, I used to throw cups of tea at nurses and, and kicking the lab testing, you know." PTI#3 (f) - P.1; L.26.

This participant described a state where her symptoms were so advanced she did not have the cognitive ability to identify and respond to her symptoms appropriately.

5.3.7. Overview of Symptom Status During Diagnosis: In summary, this theme addresses the research question pertaining to barriers and facilitators to T2D diabetes. One factor providing a barrier to patient self-referral (where symptoms were present) was that patient participants were easily able to explain away the symptoms of T2D. Patients described how their fear of negative outcomes, wider day-to-day commitments and, in some cases, co-occurring illness meant symptoms were disavowed or not acted on. These factors explained delays in self-referral. Also, in extreme cases another barrier to diagnosis may occur when the patient becomes unable to respond appropriately due to severe complications, particularly in the hospitalisation route. However, we can also see that knowledge, prior experience and access to testing of T2D facilitated or enabled self-referral in the symptom-onset and self-referral route.

5.4.Responses to T2D Diagnosis

Whereas the previous theme focused on how, and whether, awareness of symptoms led patients to self-refer for a professional diagnosis. This theme looks at the ways participants reported responding directly to diagnosis. Only one participant described diagnosis as an emotional shock and then denial of diagnosis.

"They kept telling me that I've got it, and I kept denying that I'd got it, and then I suddenly thought I suppose I'd better go and see what they talk about, information and that. So I thought okay I'll go and get some more information and see what it's like[...] but I was just sitting there thinking I haven't got it." PTI#9 (f) - P.4: L.45.

Hence, shock and denial responses to T2D diagnosis were rare in this sample. Rather, participants" responses to diagnosis were characterized by either:

i. Uncertainty about how symptoms were to be identified and responded to; or

ii. Diagnosis as having clarified and addressed the uncertainties participants had experienced prior to/during the diagnosis process.

5.4.1. Uncertainty about how symptoms were to be identified and responded to

The most common response patient participants' described in relation to T2D diagnosis was the experience of uncertainty about how to manage the physical manifestations (signs and symptoms) of T2D. This continued after formal diagnosis with participants describing their responses as being characterized by uncertainty about how to manage symptoms now defined as T2D in two ways:

a) What constituted a symptom (symptom uncertainty),

"I just thought it was tiredness, but I felt more tired, exhausted really. And I thought it wasn't right, but didn't think much of it." PTI#18 (m): P.6; L.7.

b) The seriousness of symptoms, and therefore whether the symptom warranted medical intervention or could be dealt with by the individual (response uncertainty) e.g. "Very difficult because you can only know so much, you don't know who to ring. Do I ring the GP, the on call doctor, someone at [the Hospital] or just get on with it. It could be anything" PTI#25 (f) - P.1; L.21.

As discussed in sub-section 3.2.4., participants who had a co-morbidity or dual diagnosis at the time of formal diagnosis also experienced a form of symptom uncertainty, as they still found it difficult to distinguish between the symptoms of T2D and the co-occurring illness, and how to manage the co-occurring illnesses in conjunction with T2D:

"I have asthma, blood pressure and glaucoma and I have got …and something with the liver. Hepatitis, Hepatitis C. That is something recently, they just found it recently. And so many pills, and specialist for this, diabetes nurse. When I started first I feel funny, because there is so many pills to take and I feel so sick that I thought it was the tablets. I went to the doctor as well, Dr. [Name], and said just wait and see, wait and see, and I need to go back in six months." PTI#6 (f) - P.1; L.38.

This suggests that it is important that the uncertainties that people newly-diagnosed with diabetes experienced are addressed early and in a way they can understand and apply as is the case in the

next sub-section.

5.4.2. Diagnosis as having clarified and addressed uncertainties

Many participants also reported diagnosis as a 'relief' as it provided explanation to the uncertainties they had experienced when symptoms had emerged:"I realized I was mortal. It was a real shot in the arm. It [diagnosis] explained why I had felt so dreadful" PTI#13 (m) - P.3; L.1.

Healthcare professional support at the time of diagnosis was also seen by participants as an important way of resolving uncertainty:"When I was diagnosed my doctor made an appointment for me to go and see him with my husband, and he sat down for about twenty minutes and explained everything to us. It is very good, and goes into the details of what has caused it, and what the symptoms are and what you can do to stop your sugar going up. He did spend the time with us, and I think that helped my husband as well …" PTFG#3, (f) - P.10; L.9.

Hence, it was found in contrasting these two sub-themes that the degree to which acquiring a diagnosis explained the symptoms of T2D and/or how to manage them (i.e. realized by the individual or explained by the testing process or healthcare professionals), shaped the participants' response to diagnosis, and vis-à-vis their initial confidence in understanding and managing the illness.

4.5.3. Overview of Responses to T2D Diagnosis

Participants' responses to diagnosis show that only one participant reported responding with shock. The majority experienced uncertainty about how to respond to the manifestations of T2D or how to potentially manage them. Participants' responses to diagnosis also highlight experiences which facilitated a more positive understanding of the manifestations of T2D and resolved the uncertainties patients experienced. Participants' described experiencing uncertainty about how to respond to the physical manifestations of T2D during, and even after, diagnosis. In their accounts, participants reported uncertainties relating to identifying and responding to symptoms, which acted as a barrier to both seeking help and effectively managing symptoms. Hence, given that participants had different symptom statuses at the point of formal diagnosis, it is important to remember that they will also have different levels of experiential knowledge and confidence in identifying and responding to symptoms at the time of diagnosis.

What is evident isthat participants' routes to diagnosis and their experiences of symptoms prior to, and during, the diagnosis process is that there are barriers and facilitators to receiving, understanding and/or acting on, the diagnosis. This in turn shaped participants' responses to their diagnosis as such participants' experiences can be represented as a process with multiple trajectories, as shown in (**Table 1**).

Route to diagnosis- T2D was detected/ diagnosed as a result of:	Symptom statuses a, b,c, d, e & f (see key below*)	Responses to T2D
Symptom onset and self-referral (n=12)	Symptom status: *b* (n=4)	1. Potential for response/ symptom uncertainty (pre- and post-diagnosis) 2. Potential for diagnosis to resolve uncertainty by explaining the physical manifestations of T2D
	Symptom statuses: *c, d & e* (n=8)	
Screening (n=12)	Symptom status: *a*	1. Potential for response/ symptom uncertainty (post-diagnosis) 2. Potential for diagnosis to resolve uncertainty by demonstrating or explaining the physical manifestations of T2D
Onset of complications (and/or) hospitalisation relating to T2D (n=5)	Symptom status: *c, d, e, & f*	1. Response/symptom uncertainty may contribute to late diagnosis 2. Potential for severity to lead to inability to respond to physical manifestations of T2D
Monitoring of a pre-existing condition (n=5) or a dual diagnosis (n=3)	Symptom status: *c, d, & e*	1. Potential for response/ symptom uncertainty due to co-occurrence of another condition; 2. Potential for diagnosis to resolve uncertainty by explaining physical manifestations of T2D. 3. T2D symptoms are seen as s*eparate* to co-occurring condition and managed as such (pre- or post-diagnosis) 4. T2D symptoms are seen as *related to, and managed as*, part of the co-occurring condition (pre- or post-diagnosis)

*Symptom status key: (a) Asymptomatic; (b) Awareness of symptoms and self-diagnosis; (c) Awareness of symptoms and self-referral at onset; (d) Uncertain of symptoms and delayed self-referral; (e) Apprehensive of symptoms and delayed self-referral; (f) Severe symptoms.

6. Discussion

In contributing to the literature in this area, the present study has added an additional route to diagnosis to those found in the work of Hiscock et al [2] and Peel et al [3] which were the 'Symptom onset and self-referral diagnoses route'; Screening diagnoses route; Acute onset/hospitalization diagnoses route. The present study, by taking a heterogeneous sample of people with varying periods of time since diagnosis, found a strand of participants who receive a diagnosis through dual-diagnosis or through monitoring another condition. This group appear to have specific information needs relating to managing the ramifications of T2D alongside a co-occurring condition a situation which is likely to increase given the growth of comorbidities in ageing populations [20].

Equally, the present study found that routes to diagnosis had not only common, but intrinsic, barriers and facilitators which shaped participants' experiences of diagnosis. These barriers and facilitators were shaped by: 1) How diagnosis was delivered by health services; 2) Experiences of misdiagnosis; and 3) The range of factors shaping the individuals' ability to identify and respond to signs and symptoms. Participants accounts highlighted barriers to diagnosis that were predominantly T2D-related: i.e. the nature of the symptoms can easily be explained away or confused with other symptoms which delayed self-referral, or, less frequently, T2D symptoms can build so severely its manifestations affect the individuals' capacity to respond. This suggests there is a need to enhance diabetes awareness activities within groups vulnerable to T2D, particularly around symptom awareness. This was manifest in the self-reported patient-related barriers to diagnosis that were found, such as the uncertainty and apprehension participants reported that led to delayed self-referral, denial of diagnosis and confusion about how to self-manage. This suggests some of the stigma and fear associated with T2D also needs to be addressed through health promotion. Equally, it was found that previous knowledge and experience of T2D and access to testing equipment amongst patient participants facilitated self-referral for diagnosis (acting as an enabler to eventual professional T2D diagnosis). To this end, further research into the acceptability, efficiency and feasibility of self-testing for T2D is required. At the healthcare professional/health service level, misdiagnosis was reported as a barrier to diagnosis, and instances of poor management of diagnosis were given. On the other hand, (well-managed) diagnosis was seen by some participants as demonstrating to them the effects of T2D (for example, in screening diagnoses) where the reasons for the symptoms they experienced were explained to them. Similar to the work of Polonsky et al [1] and Lawton et al [6] it was found that where participants were given time and support by healthcare professionals and services this facilitated less negative experiences of diagnosis.

The present research also uniquely captured how symptoms were managed (by participants) prior to formal diagnosis. It highlights that symptoms can be experienced as relatively benign leading to varied symptom recognition, or non-recognition, trajectories. Some participants successfully symptom-managed prior to formal diagnosis through identifying symptoms and responding by self-referring with some even self-diagnosing. Other participants were able to explain away or ignore symptoms, having more important priorities. The present study concurs with the work of Peel et al [3], Eborall et al [5] on newly diagnosed screening patients which suggest that patients are willing and capable of absorbing T2D information, and should be given information at the time of diagnosis [4]. Supporting the work of Lawton et al [6] and Troughton et al [7], the present research also found experiences of T2D diagnosis are, for some, characterized by feelings of lack of confidence to manage T2D, and by uncertainty. The present study, however, added that diagnosis can also resolve uncertainties. Building on this, the findings of the present work suggest that it is crucial to address and resolve uncertainties for those newly-diagnosed with T2D as this facilitates understanding in the newly-diagnosed of how to adapt to living with the condition. In addition, the present study found that different symptom statuses at the time of diagnosis and routes to diagnosis confer differing practical experiences of managing symptoms prior to diagnosis hence different types of experiential knowledge and uncertainty amongst the newly diagnosed. This should be reflected in healthcare professionals' informationgiving and support approaches to diagnosis.

As with all qualitative data there are limits to the transferability of the findings due to the small sample in a specific context. The study would benefit from testing whether the components of the diagnostic experiences of people living with diabetes described can be quantified and measured within the larger diabetic population. Equally, as the respondents all came from one group some cross-contamination of reporting may have occurred. This is a limitation of any group-based sampling method, but the sampling method, and multiple methods of gathering data, reduced the likelihood of this bias through triangulation of data sources. However, the reports given were retrospectively meaning there may be problems with accurate recall by the participants however, the work of Polonsky et al [1] (discussed above) has shown that diagnosis experiences can be accurately recalled 1-5 years later. Polonsky et al [1] study

found no differences in findings when comparing responses by length of time since diagnosis suggesting that deteriorating recall of events did not occur, perhaps due to the fact that T2D diagnosis is such a significant event in people's lives. Equally, given the common experiences of diagnosis identified from the accounts of a diverse range of people with different periods of time since their diagnosis it appears this effect of poor recall was minimal in the present study.

7. Conclusion

One practical recommendation of this research is that it is crucial that there is greater health promotion activity around awareness of the signs and symptoms of T2D in groups vulnerable to T2D, and the need to seek help if concerned. Equally, given the finding that some people self-diagnose, we should seek to remove barriers to people self-testing particularly given the potential for confidence-building this this type of symptom identification and management could hold for the newly-diagnosed. At the same time, the fear, stigma and apprehension about being diagnosed with T2D should be addressed at the population level by emphasising that T2D can be self-managed [21] and that support is available, indeed normalising self-testing and providing information at this point could tackle this fear, stigma and apprehension.

A second practical application of the research relates to the role of healthcare professionals and health services. If healthcare professionals wish to ensure that newly-diagnosed do not have negative experiences of T2D diagnosis, and that their patients are equipped to adapt to living with T2D, they need to address patients' uncertainties at the time of diagnosis. At this time, information, advice and support need to be tailored to each newly-diagnosed patient according to their route to diagnosis, experiential knowledge of symptoms. Equally, the uncertainties patients have experienced prior to, and following diagnosis should be identified and addressed. To this end the authors' wider research has offered various continuums and communication tools on how information and support can be graduated according to patients' needs [22, 23]. Clinical approaches to diagnosis seek to identify, classify and ultimately treat a condition. As participants are reading into, and learning from, clinical processes of diagnosis, these situations should be treated as learning opportunities for both practitioners and patients.

Finally, this research has highlighted that patients' routes to diagnosis are shaped by personal and socio-contextual experiences which position the newly-diagnosed on different, and often uneven, starting blocks. These experiential pathways have at least an equal, if not greater, impact than conferring a clinical diagnosis on how people newly-diagnosed with T2D respond to their diagnosis. As such common experiences on patients' pathways to T2D diagnosis should be afforded an equal value to clinical approaches to T2D diagnosis.

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