

# A secondary qualitative analysis exploring the emotional and physical challenges of living with type 2 diabetes

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## Abstract

**Background:** Many feel that their new identity as 'someone living with diabetes' does not fit with their biography. Some individuals may be able to re-assess life goals, adapt their identity and adjust to living with type 2 diabetes mellitus (T2DM). For others, the biographical disruption experienced with their condition may negatively affect their emotional well-being and identity.

**Aim:** To conceptualise and explore the emotional challenges experienced living with T2DM, using biographical disruption as analytical references.

**Design and setting:** Secondary qualitative analysis of data collected from 31 semi-structured interviews.

**Method:** Semi-structured interviews were conducted with people with T2DM in England. Data analysis was informed by constant comparative techniques.

**Results:** People with T2DM undergo a cognitive process when their biography suddenly becomes interrupted. Suboptimal T2DM can bring a feeling of loss of control over one's future, and loss of independence. What used to be perceived as 'normal' is now perceived as something that requires regular management, negatively impacting their daily routine and ability to carry out activities that once used to be effortless.

**Conclusions:** Living with T2DM that is socially stigmatised can lead to poor well-being and may disturb one's life biography. Strategies must take place to bring awareness to healthcare professionals of the impact and disruption that T2DM can have on an individual's biography, identity and diabetes management.

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## Introduction

Type 2 diabetes (T2DM) is a progressive lifelong condition affecting over three million people in the UK and is associated with a number of severe complications,<sup>1</sup> including stroke, kidney and coronary heart disease. When diagnosed with a long-term condition such as T2DM, many people experience significant hiatus in their lives<sup>2</sup> that can impact on both their physical and emotional well-being. This hiatus is conceptualised as 'biographical disruption',<sup>3</sup> in which an individual's expectations and plans about their future and self-concept are disrupted by their diagnosis.<sup>3,4</sup> This intrusion can alter one's identity and self-worth,<sup>5</sup> leading to a sense of 'loss of self'.<sup>3,6,7</sup> Their diagnosis can "throw people out of ordinary life, order becomes disorder, the controllable becomes uncontrollable, the understandable becomes unfathomable".<sup>8</sup>

Biographical disruption is a concept that has been applied in other long-term conditions such as cancer and chronic obstructive pulmonary disease.<sup>9-13</sup> A recent study used this framework to examine the experiences of young people living with type 1 diabetes.<sup>14</sup> Their findings indicated that people hide their illness in public spaces to maintain a normal illness biography<sup>14</sup> and present themselves as what would be 'normal' to others. They negotiate between their normal and disrupted biographies to cope with the expectations of society. Although the literature explores chronic illness and the cognitive and material processes that help individuals conceptualise the sudden change in life, some qualitative studies appear to present findings based on a range of health conditions clustered together. One study, for example, explored the experience of people with both hypertension and diabetes<sup>15</sup> whilst another study explored the hidden disruptive experiences of those living with non-visible diseases including stroke, diabetes and cancer.<sup>16</sup> Further studies should focus on each condition individually to grasp their true impact on one's biography.

Despite the wide range of research in this area, the lack of attention to the disruption that T2DM can bring to one's biography still remains overlooked. One of the few qualitative studies that explored biographical disruption and reinvention in T2DM found that the diagnosis of this condition was regarded as a major life event that had a knock-on effect on people's identity.<sup>17</sup> It was concluded that many people respond to their T2DM with fear or confusion, with many not feeling that their new identity as 'someone

living with diabetes' fits with their biography.<sup>17</sup> Some individuals may be able to re-assess life goals, adapt their identity and adjust to living with T2DM.<sup>7,18</sup> For others, however, the onset of their condition is experienced as very demanding which can change the narrative of what life once used to be.<sup>19</sup>

The aim of this study was to conceptualise and explore the emotional and practical challenges experienced by people living with T2DM using the biographical framework as our analytical reference.

## Methods

### Participants and recruitment

Our secondary analysis was based on 21 qualitative semi-structured interviews, which were conducted with people with T2DM who had attended at least one session of a structured education programme. This was part of the DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) Ongoing Study, a randomised controlled trial of an integrated approach for providing self-management to people with established T2DM.<sup>20</sup> This trial was funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research (CLAHRC) Leicestershire, Northamptonshire and Rutland, now reconvened as NIHR Applied Research Collaboration (ARC) East Midlands. Ethics approval was obtained from the Leicestershire Northampton and Rutland Committee (ref: 10/H0406/54) and it was prospectively registered.<sup>20</sup> When providing written informed consent, participants optionally agreed to be approached at the end of the study to take part in a qualitative study to discuss their experience of the education programme. Participants invited to take part in an interview were purposively sampled to achieve a range in terms of age, gender and duration of T2DM. This sampling method was carried out by inviting participants in small batches and reviewing the data.

### Data collection

Interviews were conducted in participants' homes. Informed consent was taken immediately prior to the interview and interviews were audio-recorded and fully transcribed. A flexible topic guide aimed to explore participants' views and experiences of the different types of care and the potential support and education received for T2DM management from the particular trial. Questions also explored their views and reflections on their own management of diabetes, and their views and understanding of diabetes and its implications. The qualitative researcher involved in this primary qualitative study also acted as the second coder of the secondary analysis study (HE).

In order to carry out secondary analysis on the primary data, ethical approval was obtained from the University of Leicester to ensure that any ethical issues were considered in this secondary analysis study. Inbuilt safeguards were placed to prevent identification of subjects on whom the original study was based. Personal details of the participants were not included in the documents shared from the original dataset. Demographic information was shared by the primary team, which was anonymised. Furthermore, any identifiable information that may have been mentioned throughout the interviews was removed during the transcription

process in the primary study. For the purpose of the secondary qualitative analysis, we only had access to the anonymised transcripts and the anonymised demographic table.

### Data analysis

The qualitative researcher involved in the primary qualitative study alerted us of potential data relating to the emotional and practical impact of T2DM. We thus set out to conduct secondary analysis and explore the emotional and practical challenges of living with T2DM in more detail. Originally, we adopted an inductive approach with the data analysis; however, when we began interrogating the data, we noticed patterns emerging that were common to the biographical disruption concept. With this in mind, we used biographical disruption as our analytical frame to present our themes.

Transcripts were read and coded by an experienced qualitative researcher (MH), and most of the transcripts were read and coded by a second coder (HE) to ensure consistency with the coding and analysis. The two coders retrieved and organised the data into framework charts (using Microsoft Excel) to identify patterns in the data. Use of NVivo qualitative data indexing software allowed us to organise and compare codes systematically. Discrepancies were resolved through discussion among the two coders (MH and HE).

## Results

### Sample characteristics

The sample comprised 31 individuals with T2DM aged between 29 and 87 years, with 68% aged over 60 years; 45% were female (see Table 1). Five participants had lived with T2DM for 1–3 years, 11 participants for 3–10 years, and 11 participants had lived with T2DM for >10 years. Four did not provide this information.

### Themes

The findings are presented based on our own perception of the biographical disruption and the emotional and physical challenges faced when living with T2DM. These themes are: disruption of daily activities; self-identity; concerns about the future; shame and blame; and lack of support from healthcare professionals.

**Table 1.** Participant characteristics

Characteristics	Total (n=31)
<b>Gender, n (%)</b>	
Female	14 (45)
Male	17 (55)
<b>Distribution within age range, n (%)</b>	
20–39 years	1 (3)
40–59 years	9 (29)
60–75 years	14 (45)
>76 years	7 (23)
<b>Duration of T2DM, n (%)</b>	
1–3 years	5 (17)
3–10 years	11 (35)
>10 years	11 (35)
Not known	4 (13)
T2DM, type 2 diabetes mellitus.	

### Disruption of daily activities

It was reported that T2DM was in the back of participants' minds. Whilst one participant indicated that T2DM did not affect their daily living, the remainder expressed concerns and frustrations of living with T2DM. These concerns varied from having sub-optimal blood readings to experiencing hypoglycaemia. In addition to feeling frustrated and confused, participants also reported feeling scared with the fluctuation of their glucose.

*Sometimes I have two little wafer table water biscuits before I go to bed because often my sugar drops and I daren't go to bed with it as low as that or I might have a wobbly during the night. I have had two during the night and they scared me to death.* (Participant 4, male, 51)

One participant described the impact that sub-optimal glucose levels had on their daily living and shared feelings of distress whilst having a hypo in public:

*I went down to the supermarket and I only wanted the paper and a bottle of milk. I was in there with them in my hand and I could not find a check out. I was going round and round in circles. In the end I put them down and found my way out and got on my bike and went home and checked my blood and it was 2.2 ... that was very scary.* (Participant 3, female, 80)

Participants also reported feeling 'restricted' and frustrated with their diet, particularly in social situations.

*I feel frustrated when I am going out to a restaurant and you don't know what they make it out off. You can't choose a meal ... so it is very difficult to cope with type 2 specifically because I have found that some days my sugars are reasonable and other days it is sky rocket so it depends on what I eat as to what the results are. If I test during the day, it seems to be average through the day but if I test in the morning it is high.* (Participant 12, male, 60)

Difficulties living with T2DM were expressed throughout the interviews. Experiences around loss of control seemed to centre around the fluctuation of glucose levels, which for some had a potential impact on their social and daily life. Reports were also raised on the emotional impact of living with such a demanding condition; raising feelings of distress, confusion, frustration and fear.

### Self-identity

Adverse impacts on identity were expressed unequivocally with many participants feeling overwhelmed by diabetes and feeling antagonistic to the condition defining and dominating their life. One participant was vehement that diabetes was not part of who they were.

*I think about it all the time, but I don't go around saying I am Rose the diabetic (not real name).* (Participant 7, female, 68)

Resistance to diabetes 'taking over your life' was clear in some participants' accounts.

*I want to live with diabetes and not have diabetes drive my life because it can. So I am a person with diabetes and not a diabetic trying to stagger through life.* (Participant 11, female, 48)

*I can't, I won't let it (diabetes) run my life.* (Participant 5, female, 68)

Many participants sought to retain their pre-diagnosis identity, viewing the label of a 'diabetic' patient negatively.

### Concerns about the future

In addition to sharing concerns about the day-to-day struggles, worries were also raised around the unpredictability and potential development of future complications. For some participants, the possibility of severe complications led to fear of the unknown and fear of losing independence.

*The fear of blindness, when I started to get these problems with my eyes and I thought, "Oh, heck! What is going wrong?" So the last [appointment] I had, they scared me because they said "We see something at the back of your eyes", so I have a fear of going blind. I think a lot of it is fear in my case so not being able to understand what is causing it. Is it the diabetes or is it something else?* (Participant 3, female, 80)

The impact on their own future health was a big concern for many participants, but for some, the negative impact of diabetes on their loved ones was a greater issue. Their identity as a family member and as a grandparent was also 'disrupted' by physical challenges and complications of diabetes.

*I want to be here for when my grandchildren grow up.* (Participant 5, female, 68)

*The little one (grandchild) wanted to go out and I wanted to go out but I couldn't as I did not feel well. My health was bad so the quality of my day suffered and other people suffered because of it as well. If I don't have good quality of life, then my little one doesn't have either because I can't do what he wants. His quality of life suffers because of mine.* (Participant 4, male, 51)

For some participants, the possibility of severe complications led to fear of loss of physical independence and fear of affecting their quality of life.

*... that is what I am worrying about, the consequences, but also people looking after me as well if I had my leg off or something like that, so it affects other people as well.* (Participant 10, female, 69)

*If I do lose my leg, how am I going to drive? Somebody is going to have to drive for me ... You can still have a quality of life but it drops and your expectations shrink because you know you can't go outside of the front door and get in your car, drive to see a friend, have a cup of tea, moan about the world, put it right, come back and get on with your life. If you are indoors, you are dependent on people coming to see you.* (Participant 1, female, 55)

As demonstrated, numerous concerns featured severe complications of T2DM such as loss of eyesight and limb amputation. The physical impact of T2DM, current or future, appeared to be a basis for people's sense of independence and good quality of life. Some were not ready to face the reality of the negative consequences of severe T2DM complications and did not know how to address the

'disruption' emerging from their condition. Fear of future and potential loss of independence lead to feelings of distress.

### **Shame and blame**

Many felt judged by others about their diagnosis, by being told that diabetes was their own 'fault'. Participants were blamed for not being responsible for their own health, with many being criticised by others.

*She (the nurse) was telling me that it was my fault because I drank so much fizzy pop and that basically I had done it to myself so that psychological bullying did not help.*

(Participant 6, female, 29)

*... well it's like it was our fault that we started eating out and gaining weight ...* (Participant 8, female, 65)

Other participants expressed self-blame and self-judgment particularly around the cause of their diabetes. These concepts were reported mainly for their 'unhealthy' lifestyle and for their inability to make effective lifestyle changes.

*I am a fatty who has got diabetes.* (Participant 1, female, 55)

*It can be a genetic thing or it can be you are a greedy pig and you are eating too much and look what has happened to you now. I think I have done a bit of both.* (Participant 1, female, 55)

This expression of self-blame was evident across all interviews, with a focus on past behaviours to explain culpability.

*I wish I had done something when I was younger. I just wish I had known what it entailed, [...], because, like I said, that doctor used to say, "If you don't lose weight ..." but it did not mean anything to me ... I think that if I had known more I might have done something about it.* (Participant 10, female, 69)

The same participant who blamed themselves for their diagnosis expressed feelings of anger, regret and guilt for their previous lifestyle at the time of diagnosis.

*I cried my eyes out and I thought, "bugger!" And I was very, very, very cross and I did believe some of it was my fault, because I knew I had been taking too much sugar and so I did feel guilty about it, but I can't change that.* (Participant 1, female, 55)

Overall, there were strong signs of self-blame for their diagnosis, particularly blame on themselves for living an unhealthy lifestyle and for being the cause of their condition. Due to the negative image that accompanies T2DM, feelings of shame also emerged for not preventing their diabetes, a feeling that was partly amplified by their social interactions with healthcare professionals.

### **Lack of support from healthcare professionals**

For the participants who reported that their diabetes was 'getting them really down', provision of emotional support was highly valued.

*[The nurse] knows that sometimes I feel a bit depressed. She has said that if I want to talk, to come up.* (Participant 10, female, 69)

Indeed, emotional support was articulated as essential, not just for depressive symptoms but for those who struggle with the day-to-day stresses of the condition.

*You don't have to live with it just on your own. As I say, you can get a lot of help from all the different people like the diabetic nurses. They are only a phone call away. You can get help from your doctor or anybody if you need help. If you are worried about anything like your limbs or your feet or your eyesight.* (Participant 3, female, 80)

However, participants highlighted that accessing emotional support through primary care was challenging.

*... even with the doctors here, you know, you battle, you phone at eight o'clock in the morning, you can stand here until half past eight and you still don't get through, and then when you get through, "I'm sorry, he's booked up, and he won't be here again until next week" ...* (Participant 13, female, 87)

Others reported that their diabetes consultations did not offer the emotional support they required; some expressed frustration at not being listened to, feeling judged and/or dismissed by their doctor.

*... one of the comments [the doctor] came up with was – "That's life". You don't want that type of statement.* (Participant 12, male, 60)

*It is very clear that [the doctor] was going through a set process of questions, answers and processes rather than listening to answers and tailoring the care or tailoring it to what I was saying. You can tell when somebody is going through a process and that is what is happening.* (Participant 2, male, 45)

Despite participants believing that support from their healthcare professional was fundamental for their diabetes management, empathy and overall emotional support from healthcare professionals was in fact lacking, which led participants feeling frustrated and uncertain about their condition.

## **Discussion**

### **Summary**

Our secondary qualitative analysis explored the emotional and physical challenges experienced by people living with T2DM. The analysis of the data aligned with the biographical framework. The process of our data analysis was not guided by this concept, but rather these became our analytical reference to better understand the emotional and physical impact of living with T2DM. With these in mind, we concluded that people with T2DM undergo a cognitive process when their lives suddenly become interrupted.<sup>15</sup> Suboptimal T2DM can bring a feeling of loss of control over one's future, and loss of independence. What used to be perceived as 'normal' is now perceived as something that requires regular management, negatively impacting their daily routine and ability to carry out activities that once used to be effortless.



### Strengths and limitations

We aimed to summarise the study's strengths and limitations based on the four suggested criteria for qualitative research (credibility, transferability, dependability and confirmability).<sup>21</sup> To ensure credibility, we used a strategy known as investigator triangulation, whereby two independent researchers coded and analysed the data. The two researchers held regular meetings during the data analysis process and their interpretations were compared and discussed until agreement was made. The involvement of a second coder allowed for reflective thoughts and note-taking to ensure some level of dependability and confirmability. As a multidisciplinary team consisting of academics, behavioural scientists, dietitians and primary care clinicians, we sought to explore the concept of biographical disruption in T2DM based on our diverse experiences and positions in academia and primary care.

As this study is based on secondary analysis, we are aware that there may be limitations in the description of the research process. However, we attempted to provide a rich account of data including the setting, sample size and demographics of the participants to enhance transferability and allow the reader to assess whether our findings are transferable to their own setting.

The primary dataset is not yet published; however, we provided detailed information of the methodology rigour of the parent study and its relationship with our secondary data analysis. Although data are based on secondary analysis and thus may be limited, the secondary analysis method is a valid and credible research methodology and we ensured that the data were analysed in a robust manner by two independent researchers using principles of the constant comparative approach. Even though the topic guide questions which guided the primary analysis were not directly related to our research question, they nonetheless proved to provide sufficient data on the emotional and practical challenges, recognising the association between biographical disruption and T2DM. The input of a qualitative researcher who was heavily involved in and familiar with the primary dataset was considered as a major strength during the secondary data analysis, a measure that is also highly recommended for robust secondary data analyses.<sup>22</sup>

### Comparison with existing literature

Many people with T2DM were concerned about depending on others as a consequence of losing their independence from T2DM. This supports the concept of biographical disruption, that chronic conditions such as T2DM can interrupt the 'normal rules of reciprocity', which in turn may disturb one's life biography.<sup>5</sup> Many people with T2DM adjust well to this biographical disruption and re-establish normality within their new lifestyles. Others, however, as described in this paper, may show signs of resistance to their new identity.

In addition to the emotional impact of living with T2DM, our findings also highlighted the overlap between biographical disruption and one's psychological state. For example, episodes of hypoglycaemia experienced by a person with diabetes can reinforce negative risk perceptions preventing them from returning to what is perceived as 'normal' life. We present this disruption through

quotes shared by our participants – for example, the impact that suboptimal glucose levels had on their daily living, and feeling 'restricted' and frustrated in social situations. In this case, our findings consider the detrimental impact that the disruption caused by T2DM may have had on their quality of life. This perhaps suggests that biographical disruption not only disrupts the sense of 'self' and breaks normality down within a social context (ie, work and family life), but that it also breaks normality down within their own psychological well-being.

Shame is represented as both pre-existing vulnerability and 'acquired' behaviour, with some reports supporting that people hold internal negative attributes towards their identity. As feelings of shame may come from within, they may also be triggered externally through social interactions and may thus become a learned behaviour.<sup>23</sup> Our findings echo existing qualitative findings that T2DM-related shame can be triggered by self-stigmatisation and the internalisation and acceptance of the stigmatising beliefs.<sup>24,25</sup> Our work proposes that these feelings of shame can be triggered by stigmatising beliefs and attitudes from healthcare professionals.

People diagnosed with T2DM, a condition that is considered as self-inflicted by society, may begin to feel stigmatised. Acts of being judged and discriminated against, as demonstrated in our findings, have been shown to provoke emotional responses including poor psychological well-being and overall poor self-care. This relationship between stigma, self-blame and poor well-being was also illustrated in a cross-sectional study of people with diabetes.<sup>26</sup> A recent qualitative study exploring the reflections of physicians and patients with T2DM highlighted that the latter target group expressed self-blame for failure to follow a self-care regimen, and for the lack of progress with their diabetes management.<sup>27</sup>

As reported in recent findings, people value the supportive relationship with healthcare professionals.<sup>28</sup> Respondents in this study, however, reported that this emotional support was lacking, reiterating previous surveys that the emotional support provided by healthcare professionals is minimum.<sup>29</sup> In order to cope emotionally with the intrusion of a life-changing chronic condition, receiving medical as well as emotional support from healthcare professionals is fundamental for the person's emotional well-being and diabetes management. In addition to understanding the causes of T2DM, it is also important to understand the physical and emotional consequences of living with such a demanding condition.

### Implications for research and practice

This study illustrates that concerns about the future and the consequences of long-term complications can have negative effects on the emotional well-being and identity of people living with T2DM. Many people were able to cope with the biographical disruption caused by their condition, whereas others struggled to deal with the emotional and physical challenges faced with the day-to-day management of their condition.

Biographical disruption is a concept that has mainly been applied in long-term conditions like cancer. As a concept, our study has shown that it may also be used and adapted in T2DM. This exploratory study was based on secondary analysis data, and thus it was not feasible to explore biographical disruption in detail.



## Key messages

- Biographical disruption is a concept mainly applied in long-term conditions like cancer, this concept should be considered in diabetes management consultations
- Strategies must be implemented to bring awareness to healthcare professionals of the biographical disruption associated with T2DM
- Our findings suggest that the diagnosis of T2DM may have a negative impact on one's identity and wellbeing
- Feelings of shame may be triggered by stigmatising beliefs and attitudes from healthcare professionals

We can, however, suggest that more aspects deserve fuller investigation in future research to better understand the impact of T2DM on people's biography and life narrative and, more so, to better understand what is needed to strengthen diabetes care delivery. Our findings concur with recommendations published in the Diabetes UK positive statement, that healthcare professionals must be provided with adequate training to identify well-being problems and deliver appropriate support as part of the ongoing diabetes care.<sup>30</sup>

We propose that these findings are followed up by future research to investigate the impact of diabetes at different life stages. It would also be worthwhile to implement robust strategies in diabetes consultations and diabetes care to acknowledge and address the biographical disruption associated with T2DM.

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