

Diabetes and sustainable employability: A qualitative study

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Abstract

Diabetes mellitus is one of the most challenging problems for health, impacting many aspects of individual's lives, including employment. Sustainable employability refers to one's attributes and skills to be able to perform a chosen occupation, benefitting oneself and society in the long term. It is not directly affected by diabetes, yet assessment is different for every case and highly dependent on factors such as the presence of diabetes-related complications and job type. This qualitative study sought to explore patient's lived experiences regarding diabetes mellitus and sustainable employability, using a phenomenological approach. Interpretative Phenomenological Analysis (IPA), suited to explore the lived experience of diabetics on their employment. Two participants were selected through purposive sampling and in-depth interviews were performed, recorded and transcribed verbatim for analysis. A multitude of thick data and interpretations was obtained. In line with literature discussed, self-management of the patient came forward as the central aspect to remain employable sustainably. Moreover, the study demonstrated patients' awareness and responsibility of being the central player in attaining best possible outcomes for private and employed life. Motives of safety and security played strong roles for participants at the workplace, and occasionally caused intentional behaviour that negatively impacted diabetes management. Furthermore, the invisibility of diabetes presented a major recurrent challenge, and an understanding and supportive environment were believed to be the sole aspects to potentially support sustainable employability.

Keywords: diabetes mellitus, interpretative phenomenological analysis, self-management, sustainable employability.

Introduction

Diabetes Mellitus impacts many aspects of an individual's life and, in particular, lifestyle. Besides the industrialized societies, there is also a rising trend in type 2 diabetes mellitus (T2DM) in developing and transitional countries due to the rapid pace of urbanization and modernization (1). Notwithstanding the genetic predisposition, the main lifestyle factors which currently contribute to the diabetes epidemic include a diet high in added sugar, refined grains and other processed foods and physical inactivity. All these risk factors are largely modifiable and, therefore, concrete measures to improve the exposure to these risk factors should be undertaken in order to control and prevent the worldwide toll of diabetes (2).

Living with diabetes involves constant adjustments which need to be made due to disabilities, periods of sickness and resulting absence (3). All these factors have a considerable impact on employment opportunities.

Suitable to the context of this research, employability is defined as *“a set of skills, knowledge and personal attributes that make an individual more likely to secure and be successful in their chosen occupation(s) to the benefit of themselves, the workforce, the community and the economy”* (4). Sustainable employability relates to the assets such as self-awareness, development and adaptation skills, self-reliance or self-management, job searching skills and the ability to market oneself to an employer.

Theoretical background

Diabetes as a chronic disease falls under the overarching term disability. Disability, as stated by the WHO (5), *“is an umbrella term, covering impairments, activity limitations, and participation restrictions”*. Many theories have been constructed around disability and the role it plays in society. The main foundation for these theories and their developments is the social model of disability (6). The model focuses on oppressing and disabling environments as causes of disability, rather than merely the individuals and their

impairment. The model affirms that environmental and attitudinal factors are even more important than the impairment itself in assessing disability.

In the social model, disability is viewed as a result of impairment, interacting with the social and political environment (6). In the medical model disability is seen as an individual problem and the focus is on physiological disability and those things an individual cannot do. In contrast, the social model acknowledges society to be disabling this individual, and concerns the daily problems arising from the condition in context of the daily environment (7).

Finkelstein (8) has argued that the influence of people on social wealth is the prevailing element which contributes to the disablement and rejection of particular groups. Disabled people would naturally separate themselves from those whom they perceive more disabled than them in order to claim their acceptance in community and economic independence (8). Therefore, such individuals tend to ‘surrender’ themselves to the medical model, acknowledging their bodily impairments and create their level of disability and determination of employability. This behaviour opposes the logic, since these individuals actually claim to reject the medical model, and stress the need to find supporting policies.

It is important to note that the impact of diabetes on an individual is difficult for others in society to assess. An example of a common complaint in diabetes is fatigue, which is often hard for others to see. Weijman et al. (9) found that fatigue-related health problems are more likely to develop in workers with diabetes, as they cope with additional demands their disease poses on them. Additionally, symptoms of hypoglycaemia or hyperglycaemia do not always present the same way. Where no clear causal association with a disability and a job is perceived, colleagues and employers tend to regard it a private matter and become more reluctant to be involved (3).

Employability is not directly affected by diabetes.

The American Diabetes Association has put forward a statement on diabetes and employment: “Any person with diabetes, whether insulin [treated] or non-insulin [treated], should be eligible for any employment for which he/she is otherwise qualified” (10). The common attribute however, is self-management. The diabetic is the key actor in coordinating between all parties involved - mainly employers and colleagues - in order to create the best working conditions possible. Increasing evidence has shown that improved outcomes are highly dependent on the actions of the individual (11). Moreover, studies have provided evidence that diabetes does impact patients and society by reducing employment probability. Indeed, for those employed, diabetes contributes to work loss or health-related productivity losses (12,13).

As literature suggests, the impacts of diabetes on employment have been explored. However, the majority of studies are rather outdated, and focus on health-related problems of diabetics at the workplace. There seems to be a lack of understanding of the patients’ views, needs, and attributes to support their employability.

Therefore, this study sought to explore lived experiences, meaning and perceptions related to employability among patients living with diabetes mellitus, by using interpretative phenomenological analysis (IPA). This study adopted the viewpoint of the social model of disability. The way of diabetics was explored, It attempted to contribute to the understanding how society and societal aspects may impact diabetics from a disability perspective.

Methods

A phenomenological design was chosen as a best fit for this study purpose, as this method exclusively is a study of experience. The study uses the IPA research design which tries to gain understanding of a person’s lived experiences, concerns and the meanings these experiences have for those persons

(14). Participants are the experts of their own life world experiences. IPA attempts to understand the relationship people have with the world through interpretation, focussing on trying to translate observations and descriptions of phenomena into meaning of the activities of people and the experiences they have. The researcher moves from a descriptive to more interpretative fashion, by submerging with the research process. (14).

Participants

In order to obtain thick descriptions and close contextual detail, a sample size of two persons was estimated at the start of the study’s (15). Participants were selected through purposive sampling, on the main basis of having diabetes, being employed and expression of understanding of the study’s purposes and their contribution.

Participant A is male, 38 years old at time of interview, living with type one diabetes for 15 years. He is a lawyer, economist and tax consultant and runs his own legal practice. Apart from this, he is also a member of the local municipality’s city council.

Participant B is female, 24 years old at time of interview, and is also a type one diabetic since 13 years. She is studying arts and culture and has a part-time job, for around 10 to 15 hours per week in a clothing shop for 1 year.

Study design

Semi-structured interviews were conducted and initiated with inquiries on the participants’ job description, moving on to experiences they have had with diabetes at work and continued towards finding out views and thoughts on their future in light of employability with diabetes. The interview guide included prompts which could help steer the course of the interviews. Interviews were performed at the workplaces of the participants, as both had indicated they would feel at ease to conduct it here and could therefore enhance the experiences they would express (14).

The interviews were audio-recorded and transcribed verbatim. This type of transcript included expressions of non-verbal communication. A stepwise approach was adopted for analysis as recommended elsewhere (14). The main steps taken were the repeated reading of transcripts, initial noting, clustering and developing emergent themes and finally connecting these themes. This was done separately for cases, where after the final step was to find and match patterns between cases, resulting in the final categorization of themes.

Ethics and quality assurance

Several ethical considerations were dealt with in this IPA study. The participants were informed about the purpose of the research. Participants were asked to sign an informed consent and a short profile description. Furthermore, participants were provided with the final study results for approval.

The interviews were analysed independently by two researchers using literal extracts, and assuring full anonymity and intractability. The emergence of themes was discussed until consensus was reached. Measures adopted to ensure transparency and objectivity included using the interview schedule that was established in advance, regular peer reviews during the analysis and a rigorous stepwise analysis approach to avoid dependent and preliminary conclusions (14).

Results

The analysis of both interviews put forward a number of recurrent themes, with topics ranging from diabetes experiences in daily life, to those more specifically related to employability and the future outlook. Table 1 displays the titles of the five themes that were identified. The most valuable sections that constitute the essence coming from the data are presented and described here in more detail.

Table 1. Employability reflections in patients with diabetes mellitus

THEME	TITLE
A	Applying for jobs, deciding when and what to tell
B	General work-related experiences with diabetes
C	Reflections on daily life with diabetes; personal (coping) behaviours, challenges, and the importance of physical wellbeing and activity on diabetes management
D	Reflections on societal conceptions/apprehension, expressing to others how life with diabetes is
E	Reflections on diabetes needs at work, future outlooks, sustainable employability

Theme A: Applying for jobs, deciding when and what to tell

The commonality coming forward through theme A was that both participants did not plan or give it much thought what they would tell an employer about their diabetes. Rather, they strongly followed their instincts and situational judgment.

Participant B called this: 'sensing' and acting on feelings also when talking about what she would tell her employer about her diabetes (as she did not want to overload her/him with information) and why she thought it was important for others to know. She saw this as a very logical thing, common sense, and something that would make her feel

more secure in her work environment.

“A: If someone you hire tells you afterwards I’m pregnant or whatever, you’d feel cheated on. (...) so yeah, you have to be open from both sides, so not discriminating as an employer, but also not withholding info as an employee either.”

The above extract demonstrates how participant A is very rational on the one hand but simultaneously very realistic from a patient perspective. He reckons the importance of preventing discrimination in situations where an employee tells an employer about diabetes. However, he also realises the difficulty that lies in this, seeing it from the other side. Because, if indeed someone with diabetes does decide not to tell this before or when getting a job – which he may choose to do without any restrictions - it is also understandable that an employer might experience difficulties in hearing this at a later stage.

Theme B: General work-related experiences with diabetes

In general, participants seemed positive about their general experiences. Interestingly, both had difficulty in naming a certain negative event that may have happened at some point, and needed some time for this. This may have been due to the fact that neither of them had actually experienced a very unusual diabetes-related event at work and they both just mentioned the general negative experiences of diabetes that have occurred in work environment. These experiences refer mainly to hyper- and hypoglycaemia and were mentioned by both participants.

“A: I sometimes get, ehh.. mad really easily, at other people who do something unjust in my eyes, ehh and then afterwards I realize like, yeah, I was right, but I didn’t need to express it that way or given such a response to it you know..”

Interviewer: Do you mean the way you would express yourself in such a situation..?

A: Yeah, and that’s purely caused by how you feel. If you were feeling perfectly fine, well, you

might not have done it that way. You might bang a fist on the table to make your point, but wouldn’t have gone nuts, so to say!... On those moments it’s just a little too much you know, when you cannot really handle it physically and something like a false argument adds up, which happens quite regularly in politics. I just feel that I’m acting, or especially reacting much better when I have my diabetes better controlled.”

This passage shows the consciousness of participant A with regards to how diabetes may impact something such as mood. This is something that the outside world cannot regard easily as a cause of the condition and may perceive as a character trait. Experiencing this at work, may cause substantial frustration from both sides: the diabetic not wanting people to think of him/her as a ‘hothead’, and the other party being unsatisfied with this behaviour, not directly linking this to diabetes. In fact, diabetes as an invisible phenomenon to the outside world was recurrent through other sections of the interviews.

Theme C: Reflections on daily life with diabetes; personal (coping) behaviours, challenges, and the importance of physical wellbeing and activity on diabetes management

This theme addresses times in which participants reflected on their daily life experiences with diabetes. The importance of physical activity came up largely, in relation to general diabetes management. Additionally, the awareness of negative diabetes-related behaviours was greatly present in both participants, and motives of safety and seeking security came forth as possible explanations for these behaviours.

Participant A repeatedly brought up the importance of physical activity for diabetes management, having recently experienced how beneficial this was to him. Having a sedentary job seemed to be an additional motivation for him to seek regular physical activity. In fact, he related the type of job directly to his diabetes. When the first question of the interview was asked (*‘Please can you tell me what you do*

in your job?'), the answer was not that he is a lawyer and a politician, yet that he sat all day long. Although the question was not specifically aimed at making a link to diabetes, he directly made this link by providing this answer. By referring to having a sedentary job, thus the physical aspect of his work, he puts his thought in direct relation to his diabetes.

Both participants were generally quite self-aware of the things they might do better regarding their life with diabetes. Participant B clearly acknowledged that it is a challenge to her to speak up for herself when this could only benefit her, as the following extract shows:

"B: I only feel sometimes I could speak up for myself and my needs more. You know I just told you how accepting they are and all. But sometimes still I'm too shy or something to ask for something."

Interviewer: How do you mean exactly? Could you clarify that a bit more?

B: Well, when it's busy and I know it would be difficult to miss me in store for a while, I tend to kind of neglect myself and continue work. Like when I have a hyper and I actually want a little break to check my blood glucose, drink something and see how much insulin I should give extra, I sometimes just continue my work and wait until I get my normal break. Sometimes it's still an hour away or so... yeah, that's something I should work on."

When finding reasons for this, she expresses that it might be due to the fact that she cannot always trust her own body and experiences misleading feelings. As she expresses to often feel fine while she is actually having a hyperglycaemia, she might not feel the urge to step up and act right away, even though she is very aware that it is best for her.

It appeared that this behaviour came forth from a motive of safety, another recurrent sub-theme throughout both interviews. Participants described habits or behaviours they carry out to increase

feelings of safety, even though some of these were not always in favour of their health, and they were well aware of this. Examples of this include that both participants mentioned to sometimes anticipate at events in which they cannot leave easily, by retaining their blood sugar levels a bit higher. Additionally, participant B would always keep a high glucose drink at work behind the counter, so that it would always be close in case of a hypo, and she expressed to feel safer by this measure.

Theme D: Reflections on societal conceptions/ apprehension, expressing to others how life with diabetes is

This theme came forward from sections where participants were talking about how others in both their personal and professional environment seemed to look at their disease.

Another sub-theme that emerged multiple times was the lack of societal knowledge or common misconceptions about diabetes. Important to keep in mind here, is that both participants were type one diabetic, which is much less prevalent than type two.

"B: ... People who don't know much about this difference tend to generalize with what they know of type 2, so you often get reactions like 'how can you have diabetes? You're not even fat?!'"

Later, both participants somehow realized how these conceptions or reactions of people are fairly logical, considering the invisibility of diabetes to others, another sub-ordinate theme arising under this aspect.

Participant A described this by using a metaphor for describing a situation of severe hypoglycaemia, where one is hardly able to act alone and needs help from others, yet they do not see or realise this.

"A: You see, when you're at home you simply stay calmer, take something in and wait. But when you're in such an environment (talking about the example of a council meeting), and it all goes like this (makes trembling movement with his hands),

people don't see something's wrong with you. So it's like screaming for help but no one can hear it."

This extract actually shows how experiencing hypoglycaemia at work can be even more anxiety-raising than in a home context. Even though people around him would mostly be aware of him having diabetes, they would not easily recognize or focus on the signs of hypoglycaemia during a meeting. The fact that this is a situation in which he could not easily permit himself to leave the room, and the awareness that he is still expected to be conscious, contributes to experiencing hypoglycaemia more intense, and potentially more distressing compared to being in a private setting.

Theme E: Reflections on diabetes needs at work, future outlooks, sustainable employability

Participants were quite confident and positive when describing their thoughts on future employability. They realized that later in life they might experience the more severe, negative complications of their disease, but they also were clear on the fact that most of this lies within them. They knew that worrying about what might happen, would not help them any further for now, and as technology is changing so fast, they didn't even consider it relevant to think too much of what could happen in the coming years.

"A: See, for me, the fact that I am mostly sitting, well.. that should be quite easy!"

Later in the passage, he compared his job type to construction workers, how the challenge of maintaining their diabetes managed well is even much more significant, as they carry out much physical work. Additionally, he had taught himself not to be too worried about times to come, realising there will come a time in which he would start to 'deteriorate', as he called it. Interestingly, both participants expressed their future thoughts and concerns with the same somewhat laidback attitude.

"B: I do worry about my future sometimes of course. But, you know, I've also learnt to live now.. I can stress whatever I want about how many healthy life years or something I might have lost due to my own 'unhealthy' behaviours, but where does that help me? I remember I read somewhere or heard from someone something I never forgot; 'you have to live with diabetes, and not let diabetes live you'"

It came forward that diabetics are somehow forced to reconcile with the fact that they have to live with diabetes for the rest of their lives. Additionally, they realised how much of their future lies in their own hands and expressed a peculiar strong and powerful position towards this responsibility. The latter can be interpreted as an indication of how well they have accepted the fact that they have to live with diabetes for a lifetime.

Both participants stressed the fact that successfulness of future employability is almost fully dependent on them. The combination of having a supportive environment and understanding of their situations by others, was the main thing that came forward with regards to specific needs at work. However, again, they thought the effectiveness would be very dependent of the character and coping abilities of a person with diabetes.

Participant A had no specific thoughts about employment compared to what he deemed important to living life in general with diabetes. It took him some time to think about whether he had specific thoughts on sustainable employability with diabetes.

"B: Yeah, support around you is the key to me I think. But this is also dependent on how you are as a person and as a diabetic. Sometimes you don't want it to have too much focus and maybe there are people who feel better when not everyone knows, because people sometimes can be too interested also huh, like wanting to help you too much and that is not working either!"

Again he shows his awareness of the self being the one responsible for the greatest part of one's

health outcomes. He later stressed the importance of having the right knowledge as a diabetic, and that simply being responsible and self-aware is the key to managing diabetes successfully to him, both in working as well as private life.

Participant B focused more on having an understanding and supportive environment. She did show reflections of her thoughts of being employed with diabetes, imagining it to even have a beneficial effect for managing her disease. In the job sector she would be in, she imagined having *'a rhythm and more or less fixed hours'*.

Remarkably, she also experienced that too much attention from people around her could also upset her at times.

"A: well, the normal things about health that count for everyone, but then ehh with something extra to carry! -...- and we know that if we don't take care, it will hit you back at some point."

A thought-provoking idea to denote here as well is that participant B distinguishes being a diabetic as having two kinds of personalities; one's personal character and one's diabetic character.

Discussion

The main finding of our study was the internal locus of employability perceived by the patients living with diabetes. Hence, patients included in this study viewed themselves as the sole responsible persons for remaining employable. The effort to manage successfully the employment opportunities initiates from them with self-management being a core value, as reflected in the IPA results: *'you are the expert and you know what is good for you'* (participant B).

Emotional acceptance of diabetes patients and communication with colleagues revealed as a central aspect for successful self-management at work. The main assets reflected in IPA interviews included responsibility, self-awareness, proper knowledge, and understanding and acceptance of the environment.

Results of this study show that adjustments and

adaptations at workplaces are not really what concerns participants when thinking about their employed future. Instead, their focus was largely on themselves and their responsibility, rather than the external environment. To some extent, this might be understandable due to the young age of both participants, absence of diseases complications, and job type.

By focusing too much on being responsible as a diabetic, one may limit the support that can be received from the external environment. Prior research has shown that the impacts of diabetes on a patient's life is difficult for the others to assess, as they are difficult to see or unpredictable. The effect would be that employers and colleagues become more reluctant to be involved, as they consider it more and more as a private matter when they see no clear relationship to an illness and its potential impact (3). However, this is not only due to the heavy responsibility that has been noted. The invisibility of diabetes in general, a theme that recurred multiple times in the IPA analysis, is a rather straightforward impact to societal comprehension about diabetes. It is simply hard to identify that someone has diabetes, let alone to recognize the impacts of it when one knows a person is suffering from it.

As stated by Finkelstein (8), individuals with disability tend to be submissive towards the biomedical model, by acknowledging that their impairments cause their level of disability which, in turns, affects their employability. This consideration was also pertinent to the recurring motives of security and safety throughout the interviews in our study. Thus, participants described situations at work in which they would anticipate to prevent a situation that would be undesired at that moment, even if this meant performing a certain behaviour that would not be in favour of diabetes management, such as retaining high blood glucose values.

It is interesting to consider the implications of our findings in the context of individuals living with diabetes worldwide. By its very nature, living with

diabetes imposes several demands and constrains related to behavioural/lifestyle patterns, which may also have an impact on social interaction and employability characteristics.

From this point of view, alongside the modification of behavioural characteristics, presence of diabetes may have negative consequences on self-perceived employment capability. Indeed, a previous study has reported that individuals with impaired hypoglycaemia awareness were significantly more likely to feel that having diabetes had adversely affected their capacity for employment (16).

On the other hand, a fairly recent study reported that diabetes mellitus predicted an increased risk of disability benefits, but not early retirement or unemployment (17). According to this report, all chronic health problems have a similar influence on disability benefits, but psychological health problems especially predict unemployment and early retirement. Based on these findings, the authors suggest that for workers with health problems, promoting an optimal work environment has the potential to contribute to sustainable employment (17).

Older studies on this matter have indicated that hiring practices by employers may be discriminatory toward individuals with diabetes mellitus. If employed, however, diabetic individuals face similar experiences with their non-diabetic counterparts, as long as they do not manifest disabling diabetic complications which have negative consequences on employment duration (18). Similarly, another older study has reported that diabetes was associated with both depression and unemployment, suggesting that this issue may warrant development of special employment and counselling programs for diabetic individuals (19).

A previous study conducted in the Netherlands distinguished cautiously between employability and employment (20). According to the findings from this study, having diabetes did not decrease the chances of entry into the labour market, although

some types of jobs were unavailable for diabetic patients. Furthermore, there was no higher unemployment among diabetics than in the general population. Finally, there were some problems faced by diabetic patients in the work situation, but they were generally limited to a small group (20).

Limitations, quality assurance and ethical considerations

Although type one and two diabetes differs in their natures and impact, this study has not distinguished between these two types. The underlying reason for this, lies in the fact that when it comes to employment and sustainable employability, the considerations to make are different for almost every individual with diabetes, as it depends on the type of job and personal factors, to name a few. Diabetes-related complications can occur in both types, as a result of unstable blood glucose levels. Thus, notwithstanding differences between the two types, there is significant overlap in type one and two diabetes when considering the main shortcoming in light of sustainable employability.

Both participants had type one diabetes. However, as stated above, this issue could not affect the research purposes. Conversely, the range of IPA results may have been limited by the relatively young age of participants and the absence of disease complications. All these factors may have had an influence on the level of consciousness of sustainable employability in study participants. Additionally, both participants already had diabetes before entering the job market, which may account for differences in the coping styles. From this point of view, inclusion of unemployed participants living with diabetes may have enriched our findings. Taking everything into account, this study provided insights that can ultimately contribute to revealing gaps that policies may need to address to enhance their social value and effectiveness to increase diabetic's sustainable employability.

Conclusion

The key element to support diabetics to remain employable sustainably, repeatedly points towards self-management, where knowledge and responsibility of the patient are central. Moreover, the invisibility of diabetes to others in society remains a challenge to patients and may be partially responsible for intentional behaviour change in patients, down turning diabetes

management at the workplace.

In conclusion, our findings indicate that patients with diabetes remain the central persons in attaining the best possible sustainable employability. Apprehending patients' perspectives contributes to identifying where and how policies can make a difference in advocating for patient-driven approaches to enhance sustainable employability.

Conflicts of interest: None declared.

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