

The meaning of diabetes for individuals who develop diabetic foot ulcer: a qualitative study informed by social constructivism and symbolic interactionism frameworks

ABSTRACT

Objective This qualitative inquiry explored the meaning associated with diabetes for people with type 1 and type 2 diabetes who developed diabetic foot ulcer (DFU).

Methodology This qualitative study used a social constructivism and symbolic interactionism (SI) framework to guide the study design. The participants for this study were 30 adults with type 1 or type 2 diabetes and a DFU who met the research criteria and attended a wound care clinic in Ontario, Canada, between April and August 2017.

Results Qualitative content analysis revealed three major subcategories that represent the core category (the meaning of diabetes) along with participants' perception of having diabetes and its particular complication – 1) diabetes is a life-long disease that you need to live with, 2) diabetes can damage your body, and 3) diabetes can kill you slowly.

Conclusions The complexity of self-care and the consequences of unregulated diabetes influenced participants' perception, meaning, motivation, actions and reactions to diabetes. Understanding that each person with diabetes is unique and may experience or be affected by the disease in different ways helps healthcare providers (HCPs) to better understand how to address each individual's unique and complex needs.

Keywords diabetes mellitus, diabetic foot, patient experience, self-management, meaning

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INTRODUCTION

Diabetes mellitus is a serious metabolic disorder with increasing prevalence worldwide. It is caused by the absence or inability to produce insulin to adequately exert its effects on glycaemic control¹. In Canada, preventing the disease as well as its proper management is considered a healthcare priority², particularly because approximately 549 new cases of diabetes

are diagnosed among Canadians each day³, where 90% of all diagnosed cases are type 2 diabetes, 9% are type 1 and the remaining 1% consists of other types of diabetes⁴.

Type 2 diabetes in particular is increasing the most due to factors such as rising levels of obesity, unhealthy diets and a sedentary lifestyle. However, levels of type 1 diabetes are also increasing. For example, in 2000, it was estimated that approximately 151 million adults worldwide had diabetes. Interestingly, in 2010, members of the International Diabetes Federation (IDF) projected that by 2025 about 438 million people would have diabetes⁵. However, the number is in fact greater; in 2021 more than half a billion (537 million) people were estimated to be living with diabetes, and that number is expected to increase to 643 million by 2030 and 783 million by 2045. The number of children and adolescents (i.e., up to 19 years old) with diabetes is also increasing annually. In 2021, it was estimated that more than 1.2 million children and adolescents under the age of 20 were living with type 1 diabetes⁵.

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Living with and managing diabetes can be challenging and, without the right support, it may lead to serious consequences. If not managed and kept under control, diabetes increases the incidence of complications (e.g., retinopathy, nephropathy, peripheral neuropathy) which can be devastating for many individuals and affect the many spheres of their lives. In addition, uncontrolled diabetes can also lead to a heart attack or stroke; it is an ongoing battle and a person can never give up controlling diabetes if they want to avoid damage to their bodies⁶. To prevent diabetes complications, individuals need to be prepared to adapt and change their lifestyle. Those who have developed a deep perception of the illness, including how it works in the body, and who have a higher level of self-management ability coupled with enhanced social support systems and inner recourse, are in the best position to adjust their routine, lifestyle and live well with this complex condition^{7,8}.

The daily choices made by individuals with diabetes have a direct effect on their health outcomes. The chronic nature of diabetes has reciprocal interactions with other dimensions of individual lives⁹. A major issue in diabetes is adjusting to and following a new regimen of self-care management with the acute and chronic aspects of the disease – this involves more than just the medical or physical management, but also the emotional perceptions of diabetes, actions and motivations to navigate life with diabetes^{8,9}.

By exploring patients' experiences of living with diabetes and the meaning/perception of illness, it is clear that the concepts of 'control' and a 'normal life' come up frequently⁷. These concepts reflect their perception of the illness and their wish or need to take control and adapt their life to a 'new' normal life. The meaning of living with and managing diabetes can vary from person to person. Living with poorly controlled diabetes can lead to complications (e.g., kidney disease, blindness, foot ulceration and amputation) which are devastating for the individuals; this may change the way they see the disease and give meaning to it. Living with diabetes and its complications (e.g., diabetic foot ulcer, DFU) provide different meaning and perception of the illness. While it can be frustrating for some patients, others may experience introspection and existential questioning (e.g., why me God?)¹⁰.

As the condition progresses and complications begin to be noticed, one's own ability to control the disease starts to be questioned. As a result, some individuals may display negative emotions or lower self-confidence about their self-management ability. Evidence shows that negative emotions such as anger, shame, guilt and denial can impact individuals' ability to engage in the self-management practices (e.g., dietary habits and exercise) required to regulate diabetes^{11,12}.

While the focus of most of the studies has been on the medical and biological aspect of diabetes management, a new approach is needed that focuses on understanding individuals' psychosocial needs, stories and experience of living with diabetes while experiencing its complications.

Understanding individuals' experience about the impact of diabetes complications, such as DFU, and how they make meaning of diabetes after experiencing its complications provide a foundation for the design of a new approach to diabetes care; this was the main reason for developing this study. Little is known about the meanings associated with diabetes for individuals who face complications such as DFU. This study aimed to explore the meaning of living with diabetes and its particular complication (i.e., DFU) for individuals with type 1 and type 2 diabetes.

METHODS

Research design

We used two frameworks – social constructivism informed by Charmaz¹³ and SI informed by Blumer¹⁴. When social constructivists align with SI, they view individuals in society as active subjects working collectively and sharing experience to reconstruct their world and realities¹⁵. When they use social constructivism as a framework, researchers need to be aware of the subjective meanings of participants' experience toward certain objects or things. Because participants bring a variety of multiple meanings that lead researchers to examine several categories or ideas, researchers using social constructivism aim to rely as much as possible on participants' views and experience of the situation being investigated^{16,17}. On the other hand, researchers using this approach must recognise that their own experience and background contribute to shape their analysis and interpretation of data, as supported by Charmaz¹³.

In this study, researchers use SI as first described by Blumer¹⁴ because participants' interactions occur firstly in their minds and are symbolic before they transfer them to their reality. In SI, human beings act toward things such as disease on the basis of the meaning that things represent for them. Symbolic interactionism also assumes that interaction is inherently *dynamic and interpretive* and therefore addresses how people create, interpret, endorse and alter meanings and actions in their life^{13,18}. The SI framework facilitated our understanding of the meaning of diabetes and its complications for people with type 1 and type 2 diabetes.

Study participants

This study was comprised of 30 individuals with type 1 and type 2 diabetes who developed DFU, met research criteria, and attended a wound care clinic in Southeastern Ontario, Canada, between April and August 2017. Participants were approached face-to-face and identified through purposive sampling if they met the following inclusion criteria: 1) a confirmed medical diagnosis of a DFU for at least 2 months, which ensured enough experience to reflect on the process of taking care of DFU; 2) age 18 years or older; 3) able to speak and read in English comfortably and articulate their experience of having DFU; 4) no close connection with any of the researchers prior to this study; 5) willing to engage in active self-reflection and self-disclosure about their experience of living with and managing DFU; 6) accepted to participate in this research after understanding its purpose, benefits and

risks and signing the consent form. Theoretical sampling was used to guide the simultaneous processes of data collection and analysis until saturation of each emerging category and concept was achieved. Ethics approval was obtained from the Queen's University, Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (TRAQ File #6020520). Using pseudonyms ensured confidentiality.

Data collection and analysis

Data collection and analysis occurred simultaneously and included intensive semi-structured interviews, field notes and a research journal. One-on-one interviews were audiotaped and conducted in a private room by the first researcher (IGC) until saturation, which ensured that no new properties of the research themes emerged. The duration of each interview ranged from 36 minutes and 41 seconds to 1 hour and 42 minutes. The first author, who was a PhD student and wound care nurse at the time of the study, conducted and entered interviews into N-Vivo® (Version 11.4.1) after these had been transcribed verbatim by a professional transcriptionist.

In our study, data collection and analysis occurred in a cyclic research process. This process began with initial coding (idea-by-idea) followed by focused coding. While the initial coding process generated 529 codes, the second stage, which comprised of focused coding, helped us to collapse redundant data into 250 codes. The result of this coding process, coupled with successive levels of abstraction through comparative analysis and memo-writing, led to the inductive generation of themes that described the meaning of diabetes for individuals with type 1 and type 2 diabetes who faced a diabetes complication such as DFU.

The coding process captured spontaneous reflection about the meaning of having and managing diabetes and DFU by asking open-ended questions such as: a) Tell me about the time you found out you had diabetes? b) How have diabetes affected your life? c) What does it mean to you to have diabetes? d) What does it mean to manage diabetes on a daily basis? What does diabetic foot ulcer mean to you? e) What does it mean to manage diabetic foot ulcer on a daily basis? The interview process also included the following probing questions: a) What have you learned from having diabetes/diabetic foot ulcer? b) How do you feel about it? c) Could you tell me more about it? d) Could you give me an example?

Theoretical sampling was conducted to ensure saturation and redundancy of each theme that occurred, which was seen after the completed interviews of 30 participants. While the first author (IGC) collected and coded the data, the second author and two experts in the coding process certified confirmability and participants certified and provided feedback on the findings. The experts conducted cross-coding to evaluate accuracy and whether the data supported findings, interpretations and conclusions. To ensure the usefulness and quality of this social constructivist approach, the authors followed the five criteria suggested by Charmaz¹³: 1) credibility; 2) originality; 3) confirmability/validity; 4) resonance; and 5) usefulness.

RESULTS

The majority of research participants (n=17) were aged 65 years or older, male (n=20), married (n=21), and living with their family (n=23). Nearly all (n=26) had completed high school and 12 had completed post-secondary education. Half the participants were retired, while seven were actively employed. Those unemployed were dependent on financial assistance from either family or government income support. Further information about participants' demographic characteristics are presented in Table 1.

By learning about, living with, and managing diabetes for a long time, participants began to give meaning to their illness. The data implied that the three most important meanings of diabetes described by participants showed contrasting implications of the disease for their lives. These are: diabetes is a life-long disease that you need to live with; diabetes can damage your body; and diabetes can kill you slowly. Table 2 presents a summary, with its respective sub-categories and supporting quotes.

Diabetes is a life-long disease that you need to live with

Those participants who see diabetes as a life-long disease and part of life seemed to have accepted the need to learn how to live with it for the rest of their lives. For some participants, diabetes means that they need to be careful of everything they do such as controlling diet, being active, controlling blood sugar, and avoiding collapse, such as Grumper who pointed out:

Table 1. Socio-demographic characteristics

Socio-demographic characteristics	Frequency (n=30)	Percentage
Sex		
Male	20	67
Female	10	33
Age		
<65 years	12	40
>65 years	18	60
Education		
Primary school	6	20
Secondary school	12	40
Post-secondary school	12	40
Diabetes type		
Type 1	7	23
Type 2	23	77
Diabetes duration (years)		
<5 years	12	40
>5 years	18	60
Ulcer duration (months)		
2-7	16	53
8-12	6	20
>12	8	27

But what it means is that I'm more careful of what I do now. In terms of food, in terms of drinking, in terms of activity. And I'm conscious of my... and times of weakness, I have to check and test my glucose and make sure that it's not the cause. Sometimes it's something else, I don't know. But if it's... if I need sugar, I need sugar. So that's changed part of my life in the sense that I'm conscious of it all the time. I'm getting used to it, so it's part of my life now. As long as I keep from collapsing, I'm okay.

Sometimes it is hard for individuals with diabetes to stay on track. During the interview Grumper shared that he has a weakness for sweet things or sometimes he forgets to follow a schedule of eating at certain times. The need to incorporate a rigorous balance between diet and exercise has affected his life and has caused him to constantly pay attention to his body to detect early signs and symptoms of hyper or hypoglycaemia. The challenge of managing diabetes relies on the ability of individuals to be in control of their daily living.

Furthermore, to incorporate diabetes into their daily living, some participants recognised through their own experience that it could be manageable if they adopted lifestyle changes. For example, Maverick experienced a relief of the burden of diabetes after losing weight, which led him to believe that although diabetes is an ongoing disease it also possible to be manageable:

Table 2. Summary of the sub-categories and respective supporting quotes.

Sub-categories / Supporting quotes
<p>Diabetes is a life-long disease that you need to live with</p> <p><i>"It's there forever, but you can manage it... It's something you have to learn to live with for the rest of your life".</i></p> <p><i>"... what it means is that I'm more careful of what I do now. In terms of food, in terms of drinking, in terms of activity".</i></p> <p><i>"It means that I have a disease that I'm gonna have the rest of my life... But it's a disease that can be contained if I follow directions".</i></p>
<p>Diabetes can damage your body</p> <p><i>"It means lots of damage. At first, it was only in my hands but after a while it went down to my feet".</i></p> <p><i>"It means lots of consequences. It's certainly contributed to other health problems regarding my heart and this hole in my foot".</i></p> <p><i>"Diabetes means lots of health issues. I don't follow a strict diet, which is probably leading to what's happening now".</i></p> <p><i>"Diabetes can do a lot of damage, mind you, but nerve damage and what have you, but you try to keep an eye on it".</i></p>
<p>Diabetes can kill you slowly</p> <p><i>"They say it's a nice killer. It kills you slowly. All your organs go with no pain or whatever with no pain and not feeling bad in the morning or whatever".</i></p> <p><i>"Well, what does it mean? It means that, if I'm going to lose 13 years from diabetes... I'm going to leave my wife a widow earlier than I would like..."</i></p> <p><i>"It means that sugar diabetes can kill you. You only live once so you only have these body parts once so, you know".</i></p>

It's there forever, but you can manage it. Just because, when I lost a bunch of weight a couple years ago, even though I was able to go off insulin and cut my medication and all this and was virtually diabetes free, it still didn't mean I wasn't a diabetic. The minute you go back to the old eating habits and everything else or gain some weight, it's still there. It's something you have to learn to live with for the rest of your life.

Diabetes can damage your body

Many participants expressed awareness of the consequences of diabetes on their body. For James, diabetes "means lots of damage." He has faced this damage in both his hands and feet:

It means lots of damage. At first, it was only in my hands but after a while it went down to my feet. Then a boil busted, whatever you want to call it, boil, blister, that blew up, more or less, inside my foot. It made a hole in my foot about that big.

For some participants, the consequences of diabetes were beyond a hole in their foot; it affected many parts of the body such as the kidneys, eyes and heart. For example, Butch had experienced many health issues and recognised that his uncontrolled diabetes led him to them:

Diabetes means lots of health issues. I don't follow a strict diet, which is probably leading to what's happening now with the rest of me. It affected my eyes and my kidneys and I am going to have to do dialysis for the rest of my life.

Diabetes can kill you slowly

Some participants compared diabetes to a death sentence. For instance, Junior admitted that diabetes means he is going to die earlier than he wished. He also disclosed that it is mostly because he did not adopt changes in his lifestyle and did not quit smoking to live well and longer with diabetes:

Well, what does it mean? It means that, if I'm going to lose thirteen years from diabetes, I'm grossly overweight as you can see, so I'm losing time from that. I smoke two packs a day, so I'm losing time from that. It means to me I'm on borrowed time right now, but we're all going to pass. I'm okay with the reality. I'm the one that brought this on. I'm the one that started smoking, and because of my diabetes and some other factors, I can no longer exercise, so I can no longer help to maintain my weight. It's all a contributing factor to probably I'm going to leave my wife a widow earlier than I would like, but so be it. I've accepted that, and she's accepted that. We're realistic people. Don't like it, but it's going to happen, so there it is.

Calling diabetes a death sentence led participants to think that diabetes makes death inevitable. Butch, for instance, shared with me that he was always drinking alcohol and partying because he wanted to enjoy his life before dying from diabetes. However, he is now suffering from many consequences of diabetes and blames his lack of understanding and denial to take control of it from the beginning. On the other hand, Junior considers himself a loser to diabetes because he did not adopt a new lifestyle and continued smoking. His foot damage has also prevented him from being active and therefore losing weight to control diabetes. He seems to view his situation as a

lost cause and hence has accepted the fact that he is going to die earlier than he wished.

DISCUSSION

In this study, participants developed their own meaning of diabetes, which was influenced by personal beliefs, family history, and their day-to-day experience of living with diabetes and its complications. The study's findings demonstrated that variations existed regarding the extent to which participants moved along the continuum of acceptance, as well as the extent to which they actively engaged in the process of learning about, making meaning of, and taking action toward engagement in managing diabetes. For instance, the silent nature of diabetes caught many participants off guard, as they were mostly unaware of the signs and symptoms of diabetes, and of the possibility that they might have the condition. Once diagnosed, learning to live with and managing diabetes occurred progressively, but also represented a challenge for most participants.

Our study's findings uncovered that the meaning of living with diabetes may be different for individuals facing diabetes complications. Facing the poor outcome of diabetes led participants to experience damage to their body (e.g., foot deformity, calluses, wounds, amputation, eye and kidney problems), and see diabetes as a threat to their mental health and quality of life. These participants connected the meaning of diabetes to the effects of the disease on their body and mind. For example, they saw diabetes as a death sentence or a condition that "kills you slowly". These findings align with previous qualitative and quantitative studies that explored the meaning of diabetes among individuals who faced the burden of diabetes. These studies described that the meaning of diabetes was strongly associated with both physical and mental components of quality of life¹⁹⁻²¹.

While "watching what you eat" became a crucial component in the management of diabetes, "taking care of your foot" was an essential component in the prevention of one of the most devastating consequences of unregulated diabetes. In our study, knowing how to choose the right diet and the right shoes became fundamental for participants to feel in control of the disease. Authors of a previous study that explored individuals' experience of living with and implementing diabetes self-management practices stated that the concept of control prevailed and permeated all categories of the study. An example is from participants' struggle to adapt to a daily management regime through their ability to achieve a balance between living with a progressive chronic condition and adapting to a so-called normal life⁷.

Authors of a previous study reported that even for those individuals aware that they need to "watch what they eat", their major apprehension was how to get the diet right²². Changing lifestyle presents a challenge for older adults to incorporate in their everyday life and makes the management of diabetes a difficult task to follow, but they are aware of the need to

deal with it the best way that they can and know how⁶. In our study, some participants self-labelled themselves "a bad diabetic" because they were not able to sustain the lifestyle change required to regulate diabetes. For example, they would not follow a consistent diet and incorporate physical exercise into their daily routine. Similarly, participants of a previous study also had difficulty in maintaining a consistent lifestyle. Inconsistency in maintaining a recommended regime reflects the lack of or limited knowledge about the disease, and the challenge to adjust their lives to the complexities of required daily tasks⁷. In fact, in our study most participants did not have access to diabetes education and none of them were provided with education about self-care of their feet.

Both our study and previous studies demonstrated the consequences of not sustaining a recommended regimen or lifestyle both in terms of clinical (e.g., hypo or hyperglycaemia), physical (e.g., DFU, blindness) and psychological outcomes (e.g., guilt, anxiety and frustration) as some participants in this study reflected^{7,23}. One may ask, if Maverick was conscious about the benefits of his engagement in self-management of diabetes, why he was not able to sustain it? The simple answer is that the management of a long-term condition such as diabetes is also a "lifelong battle" that requires considerable mental determination and commitment of self to adjust to a new psychosocial lifestyle^{24,25}. In fact, the permanent changes required to adopt and adapt to a new lifestyle and regimen that comes with the demands of diabetes must be understood from psychological, spiritual and behavioural aspects of the disease¹². Participants in our study perceived diabetes as a disease that they will have to deal with for the rest of their lives; they understood that lifestyle changes may not be easy to adopt, but are important to make if they want to be able to live well with diabetes and prevent serious consequences. Similarly, participants in a previous qualitative study developed in Indonesia also shared that diabetes is a disease that has no cure yet, caused lifelong stress and worry, and led to many changes in their bodies²⁶.

After facing the consequences of diabetes such as DFU or amputation, participants in our study felt guilty, regretted not taking care of diabetes from the beginning, and somberly accepted their condition. Perhaps individuals who had spent a lifetime trying to manage diabetes to the best of their ability but ended up with complications might believe that they had done everything possible to keep their lives going with diabetes. Such a situation seemed to have led seniors with diabetes to relax self-management because, believing it beyond their control, they started to normalise their condition, an outcome similar to findings in a previous study about lay perception of diabetes in Indonesia²⁶. In alignment with our findings, authors of previous studies in Indonesia and the United States reported that participants believed that diabetes was beyond their control and did not seem motivated to fight this battle; therefore, they accepted the limitations and challenges produced by the disease¹⁰.

In fact, motivation is an essential component to maintain for the person engaged in a life-long self-management task, but what motivates one person may be different from what motivates another, especially for those who are ageing with multiple chronic conditions and experiencing diabetes complications in addition to these²⁷. On the other hand, the long-term risk of developing diabetes complications does not seem to be an usual motivation for individuals with diabetes to change lifestyle; instead, they are most often motivated by perceived short-term improvements²⁸. For example, if the person has seen relatives or close friends with complications from diabetes, they may think it is a waste of time to manage and deal with it⁵ or they may become aware and engage in lifestyle changes to avoid ending up in a similar situation. Therefore, further research is needed to explore the motivation factor as a component for lifestyle change in people with diabetes.

CONCLUSION AND IMPLICATIONS

The complexity of care and the consequences of unregulated diabetes influenced participants' perception, meaning, motivation, actions and reactions to diabetes. The challenge to take in the necessary health information and make lifestyle changes to prevent disease complications often interferes with patients' perception of what it means to live with diabetes. To facilitate the uptake of individuals' experience and perception or meaning of diabetes into clinical practice, it is essential that healthcare providers (HCPs) communicate with patients to understand the battle they are facing to live with and fight diabetes on a daily basis.

Understanding that each person with diabetes is unique and may be affected by the disease in different ways (physically and/or emotionally) helps HCPs to better understand how to address each individual's unique and complex needs. It is crucial to expand research and care practice to focus on more than just the physical aspect of diabetes as a disease. Rather, HCPs would be better equipped to support individuals with diabetes when they are trained to focus on successful and cooperative management of the illness that encompasses the emotional, relational and psychosocial aspects of this complex condition.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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AUTHOR CONTRIBUTIONS

IGC is the principal investigator and was responsible for the conception of the project, funding acquisition, data collection and analysis, and drafted the first and final versions of this manuscript. PCP contributed with the design of research methodology, and revised the manuscript critically for important intellectual content. All authors reviewed and approved the final version to be published.

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