

## **An Interpretative Phenomenological Analysis of Lived Experiences of People Who Have Diabetes**

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### **ABSTRACT**

*This study investigated the role of positive emotions, namely hope, in a sample of participants who have diabetes. A sample of five people with diabetes type 1 or 2 was interviewed to investigate their lived experiences in managing this chronic condition. Four superordinate themes were extracted: behavioral changes to manage a demanding disease, cognitive skills, and lifestyle, emotional reactions, hope, and a vision for the future. This study highlights that retaining hope is essential for envisioning the possibility of improvement of health conditions and a better quality of life. Furthermore, self-responsibility and cognitive agility are fundamental to managing diabetes and adopting a healthy lifestyle.*

**KEYWORDS:** Positive emotions, hope, future, behavioral skills, chronic illness.

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The onset of a chronic disease leads to a profound change in an individual's life that demands the development of specific coping mechanisms to deal with the behavioral, cognitive, and emotional challenges of managing a chronic condition while preserving an active life (De Ridder et al., 2008). These life changes can subsequently act as triggers, potentially initiating feelings of frustration, emotional distress, and communication difficulties (Kalra et al., 2018). Individuals with diabetes must adapt their lives to maintain their physical and psychological well-being. Many studies have investigated emotional distress in people with diabetes and identified some of the most recurrent negative emotions, such as dismay, helplessness, anxiety, vulnerability, hopelessness, and frustration (Turner & Kelly, 2000). The main psychological factors that affect the emotional and psychological well-being of a person with diabetes are related to diagnosis acceptance, adjustment to the demands of self-care management, and coping with the progression of a lifelong condition (Ahlin & Billhult, 2012).

Consequently, this can lead to experiencing an elevated level of emotional distress and depression (Kalra et al., 2018; van Dooren et al., 2016). Depression is the most common psychological risk factor in relation to diabetes. Most people can experience depression to some degree during their life, with individual differences in the severity of depressive symptoms. Depressive symptoms can be sadness, negative thoughts, fear, and anxiety (Contrada & Goyal,

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2008). The experience of negative emotions, such as worry, frustration, and burnout caused by self-management demands, has been linked to poor blood sugar control, diet regimentation, and medication adherence (Fisher et al., 2010). An association is established between psychological complications, such as depression and anxiety, and poorer chronic disease self-management outcomes (Rhonda et al., 2016). This correlation between diabetes distress and blood sugar levels is also bidirectional, with high blood glucose levels a further cause of significant emotional distress (Joensen et al., 2016).

Although many studies have underlined the presence of emotional distress in diabetes patients, few studies have explored the role of positive emotions in dealing with this chronic disease. Conversely, numerous studies have investigated the role of self-management, coping strategies, and psychological interventions for diabetes patients (Collins et al., 2009; Duangdao & Roesch, 2008; Schmidt et al., 2018). Still, there remains a scarcity of research on the impact of positive emotions on quality of life and well-being (Huffman et al., 2015; Richman et al., 2005). Therefore, this study is grounded on the principles of positive psychology that focus on enhancing one's strengths and what works well in life instead of the idea of repairing the damaged life aspects (Peterson, 2006; Seligman & Csikszentmihalyi, 2000). This study aimed to investigate the emotional experience of dealing with diabetes and the role of positive emotions, namely hope, as a protective factor for psychological well-being. The main aspects investigated in this research were the role of dispositional optimism and hope in people who have diabetes to enhance psychological well-being. Psychological well-being includes what constitutes a good life (Ryff, 1989). Scholars found that the main factors that affect the quality of life were autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance (Ryff & Singer, 2008). While in this study, well-being is considered a construct that encapsulates the ability of a person to balance between physical and psychological dimensions despite the presence of illnesses.

### **The Role of Emotions**

Emotions are the personal expression of feelings and act as a form of protection from external threats. Much literature has been published on the impact of negative emotions such as sadness, worry, and despair on managing chronic disease (Benkel et al., 2020). Previous research has shown that experiences of negative and positive emotions affect the adaptive regulation of biological systems that maintain health (Ong et al., 2018). On top of this, emotional responses play a critical role in systemic inflammation, which can also lead to poor health (Cohen et al., 2012). Despite the depth of research on the health outcomes associated with negative emotions, little attention has been paid to the role of positive emotions. Therefore, it is essential to investigate the value of positive emotions in managing a chronic condition.

According to Fredrickson (1998), an essential characteristic of positive emotions is that they first activate a cognitive response, and those cognitive mental changes trigger the consequent physical response. The *broaden-and-build theory* states that positive emotions influence cognitive functions and behaviors (Fredrickson, 1998). Fundamentally, positive emotions act as resource-building since discovering novel ideas and actions enlarges an individual's physical, cognitive, social, and psychological resources (Fredrickson, 1998; Fredrickson et al., 2003). Accordingly, this process supports the development of different emotion-based coping strategies. Fredrickson considered this process like an upward spiral leading to improved emotional well-being. The ability to cope with challenges and experience positive emotions in the future enhance resilience and emotional stability (Fredrickson, 2001).

The specific emotion of hope is often one of the prevalent emotions that arise during adverse circumstances. Hope helps the person have a positive outlook for the future and accept that the situation can improve. Fredrickson (2004) has underlined that this emotion boosts one's ability to leverage resources to be more optimistic and resilient. Moreover, according to Goleman (2005), hope has healing power. A study by Santos et al. (2015) conducted with a sample of adolescents and young adults, who had type 1 diabetes, showed that having hope leads to improved glycemic control and decreased depression. Their results supported the hypothesis that positive readiness and expectancy helped chronically ill people adopt specific behaviors, such as proactivity, positive thinking, and resilience, to face challenges (Santos et al., 2015). Despite the mentioned research finding a relationship between emotion regulation and health measures, this has not translated into a study looking at the subsequent health outcomes (Wierenga et al., 2017). Researching the role of positive emotions in people with diabetes will shed some light on how they manage their condition and preserve psychological well-being.

An emerging line of research points out that positive emotions may protect health (Kok et al., 2013). Therefore, assuming that physical well-being is linked to emotional well-being, this study aimed to investigate the general effect of experiencing positive emotions, namely hope, on the daily management of diabetes.

### **Dispositional Optimism**

Dispositional optimism is one variable that might buffer the adverse effects of managing diabetes and boost psychological well-being. In literature, the construct of dispositional optimism is related to psychological well-being. A few studies have investigated psychological interventions to reduce psychological burnout and the lack of treatment adherence of people with diabetes (Bogusch & O'Brien, 2019; Ismail et al., 2004), but little attention has been paid to the role of dispositional optimism. People who show dispositional optimism have positive expectations for the future (Carver & Scheier, 2014), expecting good things to occur in their life. Optimistic people hope and seek favorable outcomes across different life domains (Rasmussen et al., 2006). Previous research has underlined how expectations are vital in triggering specific behavioral responses to health complications (Thoolen et al., 2008). Therefore, having a positive attitude toward the future leads to a significant effort, even in the face of serious threats. In contrast, skepticism about the future is linked with disengagement and less effort (Rasmussen et al., 2006). Indeed, previous research has shown that optimism and positive emotions protect from physical disease (Seligman, 2008) and improve psychological well-being and resilience (Fredrickson, 2001; Tugade & Fredrickson, 2004).

Overall, optimism and the lack of pessimism can be considered valid predictors of physical health (Scheier et al., 2021) and are linked to high life satisfaction and positive affect (Chang et al., 1997). People with high optimism should be able to use it as a buffer against adverse effects during stressful times and perceive the impediments facing them as more manageable (Scheier & Carver, 1985). Overall, in previous studies, optimists tend to make more conscious choices about health (Giltay et al., 2007). Interesting findings of a study (Vollmann et al., 2014) conducted with people with a chronic disease have shown that optimists had positive perceptions of their disease and consequently lower levels of depression. They considered their condition to have fewer symptoms, not chronic, not lead to grave consequences, more manageable through medical treatment, more understandable, and cause less emotional distress (Vollmann et al., 2014). Increased positive psychological disposition impacted the disease's cognitive and emotional coping strategies, explicitly impacting health-seeking behaviors and conviction to adopt those behaviors (Yalcin et al., 2008).

This study explored in-depth narratives of a group of people with diabetes, especially their daily management and emotional responses, to shed light on how they experience positive emotions and maintain psychological well-being. The central aspect examined was how people with diabetes managed their emotions and the role of positive emotions, especially hope. The research questions were:

1. How do people affected by a chronic disease manage their emotions?
2. How might positive emotions, especially hope, help them to maintain their psychological well-being?

## Method

Qualitative methods can be more valuable than quantitative methods when seeking to identify and characterize people's specific beliefs, lived experiences, attitudes, behaviors, and social interactions, from a humanistic point of view (Pathak et al., 2013). This approach is based on both the voice of participants and the researcher, who ultimately analyzes the data by constructing themes. One of the methodologies used for qualitative research is phenomenology. Phenomenology aims to understand individuals' subjective experiences of the world around them. The phenomenological perspective investigates social phenomena from the individual's perspective and analyzes how the world is experienced.

The specific type of phenomenology adopted in this study was an interpretative phenomenological analysis (IPA) to comprehend the participants' meaning and lived experience (Smith & Osborn, 2015). A distinctive aspect of adopting this approach to qualitative research is the hermeneutic circle, whereby the researcher plays an active role in interpreting participants' words. Firstly, participants try to express their inner experiences using specific terms, and then the researcher aims to solve these words correctly (Smith, 2004).

According to Smith (2004), interpretation and understanding are the main aspects of IPA. The subjects cognitively and emotionally conceptualize their experiences when talking. Consequently, the researcher adopts a reflexive attitude to capture the meaning of specific words and expressions, including what might not be clearly expressed (Willig, 2013). Subsequently, an essential assumption of IPA is that personal experience is not directly accessible by the researcher but is interpreted as the best possible (Willig, 2013). Moreover, IPA adopts an idiographic approach and aims to highlight peculiar lived experience characteristics and not generalize the results to a broader population (Smith, 2015).

## Participants

The total number of participants involved in this research study was five, aged between 23 and 40. The aim was to seek a sample of people who have diabetes. People were recruited through the university platform Moodle and word of mouth; specifically, people diagnosed with diabetes, type 1 or 2, were recruited. Subsequently, these people were invited to participate in the research. Participants were educated at a college level.

The themes were identified by looking at the prevalence and similarities in participants' accounts. The most recurrent themes were highlighted and collated in a table with the related data extracts. The themes were clustered to create an analytic narrative that disclosed the participants' most recurrent emotions related to managing diabetes. The primary intent was to capture the meaning of participants' emotional, psychological, and social worlds (Smith et al., 1995). The data obtained through this research touched upon participants' private lifestyles and emotional

reactions. The participants talked about their personal experiences in managing diabetes. Ethics approval to conduct this research was sought from the University of East London's School of Psychology.

**Table 1**

*Participants Details*

Participant	Age	Gender	Ethnicity	Type of Diabetes	Duration
Luisa	25	Female	White European	1	8 years
Matt	23	Male	White European	1	10 years
Claire	24	Female	White European	1	21 years
Annie	37	Female	Indian European	2	7 years
Kate	40	Female	White European	1	2 years

*Notes.* Duration indicates the number of years participants have had diabetes. The names are pseudonyms.

## Procedure

All interviews were recorded digitally to transcribe the content and analyze the data. Before starting the interviews, each participant was informed about the aim of this study, confirmed their consensus to participate, and completed the demographic form. One interview was conducted face to face, and the others via Skype video calls. The questions asked during the interview comprised a set of semi-structured aimed at eliciting responses on the experiences of managing diabetes. The interviews lasted between 45 to 60 minutes each. A safe space was created to allow the research subjects to talk openly about their experiences freely. I followed the script of the established questions and dug deeper into specific aspects that arose from the participant's accounts. During the elaboration of the study, the arguments were supported by the participants' claims and consequent interpretation.

However, it is noteworthy to acknowledge that another researcher using IPA may offer another level of interpretation (Smith, 2004). Transcription of the discussion was done verbatim. The participants' names are pseudonyms to protect their privacy. The analysis was guided by a continual effort to be truthful and respectful regarding the participants' accounts. The most crucial element was to give voice to the participants' experiences through practical and truthful analysis and interpretation. The process of interpretation went through several steps: firstly, the researcher repeatedly read the transcripts; secondly, comments on relevant elements were written; thirdly, the main themes were labeled; finally, a structure for the analysis was provided, based on clustering the main themes (Willig, 2013).

## Findings

### Behavioral Changes to Manage a Demanding Disease

Diabetes is not a silent disease; it demands daily self-care through adherence to the recommended diet of low carbohydrates, regular physical activity, constant monitoring of blood sugar levels, and taking insulin or oral medications at every meal. Previous research has highlighted that self-care is a powerful tool in the hands of an individual to manage the disease. Furthermore, self-discipline is fundamental to adopting and maintaining these self-care behaviors (Rad et al., 2013). Managing carbohydrate levels is the first step to handling diabetes. Several studies have demonstrated that choosing healthy food, practicing physical activity, and losing weight are vital

for improving the health of diabetes patients (Franz et al., 2003). People who show self-efficacy, belief in the importance of good health value, and the capacity to determine a specific outcome through their actions can manage their condition more effectively (Collins et al., 2009).

### **Self-responsibility to Choose a Healthy Lifestyle**

An emergent theme of this analysis was the importance of adhering to specific treatments, namely adopting a healthy diet, constant glucose monitoring, and injecting insulin. The onset of diabetes establishes new rules and implies a need to adopt a new lifestyle. Unfortunately, a previous study underlined that self-control, diet, and physical activity were significant challenges for young adults. These challenges can affect blood glucose levels and lead to health complications (Serrabulho et al., 2014). Kate pointed out that her diet change was a mandatory request for her well-being. However, this process was unpleasant; instead, it was a ‘pain in the neck.’

*I had to make things significant changes to my diet becoming diabetic...I have to count carbs. So, I'd have to shift to have fewer carbs, different types of carbs, different times...I'd rather just be able to eat, but um...It made me lose a lot of weight. So, I can't complain about that. It's just, it's just annoying. You can never let go yes, you can't let go out of there and don't think about it. You have to be mindful of what you are eating.*

Diabetes imposes a specific direction for preserving a healthy condition. However, according to Kate, this change was “painful, annoying, pain in the neck,” because she had no other choices. It was no longer an option for her to eat anything she wants; plus, counting the carbohydrates was a conscious reminder in her daily life. It is possible to argue that an individual’s freedom is taken away by diabetes. Then, the situation assumes different perspectives based on whether an individual is optimistic or pessimistic; for Kate, the good part was that she lost weight. Annie had the same experience and was committed to keeping a well-organized and healthy diet for her meals. She was conscious of her food choices and how some can impact her health and blood sugar levels:

*I'm trying to have something that is healthier because it's grilled. I try and introduce some vegetables. But to be honest, all the vegetables and things I like, it's all that's got sugar in it like for example like sweet corn...I end up having more of English type of food or like jacket potato which is carbohydrate. I'm having pasta, you know, things with more carbs, so I think that's how my results are...I think the stuff that I'm having like I love potatoes and like pasta [laugh] so that's what's making my sugars higher.*

Annie recognized that the food she loved contains a high proportion of carbohydrates, which was not the best choice for her condition. Even though she knew that she needed a special diet to manage her diabetes, Annie tolerated her favored food and tries not to be too judgmental, as emerged from her laughs. She recognized that external circumstances sometimes influence her diet, such as dining out with friends or being home ill, and her diet plan was disrupted. At the same time, she knew how to return to the planned diet. This was a common theme across participants’ accounts, an acknowledgment of the importance of following the rules to have a healthy diet and maintain a state of well-being. Though self-responsibility and self-determination play a vital role in this process. Instead of utilizing these facets, Annie seemed to accept her weaknesses and indulge

her taste despite the possible negative consequences this might have on her blood glucose levels. Previous research has shown this discrepancy: some people value having constant glycemic control as the primary way of improving their well-being and living longer.

In contrast, other subjects might prefer avoiding the responsibility of daily diabetes management and not following the recommended lifestyle regimen (Ahola & Group, 2013). The theme of the relevance of a healthy diet, specifically its positive impact, emerged from Luisa's account. Luisa iterated that diet choices have positively impacted her well-being, especially her blood glucose levels.

*I started the vegan diet 5 years ago and I feel like my blood sugars got better. I don't have that many spikes after meal, but I don't really know it's because of veganism and plant-based eating or just general that I have new technology.*

It is important to note that Luisa did not outline her reasons for being vegan, but this choice has positively impacted her health and her management of diabetes. She used an insulin pump to inject insulin; consequently, monitoring her blood sugar was constant, and she might benefit from better managing her food intake. Therefore, in these instances, the individual, who has diabetes, played a crucial role in managing their condition. This autonomous management can also be called self-management and is a pivotal factor in managing diabetes. Along with self-management, a further facet to consider is self-awareness of choosing a lifestyle that can help improve a condition. Matt echoed this view:

*I'm not having a really healthy lifestyle because I spent a lot of time at the University sitting in front of a computer or speaking with other people...I tend to eat healthy vegetables. I just have a variety of foods in my diet, but also it is because I just think I am aware of the consequences of bad treatment.*

Matt was deeply aware of how professional demands influence his lifestyle and tried to find a balance by following a healthy diet. The most critical factor in his self-management was the ability to help him avoid unpleasant consequences. He seemed aware that inadequate self-management can lead to worse glycemic control. It was fundamental for each participant to maintain the glycemic level stable to prevent and treat hypo and hyperglycemia. Self-responsibility in taking medicine and a healthy diet of low carbohydrates are essential factors in maintaining a state of well-being. Participants did not consider adaptation to a specific lifestyle, and following the rules of a diet with low carbohydrates was a significant stressor. For each participant, taking care of themselves and acting responsibly was a natural process, including counting carbohydrates and taking insulin. Claire clarified this aspect by saying:

*I have this state of mind that I can eat almost everything like cakes, if they are gluten-free. Uh...that celiac disease is, I think, the most difficult thing...In the diabetes point of view, I think I don't have so much special stuff that I have to do...When I'm getting my dinner, so, I try to approximate how much carbohydrates that dinner can contain.*

Claire had type 1 diabetes and celiac disease, which meant she could not eat products containing gluten. Notwithstanding, diabetes was an external perspective from which to look and evaluate possible choices. The primary demand was always counting carbohydrates and taking insulin. Despite this, her celiac disease imposed specific restrictions on her food choices. Claire seemed to normalize her food choice without feeling the pressure of any specific restriction. As much as her blood sugar is under control, she tried to enjoy her meals without being conditioned by diabetes.

Despite the possible challenges brought up by dietary restrictions in managing nutritional choices, the participants adopted a cognitive approach of not feeling restricted regarding their food selection. This may be considered a positive psychological defense not to consider themselves different from others. Therefore, the participants of this research appeared to be proactive managers (Collins et al., 2009), people who were particularly active in handling their condition. Namely, these people accept responsibility for maintaining their well-being. They also knew that achieving specific goals is fundamental to adjusting their lifestyle, especially their diet, to control glycemic levels.

### **Cognitive Skills and Lifestyle**

A recurring theme in the interviews was the importance of planning and organizing. Diabetes is a disease that requires continuous activation of executive functions, including planning and reasoning, prompt decision-making, and problem-solving (Suchy, 2009). These skills influence self-management, especially in monitoring hypoglycemia, when blood sugar levels are lower than usual, and hyperglycemia, when blood sugar levels are higher than average. Research has shown that well-developed cognitive skills positively correlate with improved glycemic control (Suchy et al., 2016). Critical cognitive skills, such as monitoring glucose levels, estimating the number of carbohydrates in the food, and injecting the correct insulin dose, were required to manage diabetes outcomes. Matt clearly explained this point:

*It requires a lot of thinking about it and a lot of action during the day in order to keep everything under control. It can be sometimes fairly easy, but it can also be very frustrating and tiring...It's uh sometimes surprising characters. So, you can do something for 10 times in a row and get it well, but 11 times something is gonna go wrong and you just get frustrated because of that.*

Control of one's condition through cognition and action was fundamental to managing unpredictable spikes. It seemed a simple task; however, it took considerable effort. The person needed to dedicate constant attention to bodily signals to respond swiftly. However, these feelings of frustration and tiredness, pointed out by Matt, displayed a sense of powerlessness despite the incredible efforts to manage everything. It is possible to argue that diabetes influences people's lives and that these people must learn to accept the direction diabetes takes in their lives. Even though people showed good self-management, the unpredictable negative effect of diabetes made individuals experience frustration. Claire highlighted this aspect with these words: "I think uh in my daily activities diabetes means that I have to plan very much beforehand."

Planning was a way to control possible up-and-down fluctuations in blood glucose levels. Subsequently, planning could also be considered a coping strategy to establish psychological safety and do practical things to reduce risks. For example, Claire stated that she constantly carries a bag with food and medicine to manage her health condition in case of high or low blood glucose levels.

It is still possible to see a sense of normality and routine in this way of thinking and acting. Also, for Luisa, it was fundamental “to keep a lot of things aligned all of the time.” An essential aim of self-management is to normalize blood glucose levels and adhere to a treatment regimen to reduce hypoglycemia and hyperglycemia risks. Many people with diabetes will have experienced the unpleasant symptoms of high or low blood sugar levels, including but not limited to unconsciousness and convulsions. In the worst-case scenario, these fluctuations can lead to death (Ahola & Groop, 2012). On the back of this, monitoring blood glucose fluctuations is vital in diabetes sufferers’ lives. Luisa promulgated this point:

*I have to look for my blood sugar all of the time that stays in range and, it doesn't go up too high or too low, because I have to treat it to be low eating something sugar in it or drinking something. When it is high, I can't concentrate, and I get a headache. So, I try to stay in line...It's my daily life, I do most of the things kind of automatically um there are a lot of thoughts in my head about my chronic condition always like behind (laugh).*

Diabetes is a constant presence in patients’ daily activities, and the physical symptoms accompanying the disease induce actions to reduce the side effects. It seems essential to balance the inner requests from the body, such as the need to eat or drink, and the external demands of being active and interacting with other people. In some moments, for Luisa, it was challenging to remain focused as she had to manage frequent headaches. Subsequently, in her mind, many thoughts echoed her chronic condition. Irrespective of these struggles, she did not complain or blame external factors. Planning and organizing were not just related to daily activities but also involve consideration of the future.

Regarding this point, Annie underlined how managing diabetes involves arranging her social activities according to a needed to take tablets at specific times. Therefore, her friends must be on time when they had dinner together, and she also could spend a night out if she did not have extra medications. The clear statement highlighted this aspect: “you can’t just up and go.” Having dinner out, a vacation, or a possible future in another country requires an in-depth evaluation and previous well-planned arrangement:

*Where other people can just up and go, you have to think. Okay I need to go and order extra medication. Just in case if I lose the medication in my suitcase, I've got a back-up. You know, it's just like you have to always like plan ahead. (Annie)*

An intuitive comparison with people who did not have diabetes highlights how managing diabetes impacts Annie’s lifestyle. Always having her medicines available was integral to her thriving and surviving. Her view of the future was not entirely positive since, in the back of her mind, she was constantly considering how she could control her life.

## **Emotional Reactions**

Day-to-day life with a chronic disease is considered, by some, tiresome and frustrating. The emotional aspect of dealing with diabetes is a dominant element identified in the interviews, often attributed to the demanding peculiarity of this disease. First thing in the morning and before every meal, monitoring blood glucose levels and taking insulin is mandatory. This acts as a continuous

reminder of one's vulnerability to the condition. Secondly, unpredictable blood sugar fluctuations are a source of stress and frustration, especially since they can be problematic and debilitating. Thirdly, the medical check-ups represent an additional stressor as these appointments and professional commitments increase the possibility of receiving bad news about their condition. Furthermore, possible complications, demanding treatment regimens, and blood glucose fluctuations compound the emotional reactions evoked by these stressors and frustration. Previous research has underlined those negative emotions such as anger, anxiety, and sadness are more common among individuals who have managed diabetes for a long time and have subsequently dealt with more complications (Decoster, 2003).

An interesting aspect to underline is that the participants of this research reported excellent self-control and were at ease when talking about their condition and related emotions. Overall, they were well-disposed to talk about their feelings about living with diabetes. None of them refused to reply to any questions, and none were reluctant to explore their personal experiences; they were also keen to know more about the research topic.

### **The Most Recurrent Emotions**

The participants reported having to continually cope with a progressing and unpredictable illness, which ultimately requires self-regulation of thoughts, emotions, and behaviors. Sometimes they perceive a lack of control over their diabetes, and unexpected blood glucose fluctuations change their psychological reactions. Generally, individuals who adopt healthy behaviors may have better glucose control and reduce their chances of possible complications in the future. However, more is needed to eradicate blood glucose fluctuations. An important aspect that influences diabetes management, acknowledged by participants, is the perception of control over their condition. Previous research conducted by Ahola and Groop (2013) has highlighted that people have different perspectives regarding their control over the events occurring in their lives. For example, people with an internal locus of control believe their efforts and commitment can affect the external reality and their condition. Therefore, they take the responsibility to shape their future and are more confident and determined to gain control over the illness. Conversely, those attributing the cause of events to the external environment, luck, or chance, have an external locus of control (Ahola & Groop, 2013). Diabetes is a disease that can make people feel disempowered and not in complete control of their lives. A recurrent theme in the interviews was that emotional reactions are influenced by self-management success in reducing blood glucose fluctuations. Accordingly, failing to achieve these goals leads to feelings of frustration, tiredness, stress, and helplessness. Matt coherently expressed his emotional processes:

*I'm always stressed out. So, stress is something and uh I tend to over think about things. It also related to my diabetes...When a day is just bad, you have to relax and accept that: it's bad. It's gonna be better tomorrow. But I don't get to sometimes I cannot, you know, accept it. That is why I started to overthink like what I do wrong. What happened? Why is it like this day? So, you know, there is always something to think about, something that you know that needs to be done. I would say that is you know my general state of mind.*

Matt seemed involved in a deeply analytical process regarding his thoughts and behaviors to find the best way to control diabetes. Indeed, it was not straightforward to find answers and definitive solutions to relieve himself from his condition since many aspects are not under his

control. Ultimately, despite his trying to adopt a positive mindset and believing that the situation would improve, a sense of anxiety and frustration stemmed from his words. Acceptance of this situation is not easy, and the immediate response was to blame himself for doing the wrong things. Matt did not want to be overwhelmed by the illness and uses all his mental energy to cope with his condition. He was a person who wanted to leverage his internal locus of control to feel empowered and act to influence his health; however, this strong sense of self-responsibility led to him blaming himself in the case of negative outcomes.

Moreover, several lines of evidence suggest that one of the most recurrent emotional reactions is diabetes distress due to the enduring worries, fears, and burdens linked to the quotidian self-management of chronic disease (Kalra et al., 2018; Peel et al., 2004). Consequently, the pressure of the self-care regimen leads to individuals feeling overwhelmed, alone or ashamed, defeated, angry, frustrated, worried about caring appropriately, or unable or unmotivated to change (Polonsky, 1999). Most of these feelings identified in previous studies also arose in the interviewees' accounts. For example, Luisa could recall the feelings of frustration and lack of control that emerged when she first received her diagnosis:

*When I got the diagnosis, I felt like very weak. I didn't know what it was that I had. So, I was relieved actually that I have a diagnosis and that I can treat it, you know. I mean now sometimes I get frustrated because, as I said, I'm very organized and I have a lot of discipline...But sometimes there are so many factors that can change my blood sugar and sometimes you just don't know why. Then I have higher blood sugar and I feel bad, but I can't do anything about it. It's just frustrating at times when you do everything you can, at the best you can, and you still have, I wouldn't say bad blood sugar but in range blood sugar...Most of time I can control it, but sometimes something unexpected happens. Yeah, I think that's the only thing that I got frustrated sometimes.*

The sense of weakness that opened the paragraph also returned with the final words. Every effort to be organized and control blood sugar levels can be futile. Diabetes can suddenly flare and cause up and down in blood sugar levels. Luisa fought this battle with the desire to manage the situation as best as possible, but sometimes, she felt defeated and powerless. The final feeling of exasperation was a symbol of that. Fundamentally, managing diabetes involves several mechanisms, such as emotional regulation and physical and cognitive resources (Fisher et al., 2018). When blood sugar levels are not normal, it triggers a negative emotional response that leads to rumination and feeling paralyzed. Then, patients feel the toll of responsibility and are concerned about dealing with the unpredictable demands of diabetes daily. The burdensome daily self-care of diabetes can lead to strong emotional distress and burnout. The main cause of burnout is frustration associated with following stringent rules and doing everything well but still being unable to control diabetes (Hoover, 1983).

Claire also expressed similar feelings to the other participants about this aspect, especially "prostration and tiredness." Additionally, her celiac disease heightened other emotions, such as anger and hunger. These emotions were particularly apparent if she did not find the right food at a restaurant:

*If I had planned that my blood glucose levels would behave in some way and if they don't do so, I feel very frustrated because of that. Sometimes, I have to wake up in the night, maybe several times, to check my blood glucose...The tiredness comes from the blood glucose level itself...So, it feels like I'm really tired. I may feel that I failed, because I don't have enough body. Then I think the celiac disease affects my anger. I would say it goes, if I can't have or if they, if someplace they cut off gluten free food so I will get angry and hungry [Laugh].*

Claire also had to check her blood glucose levels during the night. This requirement undoubtedly impacts her quality of life since her sleeping times are affected by blood glucose fluctuations. She seemed to continuously face hypoglycemia distress, which was linked to moments of low confidence in her ability to tackle her hypoglycemic symptoms; these difficulties were amplified during the night. Furthermore, due to her celiac disease, she always needed to think thoroughly about what and where she could eat. Generally, those participants had to constantly make decisions, especially about their food choices, to maintain their blood sugar levels within range.

However, from the participants' words surface, many factors remained out of their control, and the best planning did not guarantee the desired outcome. On top of this, the unpredictable metabolic process of diabetes influences physical and emotional well-being. Therefore, these reactions drained energies and encouraged tiredness which also inhibited the practice of physical activity. Furthermore, celiac disease was another element that affected Claire's nutritional choices and social moments, especially when outside at a restaurant. Her anger and hungriness might arise since her basic needs, such as nutrition, were unmet. She seemed to revindicate the importance of considering that several people have unique needs and that external society had to be conscious of this. In fact, during the interview, she claimed that it was important to plan and select a place where she knew she could find appropriate food. This might have been her way of managing her needs and avoiding the disappointment of not finding the right food. Given these points, highlighting how her sense of humor leads to her emotional regulation was worthwhile. The laughs at the end of the final statement exemplified that. Feelings of frustration and anxiety emerged from Annie's words:

*I just think that why me! You know, I feel like that because I know people my age like cousins, you know, like family members, um they don't have anything like wrong with them...Why did I get diabetes?...It just gets you down because it's not, I don't know, it's just like something for life now. I can't get rid of it.*

Annie ruminated about her condition, comparing herself to her sister and other family members who did not have diabetes. She seemed to blame her genes since her parents had diabetes, a genetic disease. Furthermore, being Indian was another factor that may have increased the possibility of diabetes. Her statements pointed out some difficulty in accepting a chronic and life-long disease. She knew that there were no right answers to her questions. However, she honestly expressed her disappointment and delusion about being the victim of a genetic disease that ran in the family. From this account emerged some of the components of diabetes distress, such as powerlessness, that subsequently relate to a sense of helplessness. This feeling arose when people wanted to control their disease, but unfortunately, it remained predominantly uncontrollable. This emotional reaction was linked to a cognitive process that judged the behavioral conduct pointing to an inability to manage diabetes well and ruminating about future complications and the

implications of not having aligned blood glucose levels (Fisher et al., 2015). Annie knew she could not heal from diabetes, and improving her food choices would not relieve her from this condition. Overall, all the participants shared the same frustrations and concerns about constantly checking blood glucose levels and the worries surrounding the impact of food restrictions on their lives.

Diabetes is a disease that transforms and shapes people's lives, impacting their emotional reactions. Treatment issues (Decoster, 2003), namely monitoring blood glucose, are the factor that mostly arises as a negative impact on emotional reactions. Decoster (2003) has underlined that the most recurrent emotions, such as fear, anxiety, irritation, sadness, anger, happiness, and guilt, were affected by the amount of time a person has coped with diabetes, the presence of complications, and the personal evaluation of self-management success.

Interestingly, some participants linked happiness to the positive decision to change their dietary choice. This accords with the following observations, which showed how Annie found a way to look at her condition from a different perspective: "I try and look at the positive side. Then I think well it's good that I found out earlier, so now I can make a lifestyle change in my life. Otherwise, I would be eating more junk food..."

The onset of diabetes had been an input to change her lifestyle and to be more conscious of her food choices. Indeed, this was an incredible challenge for Annie, with both positive and negative aspects. Adopting a healthy diet was an important aim for everyone, but depending on taking tablets daily for life requires a substantial effort. She was aware of her emotional states, especially being anxious, but she activated a coping strategy, a form of self-help, through reading positive books. Also, Kate highlighted the different emotions she felt. For example, regarding managing diabetes, she defined the experience as "frustrating and annoying." Whereas, when she talked about her emotions in general in her life, she seemed like an explosion of different colors:

*The biggest emotions: joy, pride, proud of my daughter, husband, love to fight me quite a lot, now I love care people. I'm really curious about the world, I really enjoy. A lot of my emotions are trying to be out there. I got under a lot of pressure and stress. I try to look at the positive side. (Kate)*

She expressed how those emotions (joy, pride, love, and curiosity) supported her in being active in the world. Her words surfaced a sense of resilience that helped her face life's challenges. Despite those challenges, she maintained a positive attitude. For Matt, his emotional reactions were polarized between happy and sad moments:

*When something positive is happening it makes me a lot more emotional. So, even when, you know, something is beautiful I think I have that urge to cry a little bit because I'm just too happy. When it comes to sad emotions at this present moment, I feel like you know there is no room inside for those emotions and they just don't come up.*

It was interesting to notice that he was more aware of positive moments, and through the tears, he expressed those emotions. On the other hand, negative emotions were silent and did not have any form of expression. Matt and all the other participants seemed to be aware of their emotions. Therefore, those people have advanced emotional intelligence, namely the capacity to be aware, communicate and regulate their and others' emotions. Previous research has underlined that emotional intelligence might be a protective factor for both psychological and daily management of diabetes, including glycemic control, anxiety, and diabetes-related distress. People with diabetes can have effective strategies for coping with the disease daily (Pérez-Fernández et

al., 2021). Those accounts of different emotional reactions could be considered reflective experiences of the body-brain system interacting with one's internal and external reality (Cromby, 2007). The full meaning of how those people with diabetes feel and manage their condition is rarely transparent due to the consequential emotional struggles. Henceforth, it requires phenomenological interpretation from both the participants and the researcher.

### **Hope and a Vision for the Future**

It is relevant to consider the role of psychological characteristics such as optimism in people with a chronic disease's mental and physical functioning. This study's participants seemed to have a dispositional optimism; hence, they expected positive outcomes across their different life domains (Rasmussen et al., 2006). Research has underlined the role of expectations in behavioral responses to health threats. Being confident about the future was associated with using significant effort, even in the face of serious threats, while skepticism about the future leads to disengagement and less effort (Rasmussen et al., 2006). Ultimately, it is also important to note that genetics and personality traits influence being optimistic or pessimistic (Maltby et al., 2017). A relevant factor explored during the interviews was the role of hope in participants' lives.

A recurrent theme was a sense of trust in the progress of science and access to future health technology that would improve their condition. In participants' accounts about their future, the most recurring aspects were a good job, a family, and the hope that new treatment would be developed. This sense of hope fostered their ability to dream of a better future and have a life with more minor challenges. The following account expressed Matt's point of view about having hope:

*Just hope that, you know, everything is gonna work out eventually. So, because of the way that my mind works, because of all the decisions that I need to make and because decision making is not that easy for me. So, my biggest fear is that I would make a wrong decision. So, my hope is that, you know, most of my decisions will be good. You know, if they're bad ones that there not too bad and that they're not fixable.*

Hope acted as a form of encouragement for his future. Matt felt responsible for his choices and how they could give a specific direction to his life. He seemed scared that his decision-making ability might fail and hoped to be able to readjust the direction of his life if it started moving in the wrong direction. In literature, hope was defined as a person's expectation that goals could be achieved, and it was composed of two elements: agency and pathways. Agency related to the individual's determination to achieve past, present, and future goals. Comparatively, pathways related to an individual's belief that successful plans and strategies could be established to reach goals (Snyder et al., 1991). Matt seemed to have a clear vision of his present and future. He was very resolute in establishing what was important to him:

*I want to see myself healthy. Some people say that they want to be cured someday. I say that of course that is something that we will all like. But, you know, just thinking everyday about the cure prevent you from living your life today...I think it is more important, you know, to live it live it day by day, and you know do your best every day to stay healthy and to feel fine.*

Being healthy was incredibly important for Matt. He was committed to respecting the value of health through his daily choices. It was possible to notice a connection with what he said in the previous passage: the responsibility for his actions would influence his well-being. He was candid with himself and aware that, maybe in the future, his condition would improve; however, for now, he wanted to live in the present and use his energy to achieve a good balance. Hope seemed to boost Matt's ability to use his problem-solving skills better to face problems and challenges instead of assuming behaviors of denial and problem-avoiding. Luisa's words resonated with the same themes:

*I want a job and uh of course even better diabetes treatments...I think there will be more and more technology that you can have little better your life with it...I mean that's the most important thing, I guess. Yeah, if you don't have hope, you don't have anything basically.*

Due to new treatments, Luisa dreamt of her professional career and improving her condition. She was very realistic and acknowledges that using new technology would take time. However, she maintained a positive attitude and relies on a great sense of hope. It is worth noting that hope was an essential factor in the participants' lives. Presumably, their hope levels might change due to the chronic nature of diabetes and possible complications. However, a high level of hope can support them in coping with physical and psychological challenges, being more compliant with the treatment, improving their quality of life, and managing their situations better (Ghazavi et al., 2015). The following paragraph highlights Claire's point of view about her future and her emotional coping strategy:

*I see that my career will grow, and I hope that that I would have a great job. And I hope to have a detached house in some point of my life and a good husband...I hope that the this health technology it would be more accessible...But I think that hope means for me like, I like to say like Stephen Hawking said that "while there's life there's hope". If like, if you can manage your life, there's always hope that you can do everything or almost everything as normal people can...If you can live with your condition, so well I admit that it limits you a bit, but I don't think that it defines your life that you couldn't do something.*

Claire could envision her future, objectives, and aspirations vividly. A sense of hope and positivity pervaded her words. She knew what she aimed for, including her professional development, family aspirations, dream house, and access to new technology to improve her condition. Her quote from Stephen Hawking's words emphasized that she was like a warrior fighting a tough battle with a difficult enemy to defeat. But she did not want to surrender. She seemed committed to maintaining a good quality of life, and hope symbolized the power to defeat the illness. She honestly recognized some limitations to face; however, she viewed an opportunity to adjust her lifestyle and continue to realize her dreams. Also, Annie expressed her desire to realize her goals and have a family:

*I would like to be settled down. I would like to get married and then I would like to have a baby or try for a baby...Because I live alone, I have to do everything by myself. It would be nice if you have that partner who you're both doing things together. Or, you know, that you know you don't have to do everything by yourself.*

Annie pointed out how she perceived external pressure from her cultural environment as an encouragement to accomplish specific targets, such as marriage and having a baby. In addition, managing diabetes was a source of concern for her future choices. Having a family represented a symbol of stability due to the uncertainty of the disease. A partner was seen as someone to share this experience and rely on during daily activities. The following words clarified Annie's expectations and hope for the future:

*I still have that hope that there is someone there because I would like to think I'm a good person...I think someone whoever is right for me will love me for everything about me, even my diabetes...I have the hope that I can make my diabetes reduce my intake of sugar and get my results, and get fit, and be more active again. So, in that way I've got that hope still that I'm able to do it.*

Annie honestly unveiled her vulnerability. She highlighted that she deserved to find someone who loved and accepted her condition. Diabetes was an integral part of her life that may influence her relationship with a potential partner. Indeed, she looked forward to a better future when her health condition has improved. In the final sentence, she wanted to remind herself that she had the power to change the direction of her life.

Kate's perspective about the future differed from the other participants; specifically, she was more focused on the present since "it's too painful to go into the future." The future dimension contained something uncontrollable, and this might cause depressive symptoms:

*If you worry about future, you can get very depressed. I'm not thinking too much ahead. It is too painful, and it is too hard to think too far ahead because I don't know what is going on. If I stop and think about what might happen, it could be it will overwhelm me, and it will make me worried about stuff that I can't control...I do worry about getting ill, I worry about how easy it will be to manage it when I get older, but then I also think people manage diabetes 15 years ago in completely a different way. I also cope with 15 years child then we need to make things easier. There is no point to go too far ahead. The reality will change. (Kate)*

Kate was deeply anchored in the present, and it was not easy to envision the future. Many uncontrollable variables were a source of stress and anxiety. She wanted to impose self-discipline to stay focused on the present and defend herself from suffering. She was aware that her condition could change, and she was aware of how to manage it. Despite this, she seemed concerned about possibly losing control of the situation and being overwhelmed by the illness. However, a positive emotion, such as hope, fostered her capacity to fight every battle:

*It's really important when you don't have hope and that's when you feel very miserable and that's when depression is so terrible because it pulls away all that joy and all that hope...You can see that science and medicine were just changing rapidly in a sense that not now it didn't exist years ago so that's the benefit when you talk to them about how you have to manage it yeah...Generally what gives me hope: my daughter, she is making progress...I take I take every achievement that she does massively and take much courage from that.*

She trusted the progress of science and future discoveries in their abilities to help her control her condition. It is possible to see a parallel process between her improvement in managing her illness and her daughter's achievements in learning new things. Both fought for a good life despite their difficulties, but Kate wanted to leverage all her energy to win these battles. Lastly, it is essential to underline that a review study of previous research found a positive correlation between optimism and hope with improvement from a chronic condition. Despite this, it is impossible to generalize all chronic diseases since specific illnesses and individual factors play a pivotal role (Schiavon et al., 2017).

## **Discussion**

Diabetes is a chronic condition requiring ongoing medication treatment, healthy nutrition, being physically active, glucose monitoring, managing blood glucose fluctuations, coping with moments of distress, and professional and personal adaptation (Yi-Frazier et al., 2012). The current study investigated the role of positive emotions, namely hope, in supporting the psychological well-being of people who manage diabetes. The results of this study suggest that hope is a salient emotion in how people maintain a positive attitude toward the future, trust the possibility of improving their condition, realize their personal and professional aspirations, and maintain psychological well-being. Hope drives people's self-efficacy and compliance to continually engage in positive health actions, such as following the healthcare recommendations to achieve better glycemic control. This finding is consistent with that of Makarem (2016), who underlined that hope and other positive emotions are common in people with better illness self-management.

Furthermore, another study has demonstrated that hope can improve patient adherence and enhance self-efficacy (Makarem et al., 2014). Folkman and Moskowitz (2000) underlined that some people could experience positive emotions during acute or continuous stress. This is partly possible due to the activation of specific coping mechanisms, such as positive reappraisal, focusing on the good aspects of their life, and problem-focused coping, which triggers thoughts and behaviors to tackle distress and give positive meaning to challenging moments. This is what emerged from these research participants who actively manage unexpected glucose spikes enacting a series of behaviors such as taking medicine or eating something and trying to relax their minds accepting that this is a temporary event. The interviews suggested that a sense of self-responsibility toward managing a diabetes diagnosis, adopting a healthy lifestyle, and constantly monitoring blood glucose levels were essential to maintaining physical and psychological well-being. This supports previous studies that have demonstrated a positive correlation between trusting one's ability to obtain specific health outcomes and engagement in positive health behaviors (Makarem, 2016).

An interesting aspect that emerged from participants' accounts was a deep awareness of their emotional reactions to the constant burden of managing a chronic condition like diabetes. They recognized that diabetes influenced their emotional responses, especially when experienced

high or low blood glucose levels. In these moments, when they cannot predict the spikes in blood glucose, they felt frustrated, angry, and helpless. In addition, their attempts to control the spikes did not generate immediate results, which triggered negative emotions such as frustration, helplessness, and dismay.

Although unpredictable spikes are part of having diabetes, participants showed strong self-efficacy and beliefs in their capabilities to organize and execute specific actions to control the demands of the situation. This finding is supported by previous research that underlined how self-efficacy was predictive of self-care and enhancement of effective diabetes behaviors (Hurley & Shea, 1992). People can use coping skills such as planning and organization to manage their disease effectively. This self-efficacy can serve as a coping strategy to manage the negative emotional response when spikes happen and help people bounce back from the sense of failure since they focus on handling the situation rather than worrying about what can go wrong. People who manage diabetes, at a certain point, need to accept the unpredictability of that disease and recognize the limitation of their responsibility. They can do as much as possible when a spike happens but then know there is nothing more they can do and have to wait for a spike to pass now that they have taken all the necessary steps to manage it.

Overall, participants in this study consistently expressed that managing diabetes was part of their daily routine that required cognitive and behavioral skills and emotional regulation. They have spent a large part of their lives with diabetes and have subsequently adapted their lifestyle to manage this condition. A noteworthy aspect to underline is that they all expressed a positive vision of the future and maintained hope that their condition would improve. Hope mitigated the fatigue and distress caused by the daily management of diabetes by triggering perseverance and positive beliefs that their condition might heal in the future due to the intervention of new medical devices.

## **Limitations**

The findings of the present study should be considered in the context of its methodological limitations. The current analysis rests on a specific sample: the participants were young European adults who were highly educated; therefore, the results may not be able to be applied to the broader public with great confidence. Another important consideration is that subjects participated in this research voluntarily and were aware of the topic of interest. Therefore, demand characteristics may have influenced their decision process and response content, and participants willing to volunteer are arguably more inclined to talk about their emotions. On top of this, as a researcher, using qualitative methods carried an inherent potential for subjectivity and bias in the researcher's interpretation of the accounts. However, as discussed in the literature, language may construct rather than describe reality (Willig, 2013). Expressing emotions through words, rather than using quantitative affective scales, may also affect interpretations of the events.

## **Conclusion**

This study used narratives from a sample of people to explore the emotional and behavioral experience of managing diabetes over time. Specifically, emotional responses to the daily management of diabetes were examined to shed light on how people managing diabetes envision their future and how effectively they overcome the challenges of daily glucose spikes. Further qualitative and quantitative research must be conducted in this academic area to strengthen the quality of results and deeply capture the emotional experience of managing diabetes. In addition, it might be relevant to measure the variables of psychological well-being, depression level, and dispositional optimism to clarify whether dispositional optimism moderated the relationship

between psychological well-being and depression and provide additional context for the qualitative responses. Future research should investigate the effectiveness of interventions that bolster inner strengths and positive emotions among individuals with diabetes to clarify which behavioral and emotional mechanisms may facilitate a better quality of life and improve diabetes management. Research into positive emotions' role in adaptive function during stressful events is still in its infancy. Investigating the duration and intensity of positive emotions will clarify the use of adaptive processes during stressful events (Folkman & Moskowitz, 2000). To conclude, the present study contributed to the field's knowledge and understanding of the emotional responses of a sample of adults who have diabetes. In addition, it highlighted promising opportunities for future research on the role of positive emotions in managing diabetes effectively and preserving psychological well-being.

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