Swinging between control and contingency: embodied experiences of young adults with type 1 diabetes living in the Netherlands and England

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The lives of young people are filled with changes, challenges and diverse interests. So is the case of those young adults who, in addition, live with diabetes and deal with daily insulin injections, carbohydrate counting and sugar imbalances. Yet, their experiences with diabetes have not been taken into account sufficiently. Specifically, in spite of the idea that control plays an important role in patient education and the definition of treatment, people's experiences and perceptions of it have been generally overlooked. Control has been assumed to be a biochemical concept dissociated from people's lives.

With the present study, I propose a different perspective from which to look at control in diabetes, using as a framework the embodiment perspective. Explicitly, it aims at answering the following question: How do young adults with diabetes experience [lack of] control as an embodied phenomenon, in the different contexts of their everyday life? The study was conducted with a group of six young adults (21 to 27 years old) who had type-1 diabetes mellitus and were living in the Netherlands and England during the study period (half May to July 2007). I conducted in-depth interviews with all of them, sent additional questions by email to two and read the web blogs of other youth with diabetes.

From the participants' stories it became clear that being-in or out-of control exceeds the biomedical definition and comprises a broad range of experiences that must be accounted for. What people need or want to control has to do with, but surpasses metabolic control. Sugars are affected by a broad spectrum of things which themselves are not controllable. This instability greatly affects other spheres of life such as time, emotions, moods, other activities, future plans, social relations, practices and interaction, performance, and body projects. People claim for the restitution of a certain degree of control over them in order not to let diabetes rule. In short, diabetes control is not unique, nor stable. It is dynamic, multilayered, complex, constructed, achieved - or not- in a step-by-step process, in a daily struggle.
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Theses are well-known for being one of the biggest challenges in the lives of students. Having finished this Master’s thesis, I must recognize that my experience does not contradict such reputation. I invested almost the hundred percent of my time of the past six weeks (both being awake and asleep) struggling with ideas that did not seem to take the shape I wanted, fighting against a recurrent writer’s block that threatened me since the beginning, and working against the clock in order to meet a very tight deadline. My feelings towards my work varied enormously throughout the weeks. “The live of the thesis-writer is like an emotional rollercoaster”, one of my closest friends commented. I must certainly agree with her. However, functioning under pressure made me improve my creative skills while I figured out strategies to make the process less hard. But as with so many other “battles” in life, what really took me through those days was the support of my friends, colleagues and relatives. Learning to become an anthropologist, I was taught about reflexivity and transparency. Therefore, it is not possible for me to conclude this work without acknowledging other people’s contributions to it.

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 Cover picture taken by Marleen (participant’s pseudonym) during one of her training sessions.
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That’s one of my frustrations, the biggest one! Yeah, get your insulin, it’s right and that’s it. But they don’t understand all the things that come with that. I’m not saying it’s bad, it’s a tragedy, but it’s such a big challenge! With all the things I did in my life, this is the biggest challenge, still. And I think it’s ever gonna be... it’s the biggest challenge and it’s gonna stay for the rest of my life and people don’t understand that! They just see me as a normal person, they don’t see that I have diabetes, they don’t see everything that goes behind, in the backstage. (Sasha, 24)

During the days that preceded this project’s fieldwork, I devoted my time to contact participants. In the process of recruitment, I explained the purpose of the study and said that I was looking for young adults who had diabetes mellitus. Sometimes I went further and gave explanations about the differences between type 1 and type 2 diabetes and why I was interested in contacting such a specific group of people, who at first, seemed quite elusive. I remember very well one of the replies I got: “diabetes is not a disease of young people”, one man told me (he himself said he had diabetes, but was not young). At that time, I felt very upset by his answer. I was astonished by the idea that someone could deny so categorically what constitutes an everyday experience for so many people. Still, I took it as a ‘beginning-of-fieldwork anecdote’ that would arouse nothing but a grimace at the end of it. However, it was until I started talking to the participants, trying my best to understand how it was for them to live with diabetes that I realized that his reply and my reaction meant much more. Before fieldwork, I thought that I had considered diabetes as a complex and all-embracing experience. I was, beyond doubt being naive, since some of the assumptions I had and the man’s answer were very similar in a way: we both looked at young people’s lives and could not see the sorts of things that were going on backstage.

1 Participants’ names have been changed to protect their privacy, unless they explicitly asked me to do otherwise.
Type 1 Diabetes Mellitus: what is it then?

Type 1 diabetes is biomedically defined as a chronic condition in which the production of insulin is very little or completely absent (Sherwin 2004). This implies that the individual needs an external supply of it in order to prevent decompensation, future complications and death. The disease manifests itself very prematurely in life and people are most likely to experience symptoms in childhood or early adulthood.

One of the characteristics of the disease that plays a major role in patient education and the definition of treatment, is its association with a higher risk of cardiovascular and neurological complications. From the biomedical point of view, the treatment has been mainly aimed at preventing those complications while maintaining people's wellbeing in daily life. It has been established that this can be achieved by keeping the best glucose control possible. This implies daily insulin supply (in the form of injections or by a continuous delivery from an external device), self-monitoring of blood glucose levels, and the implementation of lifestyle changes (mainly referred to as diet and exercise) (idem.).

Is this as simple?

Apart from being demanding in terms of time consumption and self-discipline, some people may say that this treatment seems quite straightforward. However, 'best glucose control' has proved to be a difficult goal to meet and people's accounts have shown that the complete story is anything but simple (Bryden, Peveler et al. 2001; Clark 2003; Gale 2005). In fact, biomedical practitioners themselves have also recognized that following the recommended regime is not an easy thing to do (Juvenil Diabetes Research Foundation 2006).

In any case, the biomedical approach to the disease is just one way of looking at the broad panorama (Clark 2003:8). It provides an explanation based on abstract metabolic concepts that are understood apart from individual experiences. But, as Clark said (idem.), “diabetes as a human matter exists in context: in an individual patient, of a particular cultural and social milieu, in a particular family at a certain age”. This is also the case for young adults, whose life stage particularities confront them with changes and
challenges that might be perceived as overwhelming. In the European context, for example, young people in their twenties are usually either moving from home to the university or starting to work (Wolpert & Anderson 2001). They are confronted with several important changes that include acquiring independence, having different routines and schedules, living away from home, needing to care for themselves, dealing with academic and work related demands and stress, and taking important decisions in personal relationships (Goldman & Maclean 1998; Eaton, Williams et al. 2001; Wolpert & Anderson 2001).

Young adults with diabetes face all these changes which are common to most of their peers as well. Yet, they are faced with additional challenges related to their medical condition. Some authors have shown that some people constantly struggle to meet the treatment demands (Balfe 2007), feeling that it is difficult to balance the new tasks, responsibilities, and lifestyles with the expectations of what they are supposed to do. Alternatively, other authors as Eaton et al. (2001) have found that people’s experiences range from not being affected at all by the disease, to needing to make constant efforts to maintain adequate control. Researchers have found that young adults with diabetes can feel threatened, powerless and angry. They experience several fears, such as being different and rejected by their peers, the acute and long term complications of the disease, and the idea that diabetes can take control of their lives (Schur, Gamsu et al. 1999).

Therefore, by listening to people’s experiences it becomes clear that living a life with diabetes does not come effortless. In spite of this recognition, the message that health care professionals and mass media give to people with diabetes, is that these difficulties can be overcome without major suffering, that diabetes can be managed and kept in control, and that living with the disease is increasingly being simplified by scientific advances (El Tiempo 2006; Mayo Clinic Staff 2007).

The Focus

The emphasis that the biomedical discourse, people’s experiences, and popular media have placed on issues of control, suggests that exploring this concept in the life of young people with diabetes could be a very suitable
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gateway into the complexities within it. Nevertheless, the few studies that have approached young adults’ experiences with it (Hernandez 1996; Wdowik, Kendall et al. 1997; Goldman & Maclean 1998; Eaton, Williams et al. 2001; Balfe 2007), have been based on a biomedical definition of control. It has been assumed that control is solely a biochemical concept dissociated from people’s perceptions and life experiences. But, is it possible that people experience control differently? Can control be a more complex phenomenon? How to look at control without falling for the biomedical definition of it?

From this line of thought, one could argue that diabetes management is aimed at making people control a body that ranges from stable sugar levels, absence of symptoms and complications, to low or high sugars, a wide array of symptoms and the risk of complications. Taking this into consideration, I would like to propose the embodiment perspective (Csordas 1990) as a suitable framework from which to look at this issue. This means that the experience of diabetes involves more than glucose levels and metabolic concepts. If people are-in-the-world with a body that ranges from control to contingency, then the idea of control must involve other experiences of being-with-diabetes in daily life. Furthermore, people’s being-in-the-world takes place in diverse contexts that have different meanings, values, demands and needs.

Therefore, there is a need to explore and problematize a topic that has been univocally understood in a group of people whose experiences have been generally overlooked. This study was conducted with the idea that understanding is a necessary step in order to help dealing with and overcoming the daily challenges of being a young adult with diabetes. Furthermore, it has been carried on with the conviction that this understanding is crucial in the efforts to reduce the gap between biomedical foundations and people’s experiences and needs.

I began this project with the idea of focusing the blurry parts of the experience of being young and living with diabetes. It was conceived as a qualitative exploratory study, aimed at addressing the following question: how do young adults with diabetes experience [lack of] control as an embodied phenomenon, in the different contexts of their everyday life?
In the following pages I do not intend to portray a drama, or to present a final scene with a clear cut conclusion. I do not aspire to produce a finale that makes readers and actors feel that there cannot be any further lines to add. What I would like to do is to outline what happens prior to the opening. What happens before we, - the outsiders, the spectators- , are presented with the final work. Concluded pieces disguise the preparation as easy and make the struggle invisible. What I would like to show is the complexity that takes shape behind the scenes.
1. BUILDING UP THE STAGE

1.1. A different type of 'homeness'

In the following pages I will describe the process of preparation for fieldwork and how I went about it, including some reflections on the situations I encountered during that time. It is my intention to be as transparent as possible, as I think that not only the researcher ought to make the participants visible, but to make herself visible as well. Hopefully, this will contribute to a final product that has more than one voice (mine) or six voices (the number of people I talked to) (Schepér-Hughes 1992). The methodology I used was based almost exclusively on interviews, so I will try to provide an account that gives testimony of that dialogue and the reflections that proceeded. They did not take place exclusively during the conversations we engaged in, but kept going as I read other people’s diaries in the Internet, in my conversations with my supervisor and colleagues, during the inspiring hours I spent traveling around this small country - the Netherlands - to meet the participants, and the ones I spent writing this thesis (Pool 1994).

When I started this research, I had been living in Amsterdam for 8 months and a half, as an international student doing a Masters course in Medical Anthropology. While learning how to become an anthropologist, as a student, I was presented with several ethnographies in which renown anthropologists went to distant geographical places, learned to speak different languages and dealt with the difficulties of being a foreigner (mostly a 'white-Westerner' in a non-western country). I saw the nice pictures of them posing side by side with the 'natives' who looked so different from them. Undeniably, I found that difference charming, as well as traveling, being exposed, amazed and challenged by other people's way of living and understanding the world. At the same time, I was introduced to the work of others with experience in the so-called 'anthropology at home' (Peirano 1998; Reis 1998), to the epistemological questions it posed and the new and diverse challenges and advantages it entailed. Anthropology has increasingly been done by natives who become foreigners studying their own societies (Brunt 1974; Reis 1998; Zaman 2005). The relationships between insiders and outsiders have shifted.
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evidently and it is not surprising to find ‘non-western’ anthropologists doing research in the so called ‘West’.\(^2\)

Furthermore, with the constantly changing and globalized world, geographical boundaries have turned blurry and it has become problematic to talk in a simplistic way about marked cultural differences linked to geographical distances. The correlation between the spatial and the social has been questioned, and authors as Appadurai have called attention to the problem of understanding culture as being bounded to a territory, in a world that is increasingly deterritorialized (in Staring, Van der Land et al. 1997:12).

Taking all this into account, one could imagine that a Colombian medical anthropologist-to-be doing research in the Netherlands could not be by any means surprising. However, when I decided to stay in Europe to do fieldwork instead of going to my home country, I realized that regardless of these changes (Peirano 1998), certain assumptions concerning what is desirable in terms of who studies whom and where in anthropology, remain unchanged. Although this does not mean that my field of choice was considered generally wrong, in several occasions it was the object of some questioning. I remember one time when I was talking with a colleague about this project, and she asked me with surprise why I was not going home to do it (as she had done during her Master’s thesis). I found myself justifying my decision and saw with consternation that economic factors seemed to her the best explanation for it. Similarly, another person suggested that I should justify my choice to do fieldwork in the Netherlands on the basis of being pragmatic. I must recognize that one of the reasons to stay was merely practical. I was living here for a short period of time and wanted to make the most of it. But at the same time, I did not consider that the way I was addressing my topic demanded that I necessarily had to go to a different location. Clearly, staying in the Netherlands meant facing the problem of not speaking the language. That is why at first I considered focusing on the Spanish speaking community. However, the difficulties of finding enough people were bigger than the potential problems of interviewing Dutch youth in English.

\(^2\) Other ‘non-western’ Master’s students of the program have previously conducted research in the Netherlands. See (Olarte 2004; Correa Farias 2004)
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In the end, language played out differently from what I had first considered, as most of the people I interviewed were originally from other countries (4 out of six). I did not think about this possibility at the beginning of the study. However, this outcome reflects the interconnectedness of our world, indicates the political and economical forces that shape the lives of young adults nowadays, and the life choices of people with certain educational and socioeconomic backgrounds. Taking all this into account, this outcome should not be too surprising. On the contrary, it is in line with the idea that we need different ways of looking at and studying the globalized world, in which populations are highly mobile and social relations and culture are no longer tied to geography. Furthermore, having participants from different geographical origins did not constitute a problem for me. Taking into account that I was interested in exploring personal experiences and not the structural factors of living with diabetes, this fact needed to be accounted for, but not considered an obstacle in itself.

I do not mean to imply that my decision did not involve certain methodological considerations that I had to acknowledge. What I found quite troubling was the need to make justifications because of my country of origin, since anthropology has been done with the aid of translators from its birth, and the use of a second language did not pose more troubles than the need for translation in other fieldwork circumstances. Do we still find remarkable that a 'non-westerner' does research in a 'Western country'? Is it still difficult to consider the 'Westerners' as the 'Others', the 'natives'? On what basis are these assumptions being made?

As I mentioned before, my arrival to the ‘field’ took place when I was not even considering it a field in itself, nor had any structured plans of what my research was going to be about. During those months I had enough time to settle down, find my way around the city, get familiar with the transportation system and interact with the ‘locals’. Therefore, when I started thinking about the Netherlands as the field for my research, I had had time and experiences

3 The European Union has created policies aimed at making European Higher Education more compatible and uniform, encouraging European students to study abroad (European Commission 2007), and also has had a tradition of receiving foreign students. The Netherlands, for instance, has a high proportion of foreign student enrolled in a higher education (125 000 in 2006-2007, more than one fifth of the Dutch student population) (van Milternburg 2007), the UK has been known for receiving foreign students, and the number of international students has raised in Western Europe in the past years (Kuptsch 2003).
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that allowed me to find myself ‘at home’. I felt ‘at home’ even though I was clearly a foreigner and could not speak the language properly. But certainly, I must say that starting fieldwork did not feel like going to an unknown place. For me, I was staying home, and had ‘become native’ in a sense.

With this, I do not intend to disallow the influence that my nationality might have had during the research process. But I would like to stress the difficulties of considering the ‘local’ and the ‘external’, ‘here’ and ‘there’ as irreconcilable opposites. As Reis argued, in an interconnected world with “ongoing processes of cultural construction and constant change” (1998: 299), these distinctions might be more a mystification than anything else. It is not assumed anymore that sharing a space is enough to construct an identity, nor that identities are separate, distinctive, stable entities. On the contrary, they are multilayered, multiple and going through constant processes of construction (Staring, Van der Land et al. 1997). In that sense, as a young international student exploring the life experiences of other young adults, I had several things that made me feel identified and ‘at home’ around them. ‘At homeness’, as Reis (1998) proposed, is relative and transcends the geographical and cultural. Shared experiences, age and gender can make us feel more at home than what comes from sharing a nationality.

Whether my country of origin was important for my informants I cannot be sure of. I did not feel this was the case while I was talking to them, although there were some situations in which I felt very conscious of being Latin American. This was the case when they told me about their experiences traveling abroad to my continent. Then, it became clear that the ‘abroad’ they were talking about was closer to ‘my home’, which for them was somewhat nearer the ‘exotic’. However, I did not feel that this generated misunderstandings or misinterpretations between us. I was even surprised when Sarah asked me whether I was Dutch, which means she did not notice or even care about that piece of information about myself. I guess the constant ja in my conversation also revealed that parts of me had ‘become local’ as well.

There is a need to continue questioning the usefulness of those categories that no longer seem to apply to the world we are living in. I was indeed doing fieldwork in a foreign country. I was certainly not doing
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'anthropology at home'. But I do not think I can say that I was being a complete outsider either. Nowadays, when doing certain types of research, the idea of being ‘here’ and ‘there’ or being an ‘insider’ or ‘outsider’ is not that clear cut anymore. I clearly did not disguise my identity as ‘researcher’ and was very open from the beginning about the objectives of the research and my motivations to do it. However, I do think that sharing an identity as young adults gave us a common ground that helped us to connect to each other.

While I was doing the interviews, I did not feel that there was a major ‘cultural distance’ that I needed to overcome. However, I was indeed an outsider in a very important sense: I did not have diabetes. This created a distance that was not possible to surmount, and as Clark argued, was even "a kind of exoticism that matters greatly for both informant and researcher" (2003:150). Several of the participants made this clear during our interviews: "people who don't have diabetes can't understand you completely". I could do my best to try and understand how it was to be young and live with diabetes. While I was talking to them I looked every time for things in my life that could help me relate to what they were saying. They were all very helpful and patient with me trying to understand, even when they deeply felt I could not do it entirely. I'm very grateful with them for that. Nevertheless, I must agree with Sarah, who told me that we, as outsiders, can only sympathize. Becoming native in the world of illness is not possible.

1. 2. Wearing a different costume

The study of diabetes is constantly present in a medical student’s life. I learned about diabetes mellitus since the first years of medical school when I had not even met a real patient. As I grew up in the process of becoming a physician, I came to believe that as a general practitioner I knew what I needed to know about diabetes: its epidemiology, physiopathology, clinical presentation, diagnosis, treatment and prognosis. Everything was there, clear, in the Internal Medicine textbooks. I saw a reasonable number of people with diabetes (mostly type 2, though) and told them how to use insulin, why they should not be afraid of depending on it for living, and the type of adjustments they needed to do in their lifestyles. As if it was that simple. I even learned to
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tell people that the biggest problem with diabetes was its long term consequences. As if their present lives did not matter.

However, soon in my career I realized that playing that role and learning those lines was not what I wanted. I decided to make a turn and gladly handed in my white coat. When I decided to do this research I was more than convinced that there was more to diabetes than what I had first learned. However, I did not conceal my medical background. I think that being a doctor was definitely a leading factor in choosing the topic for this research. Regardless of being interested in other diverse topics in Medical Anthropology, this was somehow closer to where I came from, and to the reasons I had for moving away from the medical practice.

In spite of my deliberate withdrawal from the biomedical line of thought, I must recognize that I was struck with some of the things that the participants told me. I was impressed with how little of the whole story I had heard from my medical teachers. Everything my informants told me about sugars and symptoms made perfect sense in biochemical and physiological terms. But they were never mentioned in my textbooks or lectures. I even felt embarrassed of not having dared to question such an incomplete account at that time. Doing this research was like speeding up the process of [un] becoming a medical doctor. My supervisor was surprised of hearing me referring to ‘the doctors’ with such detachment. I cannot deny I felt that way as well. During these months and the past weeks, I think I learned a more comprehensive story about diabetes than during the 6 years I spent in medical school.

1.3. Contacting people: the Internet as a tool

Having chosen the Netherlands as my field, I started figuring out the best way to contact people. I guess the methods I used for that are also a reflection of who I am, which in turn determined the kind of people I was able to contact. The difficulties of finding enough people were present since the beginning. For the purpose of the study, I defined ‘young adults’ as the group of people whose age ranged between 18 and 32 years old. I included both women and men who had a diagnosis of type 1 diabetes, who were currently
on treatment and were willing to establish a conversation in English or Spanish.

The prevalence of type 1 diabetes is not very high (the worldwide prevalence in 2003 was 2%) and its incidence in the Netherlands is not very prominent either (12-16/100,000) (International Diabetes Federation 2003). Furthermore, previous studies had shown a low response rate for similar types of research in the UK (Miller-Hagan & Janas 2002; Balfe 2007). Additionally, I did not want to use any method that could pressure people to participate. Therefore, I opted for using flyers, emails and announcements in newspapers for this purpose. I had intended to continue the recruitment by snowballing, but in the end it was not necessary, as the limitations of time (fieldwork took place during 6 weeks) made it difficult to carry out in-depth interviews with more than six people. The original idea was to work exclusively in the Netherlands, but England came up as a good possibility as well, as I could speak the language, travel easily, and two English friends offered me their help and contacts.

I built up a website with information about the project and about myself (www.adrianadiazdelcastillo.com/diabetes) (see Annex 1), as a way of providing further information and encouraging people to participate. The Internet constituted the main source of communication with participants. Regardless of the rapid spread of Internet access and use around the world, it is still considered a non egalitarian technology correlated to socioeconomic status and income (Mann & Stewart 2000). Even within countries with high levels of access, the profile of users varies according to gender, age, ethnicity, level of education, etc.\footnote{The Netherlands has one of the highest percentages of household access and individual usage within Europe (Eurostat 2006)} I must recognize that contacting people through the Internet limited and characterized the group of people I was able to reach. Those with access to and - even more important - , those who felt comfortable enough communicating through and using the Internet had a biggest chance of being recruited.

The Internet was also a good source of first hand information. By searching the web I found a blog\footnote{A blog is a website where entries are written in chronological order and displayed in reverse chronological order. Blogs provide commentary or news on a particular subject and some function as more personal online diaries. A typical blog combines text, images, and links to other blogs, web pages, and other media related to its topic. The ability for readers to leave comments is also a defining feature of blogging.} administered by Sasha,\footnote{Sasha is a young Russian woman who blogs about diabetes and related issues.} a young Russian
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woman who happened to live in the Netherlands and who wrote about her experiences with diabetes. Being able to read hers and other people's blogs was very useful during the process of preparation for and during fieldwork. It helped me to gain insight into some of their experiences and challenges and sensitized me to the issues that they consider more important. Because I was interested in grasping people's everyday experiences, online diaries constituted an exceptional access to their daily lives.

Reading others' personal web pages can pose important ethical questions. Nevertheless, ethical guidelines concerning online research are still unclear (Mann & Stewart 2000). Several authors have made attempts to clarify certain issues specific to this type of research, especially regarding privacy and confidentiality. Blogs are open access web pages and the authors know that the information posted on them is public. However, most of the ones I read were clearly directed to the diabetic community or people somehow involved with it. Paccagnella, (1997) who wrote about ethnographic research on virtual communities, argued (referring to those communities specifically) that posted messages constitute public acts intended for public consumption. By this, he does not imply that they can be used without restriction but that they need no additional precautions apart from those taken for research of everyday life. Taking into account that the use of blogs in the context of my research was mainly informative and that I did not intend to reproduce or quote any of that material, I did not consider necessary to request the authors' permission to read the blogs (except for Sasha, who became a participant in the study and explicitly authorized me to use the content of her blog for research purposes).

1.4. Getting to know the participants

When I started fieldwork on half May 2007, six people had contacted me by email expressing their willingness to participate and be interviewed. I conducted the interviews during a period of six weeks and did follow-ups with three of them. Participants constituted a very particular group of people, given

comments in an interactive format is an important part of many blogs. Access to blogs is non-restricted although some administrators moderate the comments people can post. (http://en.wikipedia.org/wiki/Blog)

6 This name corresponds to the author's nickname. She explicitly asked to be named like this.
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that 4 out of 6 had left their countries of origin, all of them had traveled around Europe and other countries several times, and had achieved high educational levels. Consequently, this sample is not representative of other young adults with diabetes, both because of its size and the type of people included.

I agreed with the participants on the date and place for our first meeting. All of them went for the public, choosing a café, restaurant or university. Interviewing in public places can be challenging in several ways, not only for strictly technical issues like audio recording, but also because some places might not be very suitable for intimate conversations. However, I insisted on them choosing the location because I wanted to talk in an environment that was comfortable for them and where they could feel at ease.

Later on, this fact made me realize that interviewing people who as me, were young adults, influenced the type of interaction we were going to have with each other in many levels, and the places we preferred for social meetings was one of them. Thus, going somewhere other than their home seemed as taken for granted. The type of information I could obtain from meeting in a café was certainly different from the one I could have gathered if we had met at their homes. However, as I was interested in understanding life with diabetes in the different contexts it takes place, meeting in a somewhat 'regular' social situation provided me with good insights as well. I recorded all the interviews with the previous consent of participants, who signed a form at the beginning of each meeting.

Scheduling the follow-up interviews was somewhat more difficult to do than the first ones. It required more flexibility both in terms of timing and method. Because of time constraints, one of the participants (Mara) and I, agreed to meet by Internet using MSN Messenger to have a voice conversation. Because we had already met and built a good rapport, this method was indeed practical and allowed us to talk again for around an hour and a half. With three others (Rick, Sasha and Marleen), meeting was difficult as well. Sasha's life became busier because she started a new treatment (an insulin pump\footnote{An insulin pump is an external device that delivers insulin 24 hrs a day through a catheter placed on the skin. As opposed to the "traditional" treatment with the pen, insulin is} ). We scheduled a second interview but she had to cancel it

\footnote{\text{MSN messenger is an instant messaging software that supports voice conversations (Wikipedia : \url{http://en.wikipedia.org/wiki/MSN_messanger})}}
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because the new device was causing her sugars imbalances and annoying symptoms. Although she did not have enough energy for a meeting, she was still interested and willing to continue helping me. Because writing about diabetes was one of her skills, we agreed on being flexible and tried an alternative research method using the email as a tool. I emailed her my questions and she provided me with detailed answers, to which I replied with further questions. After having this experience with her, I decided to email Rick with a couple of questions as well, to which he sent immediate comprehensive replies.

Sasha told me she actually preferred this type of 'interview', as it gave her more time to think about the answers. I did not consider this a disadvantage because as Pool (1994:26), I do not assume that the information pre-exists inside the informant's head, waiting to be 'extracted' by the researcher. Using email as a research tool is not a new method at all, and the fact that people can take time to think about the answers has been considered an advantage (Mann & Stewart 2000). I do consider that the information you can obtain by personal interviews is much richer, and emailing someone does not replace personal interaction. The type of information you can get is limited and so it is the kind of probing you are able to do. However, having had the chance to meet and interview them in person before, and given the difficulties to meet them again during the scarce weeks I had destined for fieldwork, I consider this as a valuable resource that should not be ruled out. Furthermore, the fact that someone preferred this type of interaction is in accordance with the fact that gradually, patients are becoming interested in writing their own stories and speaking up (Frank 1995).

It is worth mentioning that one of the interviews I conducted was different from the others in several aspects. Chilab and I knew each other from before, around four years ago when were both living in Colombia. Moreover, he is a medical doctor who knew me as a doctor as well. I knew that he had diabetes since then, and it was a regular thing for me to see him injecting insulin when we went out for drinks or food. Yet, at the same time,
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the kind of things I knew about his life with diabetes were rather scattered, second hand bits and pieces of information. I decided to interview him because he had been living in England for the past two years. I was aware that our previous relation and the fact that we still have friends in common would influence the kind of conversation we could have. Nevertheless, knowing each other made it easier to meet through Internet, using Skype.\(^9\) However, I was not sure how willing he would be to share very personal things with someone he knew and could continue meeting in social circumstances in the future. Besides, because of his biomedical background and the fact that he does research in basic sciences, he might have had different expectations about the type of conversation we were going to have. However, I consider that it was helpful that we had not talked about diabetes before as friends, so the topic was new in our relationship. Furthermore, being able to speak in our native language was, without a doubt, another particularity of this interview. I felt we did not just speak the same language, but spoke using very similar terms and references.

Likewise, it must be acknowledged that the methodology I was able to employ during the short period of fieldwork provided specific types of data. Having only six weeks implied that I had to make choices regarding the methods that were more suitable for the group of people I was working with. Participants are busy adults who work or study and have additional activities at the same time. This implied that given the short interaction we were able to have, the chance to ask additional things from them was limited (i.e. spending an entire day with them to perform observations). Interviews constituted a very good source of information, but at the same time they did not provide the kind of data that can be gathered with other types of interaction. In this case, for instance, I could not observe people's treatment practices in different contexts, medical consultations, their preparation to go out or how they deal with daily difficulties.

\(^9\) Skype is a peer-to-peer Internet telephony network that allows users to make calls, video conferences, send files, etc. to the contacts in one's directory. The service is provided for free or for a low price. (Wikipedia [http://en.wikipedia.org/wiki/Skype](http://en.wikipedia.org/wiki/Skype)).
Since the beginning of fieldwork I felt very committed to the participants. All of them were interested in receiving copies of the entire document and were invited to provide feedback as a means to increase the validity of the study. However, due to time constraints, their comments could not be included in the present but will make part of a following version of this document. Having said this, I must make clear that I do not imply that this text is going to represent their stories as if there was a unique and graspable version of the 'truth' about them. I would like to follow Fabian (1990:755) when he argued that "the Other is never simply given, never just found or encountered but made".

What I present here is the product of interpretation, reflection, and the dialogue that was established. It is the product of what we created together. They decided what to tell and how to tell it, probably having made certain assumptions about the research and myself. I am sure that the moment in which we talked determined the content of our conversations: how they felt about their diabetes that particular day, how it had been for the past days or weeks, and even their sugar levels during our conversation could have played a role in what they said. In turn, I posed the questions based on several theoretical and personal assumptions about diabetes, reacted to their answers, answered their questions and told them about myself as well. The influence that all these had on their answers and on what I can tell about them must not be overlooked (Pool 1994).

It might seem commonplace to say that young people’s lives are very dissimilar and having diabetes is an entire individual experience. However, after listening to these women’s and men’s accounts, I was struck by the way in which their stories both differed from and resembled each other, and by the extent to which those nuances shaped their perceptions of diabetes, what they considered acceptable or not, and their priorities regarding control. This is why I consider important to give them a voice but also a face and a place in this paper. However, I do not intend to provide a complete description of who they are or of their lives. I will include stories of the six of them (interspersed inside the following sections) as an illustration of the different spheres of control,
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highlighting what impressed me most about them and what I consider more relevant for the analysis.
3. THE COMPLEXITY BACKSTAGE

3.1 Reading the script

I would like to begin these sections by looking at what seems to be the parameter that has dominated the discourse on diabetes control: the biomedical understanding of it.

The biomedical paradigm

The rule of thumb is: food makes blood glucose levels rise; exercise and insulin make blood glucose levels fall. (Juvenile Diabetes Research Foundation)

I do not mean to imply that doctors do not acknowledge the difficulties behind diabetes management, nor that biomedically speaking the disease is simple. Medical experts on diabetes have made calls to recognize the difficulties involved in following the regimen, the non-medical factors that play an essential role in dealing with it, and the differences between people’s and doctor’s priorities. Some authors are explicitly aware of the particularities of young people’s lives and the need to find new paradigms that can prove to be more helpful for them (Newton, Connacher et al. 2000; Wolpert & Anderson 2001; Gale 2005). However, during the interviews I found that the gap between theory and practice, patients and practitioners, textbooks and everyday life seems to surpass the majority of those attempts.

What do medical textbooks say about diabetes? What kind of information is available for an average doctor to learn from?

Diabetes management has been generally defined as “the constant balancing of diet, exercise and medication to maintain blood glucose levels as close to normal as possible” (Juvenile Diabetes Research Foundation 2006). It is said that a health care team must work together with the patient to achieve the glucose targets aimed at reducing long term complications (Larsen, Kronenberg et al. 2003). The patient is expected to learn to administer insulin and adjust the doses to food consumption and physical activity, balance energy intake and expenditure, learn and practice dietary restrictions, master the appropriate carbohydrate consumption and avoid overcompensation.
during lows, recognize symptoms of hypoglycaemia and deal with them, know about acute and long term complications, and have regular check-ups with different specialists (Sherwin 2004).

At the same time, the importance of self-monitoring of blood glucose is strongly emphasized, which “actively involves the patient in the treatment and provides him [or her] with the tools to assist in managing their disease” (idem.). It is recommended that the patient should be encouraged to monitor before each meal, at bedtime, before, after and during physical activity, and whenever symptoms occur. "The success of insulin therapy depends on the frequency with which the patient performs self-monitoring" (idem.). All this is achieved by the use of glucose meters, which, it is said, have been designed to be comfortable, portable, easy to use and to provide less painful blood sampling. Similarly, lifestyle changes are intended to "facilitate insulin treatment and optimize health" (idem.). The Cecil Textbook of Medicine (idem.) stated that when patients are sufficiently motivated and properly managed, they should be able to eat the types of food they like and fully engage in exercise practices.

Textbooks highlight the complications of insulin therapy, two of which are hypoglycaemia and weight gain (Larsen, Kronenberg et al. 2003). William’s textbook of Endocrinology (idem.) said that the risk of the former can be reduced when patients learn to recognize symptoms early enough and how to manage them. The latter is said to be common, but the book does not provide any strategies to deal with it.

Both William’s textbook of Endocrinology and the Cecil Textbook of Medicine (Larsen, Kronenberg et al. 2003; Sherwin 2004) acknowledged that diabetes management is complex and should be adjusted to inter and intra patient differences. They stated that a treatment plan must be attuned to “life patterns, age, work and school schedules, psychosocial needs, educational level, and motivation of each individual patient”. However, it seems that a couple of lines in a book chapter are not enough to teach doctors how to deal with and think about those differences. The chapters on diabetes do not leave any space to learn about patients’ priorities or from patients’ experiences. When I practiced clinical medicine myself, I was fully aware that each patient attended the medical visit with a different baggage to deal with, and that I had
to acknowledge the 'psychosocial' aspects of illness. However, I was not taught about the extent that the complexities of the concept entailed. What was stressed during my medical education was how to deal with the complexities of those things that were easier to look at, listen to, touch or measure.

3.2. Pulling back the curtains

I feel a lot of pressure when I read these things because it's always 'you have [her emphasis] to do this'. I have this image when I get this sort of advice: this good diabetic that does all these things and follows all the advice, which I used to be, and then the bad diabetic, that doesn't follow all the guidelines precisely, doesn't feel in her blood sugar diary and doesn't take note of everything. I feel that there's a lot to ask of me. Maybe I shouldn't feel that pressure, just take it as constructive criticism and advice... But as I grew up and became more independent I didn't want those restrictions on me. I felt I had a lot of things to do and it's a hassle, a lot of hassle to constantly think about what your blood sugar is and how it might be if you eat this, or do this or if I eat this or go out for a walk or went out with my friends to a night club. It is hard; I do feel a lot of pressure... I know what to do, and I know in a sense it's just to help, but at the same time I'm 'you just don't understand'. Because I don't have that much time to devote to my condition. I want to live life. That's what I'm here for. I'm not here to be the perfect patient. Sorry doctor. That's how I feel about it

(Sarah, 21)

People with diabetes talk about control as well. In their accounts, participants very often referred to it in the same way a doctor would do. They talked about numbers - 'good' and 'bad' numbers-, blood sugars, measurements, carbohydrates count, insulin doses, and symptom recognition. They knew perfectly well the things they had to do and why they had to do them. But they talked about other things as well. They talked about such things as traveling, going out with friends, drinking beer and smoking, dancing, working, giving lessons, commuting, driving, watching movies, eating cakes and cookies, meeting people and worrying about weight. They talked about having fun and feeling happy, strong and proud. But they also mentioned that they felt scared, embarrassed, stressed, frustrated, depressed, and annoyed.
This is part of the difference. Even though the biomedical approach to control is continuously present in what people say and want, this is not where the story ends. There is much more in life than managing diabetes or having a body that needs an external supply of insulin to 'function properly'. But again, this is not that simple either. Just as daily life is inseparable from the fact that we experience and manage our own and others' bodies (when we sleep, eat, groom, have sex, work, travel, etc) (Turner 1989; Shilling 1993), diabetes does not exist in isolation. I would want to argue that when our bodies do not function well, as in the case of diabetes, social relations, encounters and the social self are disturbed. If the body is perceived as being-out-of-control or needing-to-be controlled, the other situations that are influenced by our embodiment must be affected as well. To better understand this, I used the paradigm of embodiment as part of the framework that guided my thoughts and analysis.

Thomas Csordas (1990) argued that the body is above all an experiencing agent instead of an object, and it should be recognized in its experiential terms. Our bodies are not objects to us, but an integral part of our beings. He used Merleau-Ponty's concept of being-in-the-world as it precisely lends itself to speak in terms of existence and lived experiences and challenges the dualism mentality. The body is in the world from the onset, is pre-objective and constitutes the terrain of all our perceptual processes. In other words, our body is 'the living centre of all our being and acting in the world. Through our bodies we are engaged in the world prior to reflection; and all consciousness and action ultimately derive from this bodily and pre-reflexive inhering in the world' (Gammeltoft 1999:8).

The term embodiment finds itself in opposition to the material-biological body, closer to our experience, and defined by "our perceptual experience and mode of presence and engagement in the world" (Csordas 1994:12). In short, we exist as embodied human beings and our experience of life is mediated through our bodies. Csordas stated that embodiment is the "existential ground
of culture" and argued in favor of using it as a starting point to rethink culture and self (1990:6; 1994:39).

Moreover, as Shilling (1993) and Turner (1989) said, our bodies are the most concrete feature of our selves and necessary for locating ourselves in society. Our embodiment is essential for establishing and maintaining social relations. Goffman (in Shilling 1993) argued that our bodies are central for the basics of social interaction and the structuring of encounters. Our physical appearance, movements, and bodily practices and language let us play specific roles in society and interact with each other.

Similarly, Scheper-Hughes' and Lock's (1987) concept of 'the three bodies' can be particularly useful for understanding the experiences of [lack of] control of young adults with diabetes. The authors stepped further from phenomenology by acknowledging the social and political dimensions of embodiment. They highlighted the constant overlap and exchange of symbols and meanings among the three bodies,11 and suggested the role of emotions in linking them.12 As they argued, the individual body constitutes "the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle" (1987:31). In the context of this research, this approach can be used as a tool to look at those experiences from the individual perspective, and by the way they unfold in and are affected by the young adults' social environments, identities, and relations.

In the following sections I would like to present the other side of the story. Those events that tend to take place backstage and are easily overlooked by the outsiders.

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11 The individual (the body as self), the social (the body as a symbol for nature, society and culture) and the body politic (the regulation, surveillance and control of bodies) (1987)

12 The usefulness of these concepts for the study of societies, culture and health-related issues is exemplified in Scheper-Hughes' own book "Death without weeping" (1992) and in Tine Gammeltoft's "Women's bodies, women's worries" (1999). By presenting women's daily lives in two different contexts (Brazil and Vietnam respectively) and focusing in two types of health issues (child death and family planning), the two authors clearly show how social conditions and politics unfold into individual bodies, and how those same bodies act upon their social and political contexts.
Sasha is a 24 year-old Russian woman who came to Europe at the age of 16 to pursue her undergraduate studies. At that time, she had been diagnosed with diabetes for seven years. The decision to leave her parents’ home at a young age was originated in a strong determination to live on her own and make the best out of life. She attributed this motivation to diabetes, which she said, makes her strive more and be more determined and organized. She considered that this major change started her real relation with the condition, as she had to learn self discipline and deal with the emotional issues on her own, away from the support of her family. However, she described her student years as smooth in terms of diabetes and associated with positive emotions, traveling, partying and having new experiences.

Sasha described herself as a person that needs to be active all the time, stubborn; someone who lives life at a very fast pace and likes being analytical, critical and over organized. I found her very strict and disciplined with her diabetes management, keeping schedules and controlling her meals, recording her sugar levels, carbohydrate consumption, insulin doses, moods and exercise on a daily basis.

Talking to her was very pleasant as she is very open about her diabetes, enjoys talking about it non-stop and writing about her own experiences in a blog has made her reflect on several issues. Her narrative flowed easily, it was clear and detailed, embellished with some very nice metaphors. Diabetes is a spoiled child, she told me. At the time we met she had been having very tough times with diabetes during the past months. Her life was being constantly interrupted: her sugars were ranging between extreme levels several times in a day and she needed to wake up at 3 in the morning to test her blood sugars, deal with all the symptoms that came with the unstable glucose, and struggle with a health care team that she felt was not listening to her properly. In spite of being so active, she had decided to reduce her working hours in order to devote more time to try to fix her health. However, despite her efforts, she had not been able to sort it out. Therefore, her account was imbued with strong feelings of frustration, anger and sadness.
A Typical Day

I asked Sasha about a typical day for her:

In the morning it starts when I wake up. I take my blood sugar. I see what the numbers are. I take the insulin correctly, straight away. Then I go to rest, so I always wait like half an hour before I take breakfast because of the highs. And I eat breakfast. Breakfast is always the same, always the same, already for half a year. In terms of, the same exact food, the same exact amount. Because that makes my life much more easier. ... And then, usually, if I have time, if I don’t have time I don’t, but if I have time I check 2 hours after the meal, to see if it’s going down. If not, I take some extra insulin, and maybe, if I don’t check 2 hours after, I check before lunch, or something. So, to see how much I need to take for the food, and then I usually check after work or before dinner or something like that... Lunch is always at 12, so that is also quite scheduled, stable. Lunch is also quite the same at least in the food, the amount or something like that. And dinner, I also have it always probably at the same time, at half past 7. There are also a number of dishes that I’m always repeating through a week or two. So it’s always kind of I know how much I need for that, how much I need for that and so on, and so on. In that part it is quite easy, you get to learn basically every food you eat, how much you need, or if you shouldn’t eat that at all [laughs].

Deciphering numbers

From the previous account, measuring blood sugars stands out as an essential activity, one that Sasha performs along the whole day. This is true for some other people with diabetes as well. Some of the other participants test even more times than Sasha. Others forget to, or prefer not to do it that often. In any case, looking or thinking about numbers is an ordinary activity in a life with diabetes. But, what is the meaning behind the numbers? What are the implications of reading a 10 instead of a 6\textsuperscript{13}?

Most of my informants coincided in saying that they measure to see how things are and to know how well they are doing. Numbers are seen as a reflection of good control and as a guide to know what to do. Mara, for example, told me that numbers are the first thing she thinks about, automatically, as a practical matter. In general, by looking at them it is possible to know how much insulin to inject and act on time, controlling for symptoms before they appear. At the same time, they help confirming certain feelings (when it is not clear how low or high sugars are), or identifying hypos when people are not recognizing them early enough.

\textsuperscript{13} Blood glucose is measured either in mmoi/L or mg/dl. The biomedical goal with intensive therapy ranges between 4 - 6mg/dL or 70 - 120 mg/dl (pre-meal) (Cecil Textbook of Medicine)
Textbooks say that morning testing is crucial, because a failure to control morning sugars implies the maintenance of high glucose levels for the rest of the day (Sherwin 2004). This is also true in non biochemical terms. As Sasha told me, the first numbers she sees on the screen have a potent psychological effect. They determine her moods, her emotions, the kind of things she is going to be able to do for that point onwards, the type of actions she has to take, and even her willingness to get out of bed. Therefore, it seems that glucose metabolism takes control over the rest of the activities of the day. Changes have to be made and plans might be postponed. By checking the morning sugars, people try to regain a certain sense of control through the reduction of uncertainty.

Likewise, because numbers are a reflection of how well managed diabetes is, they are useful to control the risk of complications as well. 'Good numbers' make people feel proud, safe, relieved. On the other hand, they can be a powerful source of stress when they are higher than the expected. 'Bad numbers' produce fear, stress, frustration, annoyance. Feelings that can be difficult to deal with and that can ruin an entire day:

...There is when your whole day is screwed. Such a little thing can ruin everything easily. Emotionally speaking. Because you don't know what you are doing wrong. And then you start thinking: okay, in 10 years..not not even 10 years. Three or 4 years. In 4 years, am I going to be blind? In 4 years, am I going to have kidneys? (Chilia, 27)

One of the biggest problems that participants find in numbers is that they can be difficult to understand. Sometimes there is no possible explanation for a high or low number. A person can do everything by the book, follow all the recommendations, eat the exact type and amount of food, use the exact dose of insulin and do the same thing as the day before, when the glucose was on 6. But then, the meter shows a 20, the symptoms of hyperglycaemia start appearing and the emotional cascade develops. Numbers are not stable, as people's lives are not stable either. They change all the time according to all sorts of situations, such as watching a funny movie, having too much stress at work or sunbathing.

In this context, "maintaining blood glucose levels as close to normal as possible" is not anymore the rational, obvious, desirable, 'evidence-based'
A Typical Day

recommendation that can be read in a book. In fact, it can become an impossible target that generates frustration, as it seems incompatible with the rest of everyday life's demands. Most of the participants had strong feelings about the established standard of 'as optimal as possible'. Even though they were doing their best to maintain a stable glucose average within a desired range, at the same time they were very much aware of its unfeasibility. In turn, this contributed to their frustration to a great extent: "for me, perfect control would be to be able to have my sugars in the correct levels, the normal ones, for as long as possible. But the thing is that I've learned that is a utopia. It is something you have to learn and that frustrates you as well", Mara told me. Similarly, Chiliab argued: "the medical literature and doctors don't have any idea about glicaeic control. The guidelines they provide are not realistic! I'm not saying that they lied to me. But they didn't tell me the truth! They don't explain that blood measurements are basically a goal. They tell you that glucose needs to be below 120, but they never tell you that eventually it can be higher and that is not wrong! And then, as a patient, you feel that you are failing."

But having the 'perfect' number is very important indeed. Some people try everything they can to keep a good glucose average, sometimes with undesirable consequences. For instance, they inject more insulin than they need; in turn, they have to deal with constant hypoglycaemias and be busy compensating for them. Still, some of the participants said they knew that 'average' can be a deceitful concept that does not tell the whole truth about what is going on.

Similarly, 'good' and 'bad' numbers are not straightforward in everyday life. A good number is determined by what biomedicine establishes. But it is also defined according to situations and their particular needs. The kind of thinking and preparation required for a day at home, a busy day at work, a hiking trip or a good night of sleep, are different. Some people choose to have a slightly higher number because it allows them to perform well in certain situations (i.e. driving a long distance or meeting some friends after riding a bike) without risking a low. Marleen for example, has learned to compromise a perfect number in order to be able to perform well at what she loves most (dancing). Because dancing requires so much concentration and physical
skills, her performance can be greatly affected if her sugars are not under control. She explained that if you perform as a dancer, it can be desirable to have your blood glucose in 10 before going out on stage. That way, you can assure it is not going to get too high or too low during the show. Similarly, being low during a training session can be risky for her and for others, and needing to stop frequently to test make her lose steps, get cold and lack the required concentration. However, for her, dealing with this does not mean 'optimal control' as it would be understood by a doctor. She tests her blood sugar constantly to check if she has the 'adequate' numbers, which are those that allow her to exercise without having any interrupting symptoms. As she understands it, control is more related to being able to test and act in consequence, instead of having optimal numbers. Marleen knows that a strict doctor would not be happy with her glucose average. But she has accepted this and is fine with it. By doing that, she is not controlling diabetes strictly, but she is doing something as important: controlling her performance and life projects.

Following a routine

What participants told me about routines was difficult to put together at first. While some of them were in favor of keeping strict schedules, or at least trying to, others rejected them completely and even felt rebellious about them. The spectrum was ample.

In the first case, keeping a routine as strict as possible is perceived as a strategy to make life easier. It reduces the uncertainty of not knowing how the sugars are going to react to a specific activity or a new type of food. Therefore, it contributes to the control of symptoms and the interruptions they cause and the emotions linked to obtaining an undesirable number in the meter. By doing that, the rest of life appears to run smoothly and it is possible to follow plans without major interruptions. As Schur et al. (1999:229) argued, control in diabetes is related to taking the necessary steps to practically manage the disease, keeping it in place and making possible to go on with the rest of life. Conversely, as Sasha pointed out, when you do not keep the schedules you feel diabetes takes control of the situation because you cannot anticipate what might happen and then be ready to act in response. Therefore, for her, control is very much related to the ability to predict. Routines are not easy to keep,
A Typical Day

though. This is so in all sorts of daily situations, like having a very busy day, being on holidays or away from home, sharing a day with a group of people with different schedules, or living in a less structured environment.

On the other hand, following a schedule can be experienced like living under a military regime, as Mara jokingly said. People have different preferences in terms of how they want to live their lives, and that is not an exception when they have diabetes. Rick told me that he prefers spontaneity and flexibility, to eat whenever he feels hungry or spend the night away from home without extra planning. For some, keeping a schedule is unnecessary, or perhaps a goal that takes time to be achieved and is more suitable for a different life stage. By not following a strict schedule, people are able to feel in control over the rest of activities of life, those that are not diabetes-related and that are equally or more important. This is consistent with what Balfe (2007:143) reported in his study with college students. Using the example of a participant that did not follow the dietary restrictions strictly, he argued that refusing to engage in disciplinary activities is a way of feeling “in control of, rather than controlled by, the condition”.

These perspectives on following a regimen are in accordance with what Arthur Frank called the problems of embodiment (1995). He argued that “being a body always involves certain problems”, especially when confronted with illness (1995:28). He delineated control as one of those problems and defined it as the capacity to predict our body’s performance (1991:51). There is always a great degree of contingency in life. During illness people live their bodies within a continuum that ranges from predictability to contingency. Living with an illness implies that people need to learn to live with lost control. Frank proposed three other dimensions of being-bodies. These four dimensions generate certain types of bodies which Frank emphasized are not linear or fixed, but a wide array of possible associations from which people make choices in different points of their lives. The disciplined body tries to

14 : 1. Body-relatedness, which implies the ability to associate to one’s own body: Do I have a body or am I a body? 2). Other-relatedness: concerned with relationships between bodies; what does one’s corporality mean to others who are bodies as well? How does one relate to and affect them? 3) Desire: defined as the want for more, expressed for, with and through our bodies. (1995)
Typical Day

make itself predictable by following a regimen: "so long as the regimen is followed, the body can believed itself to be predictable" (1991: 55). However, in the case of people with diabetes, the sense of lack of control can persist even when the regimen is followed (Balfe 2007), as there is always a remaining degree of uncertainty:

...even if you test so often, even if you keep it in control. Still, you're in a dark room, with a really [her emphasis] little flash light, and it kind of gets bits and pieces, you know? It lights up. That's how I feel about the whole picture of getting it. (Sasha, 24)

As Frank argued regarding the types of bodies, when living with a chronic condition there are not stable or definite choices or situations. Sarah's experience is helpful to better understand this. After being diagnosed, she "threw" herself into what she called the "diabetic lifestyle", following a very structured regime and making her biggest effort to stand up to the challenge. However, she lost motivation with time. Having proved she was capable of being the "good diabetic", she just felt she could not be bothered anymore. Her priorities are different now, and although she tries to keep a certain structure and is still very strict with her dietary restrictions, she is not as rigid as she used to be.

What I found relevant about this issue is that routine and schedules are not as cut and dry as they seem to be in a medical book. They cannot constitute guidelines to be adapted and followed. Furthermore, given the participants' experiences, the degree to which doctors are able to impose certain regimes on their patients and the desirability of that practice need to be questioned. People's motivations are very different and vary throughout life. However, the rationale behind that motivation is again similar: people look for the strategy that allows them to live without too much interruption, annoyance, hassle or stress. Whatever that is, for each one of them. What I found in the end, is a strong need to control the disruptions that diabetes causes in the other aspects of life. In that sense, what matters most is precisely what falls outside the schedule and the parameters of 'good care'.

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Calculating doses

The current biomedical approach to insulin therapy is based on the idea that people can eat whatever they want (with certain restrictions, though), as long as they compensate adjusting the insulin doses. This implies that people need to be aware of the amount of carbohydrates included in a meal, and then calculate how much insulin they need for that. This might seem a simple mathematic equation in theory. However, in practice, doses can be tricky. It might happen that the meal turned out to be richer than the expected, and the insulin is not enough. This means that there is need to inject a second time, which can be annoying or inconvenient because people can be in a hurry, surrounded by strangers in front of whom they do not want to expose their bellies, or simply because they do not feel like having a second shot.

People manage their doses in different ways and do not necessarily follow 'the rules' all the time. For instance, the fear of having a low can make some of them choose to inject less units of insulin. By that, they jeopardize the perfect number, the 'as optimal as possible'. But instead they are able to better control the present situation in which they need to be completely alert (like attending a meeting at work or a social event). Previous research has reported similar situations (Dunning 1995), in which people adjust insulin to avoid the short term consequences of sugar imbalances. Similarly, in Conrad's (1985) study about the meaning of medications in the context of epilepsy, he found that before stressful situations, people changed the doses of their medication to diminish the risk of a seizure and guarantee certain performance. He argued that this gave them some degree of personal control over the condition, better suiting their needs in particular social environments.

At the same time, by not risking a low, people keep their emotions in place, as hypoglycaemia was described by some as the most horrible experience they could have. Robinson et al. (1995) found a similar situation in a preliminary study in the UK, where young people took the decision to have higher sugar levels. The avoidance of hypoglycaemia in the present was worth the sacrifice of freedom from complications in the future. On the contrary, other people can choose to use slightly higher doses in order to achieve 'better' numbers and control the risk of future complications. This has a very
A Typical Day

strong emotional component as well, because the thought of having complications can be as horrifying.

On a different part of the spectrum, insulin doses can be adjusted to meet certain body projects, like losing weight. Trying to lose weight when having diabetes can be problematic. It implies the control of several variables and the necessity of fitting insulin doses to eating habits. However, people learn to control their diet and treatment in order to achieve those specific goals. Even though gaining weight as a complication is generally overlooked by health practitioners, controlling physical appearance and weight is certainly very important in people’s lives (Dunning 1995). Marleen commented about this: “I think I’ll always keep busy losing weight, losing weight because of this experience that I had [gaining weight after starting treatment and developing an eating disorder]”.

Therefore, it seems that doses do not merely control blood sugars and having numbers in control is not people’s only aim. The mastery of numbers, routines and doses can be used to prevent symptoms, maintain a desired sugar level that does not necessarily coincide with the biomedical target, control performance, carry on with social life and other daily activities, and keep emotions in place.
5. FEELING YOUR BODY

When she first contacted me, Marleen told me that her experience with diabetes had been one of struggle, as her professional aspirations and diabetes management had been very difficult to combine since the beginning. When it all first started, she was a 13-year-old disciplined sports-girl. She had an unfortunate start with her health care team and the diabetes treatment they prescribed. She gained weight, and in her efforts to compensate and go on with her life, she ended up having an eating disorder. The first 8 years after diagnosis were very hard and painful times for her. Having too many things to deal with, she decided to change her professional aspirations and chose a different but related type of interest, dancing. It demanded discipline, hard training and a lot of physical activity as well.

This choice has made her diabetes management very challenging. She needs to adjust her insulin doses, sugar levels and treatment schedules to her life routine, in which physical activity takes the most of her day. In turn, this means that she has to measure her sugars around 13 times a day, and be constantly aware of the slightest symptoms, in order to carry on training and maintain a certain level of performance. She needs to stand up to her teachers and work hard to prove that she can do a good job.

Regardless of the obstacles, Marleen has managed to keep up to her dream. She said that her choice to continue was in part owed to the need to prove to herself that she could still do what she wanted, in spite of having diabetes and knowing it was not the easiest choice for her. Being originally from Germany, she moved to the Netherlands to pursue her studies. As a 26-year-old woman, she is currently very busy training and giving lessons.

People with diabetes learn to recognize highs and lows by different body sensations. Most of the participants told me that they were very good in detecting lows on time. They said that their bodies talk to them clearly, telling them what they need. Even while sleeping, some of them wake up or dream about food if they are having a low. "There are plenty of signals!", several of them told me: fatigue, thirst, hunger, sweat, a special taste in your mouth, a feeling in your stomach, blurry vision, weakness, tremor, inability to
concentrate, sleepiness, feeling your arms heavy and your moves slow, coldness, etc.

On the other hand, when those mechanisms fail and people do not recognize a low on time, they cannot rely on themselves exclusively and have to test more often. Not being able to trust their body anymore can be particularly scary and is closely linked to the idea of control. With regards to this, Chilhab argued:

For me, control is, has always been, and should be, - though it is not-[in practice], basically being able to recognize signs that can tell me whenever I am within an optimal glycaemic range. Because at least for me, and that is why I do it, it is not to have the numbers, it is not to see how my glycaemia is, because I don’t really care. What I need to know is how I am feeling when I am fine [the glycaemia is fine]. Because no one wants to be shooting himself 15 times a day. That is why I really do it. What I would find ideal would be to have a system that could tell you: ‘look, this is how you should be feeling when you are fine’.

Ups and downs: being high or low

Recognizing fluctuations in sugar levels can be of great help. Among other things, they serve the purpose of controlling the fear and uncertainty of being too low or too high. However, those same sensations imply a variable degree of annoyance and disruption, depending on their severity, frequency, predictability, and the situations in which they arise. They can be easy to fix, by injecting more insulin or eating sugars. Conversely, on some occasions, they do not respond to the usual maneuvers and cause great disturbances.

In general, people in my study found lows harder to ignore than highs. It can be possible to control the awareness of a high in order to keep doing something (like physical activity), but this is not easy with lows. However, this also depends on the situation. When there is a need to concentrate (like at work), being high can be very disturbing, whereas it seems almost invisible in certain social circumstances (i.e. having a café with a friend). In opposition, lows are very difficult to ignore: “being low you feel annulled “, “it’s rubbish”, two of the participants said.

I was impressed by the extent to which moods are affected by and affect sugar levels. Changes in blood sugars cause grumpiness, bad temper,
Feeling Your Body

anxiety, sadness, disproportionate madness and even aggressiveness. In turn, being happy, sad, mad, stressed, etc. can affect glucose stability. Two of the participants told me that sometimes, while having an argument with their boyfriends and feeling very mad, they used to check whether their sugars were contributing to the bad temper. They found these swings very annoying and frustrating, because they were not able to control them. For example, Mara said that when being low, you do not want to be annoyed and can feel grumpy with no reason; some people do not understand that moods can be affected so easily, they get annoyed, do not believe you anymore and stop being understanding. They do not see what is happening and might think you are lying, Sasha said. Besides, the need to apologize for a bad behavior because of sugars is irritating. In consequence, symptoms can take control of social performance (i.e. the ability to focus on the conversation, speak properly, keep an appointment or go for a previously planned trip), as well as social relations.

There are different strategies to deal with this. Some people choose to leave or hide until they feel better, others tell people around them to leave them alone, while some others resorted to make up excuses. Others, as it was said in the previous section, opted for keeping higher or lower numbers that allowed them to function easily in certain contexts. Nevertheless, using symptoms as an excuse for something else was considered unacceptable for most participants. Mainly because that would be like letting diabetes control the rest of their life (and other people’s lives as well), or allowing others to feel sorry or annoyed by them.

In short, the reasons to look for a ‘well controlled diabetes’ can surpass the strict biochemical rationale. Keeping sugars in place implies feeling well at different levels; physically and emotionally. Having a symptom-free day in which people are able to carry on with the rest of their activities, keep their moods and emotions more stable, and maintain social relations unaltered contributes to enhance their sense of control. Most people in my study were not willing to easily give away an uninterrupted level of performance (whether emotional, social, at work, or at other activities) in the name of diabetes.
Mara is a 29-year-old Spanish woman who came to the Netherlands to study when she was 21. She wanted to gain independence from her family, make her own decisions and learn to be more responsible about her diabetes.

Her story with diabetes has been a tough one as well, and the pain that has come along with it is present from the beginning of her narrative. She was diagnosed at the age of 12, a start that she described as very traumatic. The process of adjustment has been very slow and hard, ranging from her not taking care of it at all during the first years, to making very strong efforts to follow the regime and cope with it at other points in her life.

Mara described herself as a rebellious woman who likes to enjoy life and be spontaneous; someone who does not enjoy following strict schedules and discipline, and who finds it difficult to bear people’s interference and criticisms. During the interview, she explicitly talked about the difficulties she has had dealing with the social aspects of diabetes. Until very recently, she did not feel comfortable talking to other people about her condition (some of her close friends do not know she has diabetes), she did not like to inject or check her sugars in public, and used to hide all her diabetes paraphernalia when she had visitors at home. Two years ago, she decided to modify those aspects that were not helping her to cope, and changed to an insulin pump. She took this as an opportunity to open up, talk about diabetes more overtly and get on top of it for good.

Diabetes treatment practices very often take place in social environments, penetrating social spaces in various degrees (Clark 2003). Among other things, this implies that the issue of dealing with other people (regardless of how they might choose to do it), becomes a relevant concern for those with diabetes. It is not possible to say that everyone finds it hard to talk about it, nor that treatment practices are so straightforward that injecting in public ceases to be relevant throughout the years. Whatever the case was for the participants of this study, the topic of ‘the others’ came up inevitably during our conversations. As fieldwork progressed, I realized this was closely related to the topic of control. People try to preserve certain spheres of their
lives as intact as possible from the effects of diabetes. Simultaneously, they seek to keep diabetes out of the scope of such spheres. Control works both ways here. It means that diabetes is controlled in such a way, that people’s social lives, social relations and personal interaction can be kept as intact as possible. At the same time, the social spheres of life have to be kept separated from diabetes, because other people’s involvement can deeply affect such things as emotions and treatment practices (to name a few).

The social aspects of diabetes are complex, and involve quite a few of other topics which are extensive and complex as well. Issues of disclosure and stigma\textsuperscript{15}, for instance, are always present when discussing this matter. In the context of this research, these topics are going to be addressed to the extent of the role that they play in shaping the broader picture of control. It is, therefore, beyond its scope to explore them in depth.

Controlling Information

In diabetes, as in some other conditions, the distinctness of having a disease is not immediately evident in a social encounter. In these situations, as Goffman (1963) suggested, the relevant issue for the person becomes the control of information: what to tell, display or let on, and to whom, where, when and how.

I asked the participants how they dealt with talking to other people about diabetes. Whether they told me that they had difficulties with it or not, all of them, in one way or another, had some concerns. Some of them told me that they were uncertain of people’s reactions, whether they could like them less, leave them (in the case of friends of partners), feel sorry for them, or behave differently or in ways that they consider annoying (i.e. being overprotective or telling them what to do). This is in accordance with what Goffman (1963:24) called one of the “primal scenes in sociology”, in which the individual feels unsure of how the so called ‘normals’ will identify and receive him or her, not knowing what the others are really thinking.

Regardless of having lived with the disease for several years already, a number of the participants still had difficulties dealing with this. Mara said it

\textsuperscript{15} Stigma has been conceptualized differently by several authors. Crocker proposed that "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (in Link & Phelan 2001)
The Others was troublesome for her to find the appropriate moment to tell. After some time of not having told someone about it, disclosure became too awkward and she rather chose not to do it at all. Most of them decided to tell people in those occasions in which the topic came up spontaneously: when they injected or tested in public, had symptoms they needed to deal with, or were going to share a special situation (traveling was very common), in which disclosure became essential.

The degree of information they provide and to whom they do it is relevant as well. Two participants said that "not everyone needs to know", nor have detailed explanations of the condition (i.e. how they are dealing with it or how they feel about it). The reasons for this were several: it can be annoying to talk in depth with strangers about something that "is non of their business", there is no need to make some people worry too much or make them feel responsible in any way (i.e. in-laws or house mates), and it can be embarrassing to recognize they are having hard times with the disease or not being "controlled".

Besides, several said they had been annoyed by people who, having been told they had diabetes, started blaming them for eating too many sugars, telling them what they were supposed to do or not, or even making hurtful or stressful comments:

Day-to-day is really not that bad. It's sort of the odd occasion when it comes up. Where I'm having a conversation and I wear glasses and one of my friends passes and 'Oh! Is that secondary complications of diabetes?' I don't think that he really [her emphasis] realized what he just said. Is that kind of comments. (Sarah, 21)

Goffman (1963:27) said that the stigmatized person feels exposed to invasions of his or her privacy. In some situations, strangers engage in conversations with what is perceived as morbid curiosity, or offer help that is not needed or wanted. Participants find these episodes particularly disturbing:

...it has always been easier for me to know that I'm diabetic but that I don't need to tell anyone else. It's easier, it makes interaction easier, and the thing is that people can be really annoying with you. There is an extreme group of people that is always watching what you are doing: 'Hey! Are you allowed to eat that? Aren't you diabetic?' Give
The Others

me a break! It is annoying! ‘Why do you drink if you’re diabetic? why do you smoke if you’re diabetic?’ Then, sometimes it is preferable to keep quiet. (Chiliab, 27)

Therefore, by choosing not to tell, people keep control of the information that might arouse undesirable reactions or emotions. In turn, they control those reactions and emotions as well. The decision of not disclosing is also closely related to the idea of ‘felt stigma’ (Jacoby 1994). In this case, the fear of or the concern with others’ possible discrimination (not necessarily exclusion and rejection but a change in attitude in which they are not treated as equals), make participants choose not to tell or strategically control the information they provide. In this case, it seems that ‘felt stigma’ exceeds ‘enacted stigma’, since most of the participants recognized that the actual “bad reactions” they had had experienced were limited. This has been reported in other studies as well (Schur, Gamsu et al. 1999). Conversely, some people said they do not care about people’s reactions: “if they have a problem is their problem, not mine. Why are you afraid that I am diabetic? Is not catchy”, Sarah said. Underlying this statement, there is still an assumption that someone might consider it a problem. The way of coping with the resultant emotions might be diverse, but the perception of being different is nevertheless present. As Clark (2003:30) argued, stigma is not a fixed feature of having a certain illness, but “rather a byproduct of interacting social dynamics”. In this case, having diabetes might not be in itself a discrediting feature. However, the restrictions it may cause in social interaction, constitute a reminder of the stigma of being exceptional.

On the other hand, telling some people about diabetes can be perceived as helpful. This dual function of disclosure was reported by Schur et al. (1999) as well, in their study about young people’s perception of diabetes. Letting friends know they have diabetes is a way of getting support from them. That way, they can be prepared to react properly if something happens (i.e. they pass out), or can help with small but important things such as reminding them of the insulin, carrying their supplies or advising them to eat something before drinking alcohol. In addition, disclosing the condition is also perceived as a way of showing people, and themselves, that diabetes does not make them different persons and it does not need to be kept secret.
Disclosure can also be seen as a way of controlling relationships. Other people’s reactions to disclosure are very important for some participants. The way they feel about others, or what others become for them afterwards can be deeply affected by their reactions. Nevertheless, the criteria are different. Sasha and Mara, for example, appreciate when people ask questions and display curiosity, perceiving this as a symbol of how much they care. Conversely, when people react as if nothing had happened, as if diabetes was not important enough, they tend to feel disappointed and cannot help changing their feelings towards the other. On the contrary, other participants, as Sarah and Chilib, prefer that people do not ask too many questions. They do not like to give further explanations.

Thus, diabetes can also serve the purpose of testing new or existing relationships:

I would never trust a person that has a problem with it. When people are getting close to me, they have to know. Anyway, you can’t hide it forever and if you are really interested, you have to tell. I think that if I feel that the guy would have a problem with it, he wouldn’t be interesting for me anymore. (Marleen, 26)

Controlling practices

Diabetes does not have an external symbol that can pinpoint an individual as diabetic. However, the treatment practices alone can constitute a visible marker of the disease. Once the diabetic condition has been disclosed, or precisely as a way to keep it concealed, the management of those practices emerges as an important tool to minimize potential stigma (Conrad 1985).

People have different strategies to deal with this issue. The most common is going to the toilet to inject the insulin or to test the glucose, or doing it while others are not looking. (Conrad 1985; Tak-Ying Shiu, Kwan et al. 2003). A strategy to which Goffman (1963:125) referred to as “covering”. This strategy makes it “easier for himself and the others to sustain spontaneous involvement in the official content of the interaction”. Sometimes this can interfere with the prescribed treatment, causing delays or omissions if the conditions are not adequate. Participants gave several reasons for doing this: they feel embarrassed, uncomfortable, and do not want people to react negatively, feel sorry, or even complain. “I also think people don’t find it nice to
look at someone who’s injecting himself”, said Rick. Besides, injecting in front of someone implies the need to explain, which sometimes people want to avoid. On the contrary, other participants perceive this type of concealment as a hassle, and always inject in public. They said that they do not want to hide something that is part of who they are and do not see the need to do it secretly.

Regardless of the decision they make, what seems to lie beneath the choice of a specific practice, is the need to take control over the condition in each one’s own terms, to control other people’s reactions and the emotions attached to them. By changing practices, ‘perfect control’ might be compromised. However, as Tak-Ying et al. argued (2003:150), “patient’s understandings of appropriate self-management may not translate into practice if social stigma prevails”.

The use of different treatment devices generates diverse experiences in the social context. The insulin pump, for instance, has contrasting effects. On the one hand it makes interaction easier, as people usually do not know what it is and it can be disguised as any other electronic ‘gadget’. Giving yourself a dose is easier than with the traditional pen, since you just have to push buttons and there is no exposure involved, Sasha commented. On the other hand, the pump can serve as a marker of disability and cause embarrassment (conversely, the pen can be hid while it is not in use). This becomes more prominent in certain circumstances as wearing a bathing suit, a dress or a skirt. However, most of the participants who used a pump had learned strategies to deal with this as well, and control the effects of the pump on their physical appearance and identity.

There is another way by which the management of treatment practices contributes to gaining control; by ritualized behaviors. Participants have different rituals or habits related to treatment: covering the meter when they measure so other people cannot see the number, injecting through their clothes, changing the needles every time or just once a day, washing their hands every time they test or inject, or injecting in specific body sites and switching them to avoid changes in the skin or fatty tissue. Similarly, Chiliab told me that he perceives the diabetes ‘paraphernalia’ as something very private, for which he has established certain limits that others are not
supposed to trespass: “For me, someone touching my insulin pen is an insult. It is mine”. Therefore, he considered that showing his partner how to inject him was an important step into greater intimacy, which he is not willing to share with everyone. Other participants had different types of limits, such as not letting anyone else inject them, or putting away all the diabetes ‘stuff’ when having visitors. These practices serve the purpose of control by such things as limiting other people’s involvement or controlling physical appearance (by switching or choosing specific sites). In this regard, Clark (2003:36) explained that because people cannot control having diabetes and treatment practices invade life and body, they seek to keep some “control over the concrete, felt impact of the treatment” by rituals or games (sometimes people ‘play’ with numbers, guessing or making friends guess what the glucose level might be and checking with the meter).

Moreover, not limiting their social life because of diabetes was very important for most of the participants. Sarah, for example, said that she does not let diabetes affect her social life by not talking about it, not showing others when she finds it hard, and not depending on others to take care of her. Chiliab said that he is not willing to restrict himself in certain social circumstances because he does not want to affect others or behave as the “really boring guy that is always saying that he can’t eat that because is too fatty, or has too much sugar, or can’t drink beer”. He considers that being a chronic condition related to lifestyle, the biggest impact of diabetes is in social issues. Therefore, he chooses to compromise, and makes interaction easier enjoying with his friends with no dietary restrictions (sometimes doing things he rather not in order to please them) and compensating afterwards when he is alone. This is very much related to “covering” as well.

Crossing the line: from support to meddling

For a child with diabetes, parental involvement is essential (Clark 2003). For young adults, family support is also important. However, as participants recall it, it is experienced very differently. Being independent adults, they have very clear limits on how active they want their parents - or others- to be, concerning their diabetes. They make sure to take actions in order to keep those limits.
All the participants live on their own and some of them live quite far away from their families. Yet, most of them described their parents as somewhat overprotective. They took care of them during childhood, but they are not expected to do that anymore. Parents 'support' is very often experienced as interference, annoyance and even harmful or stressful:

[her parents] ... they are involved in the wrong way. I don't need them to tell me what to do, I have diabetes, I pretty much know what to do and I don’t need them to scare me with the talk of all the possible complications. I’m scared enough, more than enough. (Sasha, 24)

Besides, parents have to deal with the fear of diabetes in their own way and they worry as well. Participants are aware of this, and recognize that they mean well. However, they feel the need to control their parents’ emotions and interference, and their own emotions resulting from this. Hence, the majority has chosen not to tell their parents how they are really doing with diabetes, or to tell them only the good news. It is easier to say that everything is going fine and avoid confrontations.

Conversely, participants appreciate the support they receive from others (parents or not). People can be supportive by being there, just listening, being encouraging and thoughtful, helping with little daily things that make the load less heavy, and being available if by any chance they need extra help (i.e. calling them in the middle of the night to check if everything is fine). Some of the participants’ partners are very involved with diabetes management and know all about insulin injections, symptoms and dealing with acute complications. But there is a limit. Support can become interference when people try to tell them what to do, criticize them, or warn them about things that they already know. Their usual reaction to this type of intromission is to, in one way or another, tell people to “shut up”.

Still, participants recognize that there are things that others cannot do and the underlying idea is that they have to deal with the disease themselves. They do not want to depend too much on others, given that they already depend on external things in a daily basis. By this, they claim a certain degree of control on those aspects of their lives that they are still able to rule.
I went to London to meet three other participants of my study. In the end, I was only able to talk to Sarah, a 21 year-old English woman who has just finished her undergraduate degree in biology. One of the first things she told me was how frustrating and hard diabetes had been for her. In the beginning, when she was 15, she started having symptoms that people attributed to an eating disorder. Thus, when she was finally diagnosed with diabetes it was almost a relief because no one was listening to her before. After starting the treatment, the annoying symptoms receded, but at the same time she began gaining weight. Because she followed the treatment very strictly and had a very structured routine, she got fixated on food and, paradoxically, developed an eating disorder. During that time, people saw her as a “good diabetic” who had sugar levels that were just what her doctor wanted. However, she felt really unhappy. After finishing high-school and having had psychiatric treatment, her eating habits turned to the opposite, and so did her weight, her glucose and her relationship with her doctor. Having had lost control, she felt guilty and embarrassed.

At the time of our interview, she felt that after having been so strict she just did not have enough motivation to keep doing it that way. She tried her best, but she was not as severe as she used to be. She still found it really hard to deal with the condition and thought it was hurtful when people assumed that she was just not trying enough. She said she was scared to death of complications, but try to be as emotionless as possible when she saw a high number in the meter. She repeated several times during the interview that diabetes is a hassle. Her life is very busy and she just wants to live it and enjoy it.

Diabetes can be seen as an overwhelming experience in the practical sense that the treatment is very demanding. However, from the participants’ accounts, in the end, the merely practical aspects of the disease (as learning how to inject or test) seem to be the less difficult to manage: “That becomes more or less automatic. The injections, the blood testing, the carbohydrates, there is a point in which those things go the subconscious”, Chilab told me.
On the contrary, emotions that result from the experience of diabetes can be very distressing. Chilialb continued: "But sometimes a very low or high glucose, or the 'Oh! I didn't bring the insulin so I have to go back home', those things are huge [his emphasis] stressors. There are little things that occur in a day-to-day basis that make one think 'shit!' Usually, diabetes is in a kind of background but there are very tiny things that make one feel, 'Oh my God!'".

Participants' narratives were filled with references to emotions. Most of them told me about frustration when people try to give them advice without knowing much, when symptoms appear unexpectedly and they cannot do anything about them, when they do their best and still the sugars are not optimal, when they feel grumpy or mad without any apparent reason, or when they have to postpone something because they are not feeling physically well. Others talked about stress when symptoms interrupt their plans and they feel the need to fix them as quick as possible, or when their sugars are too high and remind them of complications. Some participants talked about sadness when people in their lives do not seem to understand that they are trying their best, or after having treated someone bad because of a low. Others said they feel guilty when they are not able to control sugars or when they affect other people's plans for the same reason; embarrassed of letting others know they are having hard times or of showing they have a disease that others can perceive as a disability. At last, almost all said that complications are terribly scary.

Emotions are very much linked to the idea of lost control. Because the feelings associated with diabetes are so strong and influence people's daily lives to such a great extent, there is a strong need to regain control over them as well. As Schur et al.(1999:229) argued, "control over diabetes also meant control over anxieties and emotional fears". But then, what are the strategies to control emotions, given that they can be as restless as sugars?

On the one hand, participants control their emotions by controlling the practical things directly related to diabetes. As it has been shown in the previous sections, this means that among other things, they take care of their sugar levels, try to follow certain routines or on the contrary, reject strict disciplines. Additionally, they learn to recognize and deal with symptoms and prepare themselves carrying supplies or telling others what to do if something
Trying For Emotion-less

unexpected happens. Furthermore, participants have strategies to deal with social interaction and control the degree of involvement they tolerate from others. As Schur et al. (idem.) stated, practical control over diabetes is one way of enhancing the psychological sense of control. This applies to the participants of this study as well. However, things can be more complex, as people choose to make trade-offs in 'practical control' when other goals take precedence (i.e. going out with friends, "covering", or keeping one's professional goals). In that sense, the psychological feeling of control is also enhanced when people are able to master other areas of their lives as well.

Together with this, participants make use of several cognitive coping strategies that allow them to keep their emotions in place. This has been found in other studies with people with diabetes (Schur, Gamsu et al. 1999; Gillibrand & Flynn 2001; Karlsen & Bru 2002). According to Lazarus and Folkman (in Karlsen & Bru 2002), people use a combination of problem-focused and emotion-focused strategies in the process of coping. For example, since sugars are potential stressors, some people try to face them as if they were any other piece of information, without further meaning, that needs to be dealt with:

[a 'bad' number]. ..I try no to talk about it, or to take action in whatever way, hopefully, and try to sort it out. I just try and get it back into shape. Lower it or increase it. Just try and think about how and solve it. I try not to think about it. I try my hardest to be well controlled but I try not to beat myself at the same time, so I try to be as emotionless as possible when I see the blood sugar and if it's good it's good, great! That's brilliant. And if it's bad then okay, that's a problem. So I try to do this and try to stay as emotionless as possible. Because that's easier for me. (Sarah, 21)

Similarly, Sarah considers that one of the reasons for her not liking to test, is because the meter gives her information about how well or bad she has been. And she does not want to face that so often.

As far as treatment is concerned, sometimes people feel too pressured to follow the regime strictly and this generates stress. Then, they set some goals for the future which allows them to carry on with those activities that they are supposed to be more restricted or careful about (i.e. drinking, having a strict schedule). In Mara's case, she has also found that the use of humor can be of great help to deal with the annoyances that diabetes implies. "When I'm
being difficult and behaving like 'leave me alone!' my friends say things like: 'Ok! let's see, turn on the pump, you must have it off!' . They make her laugh and help her being more open with her feelings. Clark (2003) addressed the use of humor as a coping strategy for children with diabetes. She argued that jokes can reshape a negative experience as positive, providing a "micro-vacation" and offering different interpretations to taken-for-granted assumptions.

Another way of dealing with the difficulties of living with diabetes is trying to look for the positive aspects of it. Some of the participants said that diabetes has also been constructive, making them more responsible, organized, strong, and mature. Sasha, for instance, said that diabetes makes you strive more and try harder because you have it a little more difficult than others.

Diabetes threatens people's sense of mastery in several ways. The sphere of emotions constitutes another area perceived as in need of control, given that the condition can cause great distress. When emotions become overwhelming they contribute to people's perception of not-being-in-command anymore. However, in this case, the struggle is a tough one. Negative emotions still prevailed in the participants' accounts, whether in the shape of daily or occasional interruptions: "My hormones or sugar or whatever, they control the emotions", Sasha commented.
Struggling with Doctors

8. STRUGGLING WITH DOCTORS

Chiliab is a 27-year-old Colombian who has had diabetes for 19 years. When he was 18 years old, he realized that the type of health care he was receiving was not really useful for his diabetes management. Frustrated, he decided not to go to the doctor anymore, and being a medical student himself, took care of his own treatment. He managed to keep his sugars in a good range until two years ago, when moving to England changed his lifestyle and his blood sugar levels increased. Because things worked different there, he had to join a Diabetes Clinic and started a new treatment regime. He is still very critical and has very strong opinions about the biomedical perspective on the disease, its treatment, and what it is expected from it. He insisted that doctors do not know how to manage diabetes and do not understand the power they have on their patients.

Chiliab said that he has not been the model diabetic. When he was a kid, he was taught to fear diabetes complications and he grew up thinking that his plans for life needed to be short-term. Nowadays, he thinks that the course of the disease can be different and has a somewhat different perspective about the future. He feels that having had diabetes all his life, has made the practices automatic, and the disease has become another part of the background that interrupts once in while when things do not go as smooth.

All the participants, in different degrees of frequency and intensity, had had bad experiences with doctors throughout their lives. This issue came up spontaneously during our conversations, as they expressed that some of their frustration, anger and fear had been triggered during their interactions with health care teams. In general, there is a feeling that doctors, as any other outsiders, cannot understand what it means to deal with diabetes on a daily basis. Therefore, some of them have taken measures to be able to do what they consider necessary, important or convenient with their treatments. Regulating treatment and struggling for a voice in their relationships with doctors, constitutes another claim for control.

People assume different positions in their relations with health practitioners. Sasha and Chiliab, for example, are open in their criticisms and
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demands. She clearly tells doctors what she considers best, urging them to work at a faster pace and asking them for the changes that she regards as appropriate. For example, while her doctors were refusing to prescribe the insulin pump until her sugars were more stable, she bought the device, kept it on her desk, and insisted on it until they accepted that it was worth trying. Chiliaf considers that doctors do not understand how glucose measurements work in real life, and therefore set impossible goals for treatment. "When you are not able to achieve them, you feel frustrated and guilty for doing things wrong", he said. Chiliaf took full command of his treatment and decided not to go to the endocrinologist anymore. Marleen, as him, feels that doctors do not take into consideration that people have different lifestyles that do not fit with what books say. Being young, people engage in a wide range of activities that pose different challenges for diabetes management (i.e. drinking, having crazy schedules, traveling abroad, etc.) and they feel that their doctors do not provide them with the tools to deal with them properly.

Moreover, it is common for doctors to be judgmental and blame their patients when they do not obtain the numbers they are expecting (Newton, Connacher et al. 2000). Some of the participants told me that this makes them feel frustrated, sad, lonely, and even stupid.

I saw Dr. B. when I first got diagnosed and he loved me because my Hb1Ac was very good. And then, I came back from my gap year and he was ‘Oh! My God! What the hell have you done?’ I think my relationship with my doctor deteriorated pretty badly. I didn’t like him because I just can’t be bothered, you know? ‘You’re giving me all this jilt and because I was anorexic [her emphasis] I was so good before! This is me when I’m normal!’ So that was very frustrating. (Sarah, 21)

Marleen has been very active in her search for a doctor who can be suitable for her needs, struggling to keep control of those other aspects of her life that are important to her. She changed practitioners several times because she could not find anyone that could advice her properly on how to combine the disease and dancing. Some doctors told her that dancing is not good for diabetes. But she sticks with it, and tries different solutions because she is not willing to stop.
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However, these confrontations with doctors are not necessarily the norm. After having had very bad experiences in the beginning, Mara feels very well treated by her current team, which she described as more flexible and understanding. In addition, this is also influenced by how smooth the diabetes goes. Rick, for example, is satisfied with his health care team and because his diabetes is relatively stable and recent, he has had lesser issues to deal with than the rest.

Conrad (1985:36) stressed that regulating medications can be seen as “an attempt to assert control over a condition that appears at times to be completely beyond control”. Apart from regulating insulin doses and practices, participants told me other ways in which they take treatment on their hands. Most of it is related to adjusting the recommendations to what is more suitable for them or for their coping strategies. Rick, for example, usually does not have breakfast, nor measure in the morning. He said he does not have time for that as he is usually rushing for the train. Chiliab does not measure as often either because his working environment (a microbiology lab) is not safe for testing. In addition, he said that he has learned to adapt the treatment to his life.

I adapt the treatment to my life, as far as I can, as far as I have learned my limits are. For example, I learned that my limit is one night. If one night I don’t go home, there is no insulin, and the next day I arrive home late and haven’t eaten, it’s okay. Yeah, I’m going to have a very bad time during the weekend or the rest of the days, but it’s okay. I got my night. I just take it out of my system. (Chiliab, 27)

Doing this, Chiliab compromises feeling well during a day, but sets himself free in order to engage in what is more relevant for him at the moment. People set priorities and act according to them. As opposed to what doctors might expect, diabetes is not automatically the first on the list.

Similarly, participants can be very autonomous in their decisions regarding treatment, such as asking for specific types of insulin (i.e. because they are cheaper), or deciding to change to the pump just after everyone has stopped suggesting it (like Mara). Moreover, they are willing to take actions themselves if they are not listened. Marleen for example, asked to spend some days with the pen instead of the pump because she was going to the
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beach and did not want to wear it in the open. Because they did not help her with that, she just managed on her own and got the syringes somewhere else.

All this is a reflection of the changes that the doctor-patient relationship has undergone. It is recognized that patients are not willing to comply with treatment prescriptions without question (Harvard Health Letter 2005). Being experts in "their own bodies, values, preferences and life situations" (Goodyear-Smith & Buetow 2001:451), they are keen to exert their power as valid decision makers. The fact that their rational choices might not necessarily agree with the doctor's, and can even oppose the established treatment goals, contradicts the idea that biomedical treatment is necessarily benign or desirable (Clark 2003:13). As Clark argued, this is based on biomedicine's "taken-for-granted cultural position of privilege" and does not correlate with people's life experiences. This is so to the extent that people are eager to use the available strategies, in order to control their bodies and live their lives according to their own standards of wellness.
Rick is a Dutch man who is currently finishing his studies to become a teacher. He is studying and giving classes in a school at the same time, spending several hours in trains commuting from one place to another. His history with diabetes is somewhat particular, being diagnosed when he was already an adult, just 3 years ago when he was 24. He described the beginning with diabetes as very emotional. Although he said that the practical things of treatment turned out to be easier than he first expected, he still prefers to inject insulin in private and holds back in being too open and showing his disease to others. He has managed to adjust to the treatment routines, and these past years with diabetes have been relatively smooth for him, without any major events or complications. He thinks the whole process needs to have a step-by-step course, in which he will be able to get stricter with time as his life becomes steadier.

Diabetes is not the only chronic disease that Rick has had dealt with in his life. As a child he had asthma, and he has been on medication for an epileptic disorder since 16. He feels he has gone through a lot already (in what health is concerned), and the possibility of suffering from something else scares him greatly. These experiences have shaped the way he feels about the future, being particularly fearful of any other diseases or the complications that might happen. He said that this worry is the biggest effect that diabetes has had in his life.

Complications are a main concern in the biomedical discourse. Its prevention constitutes one of the targets of treatment and the ability to diminish the risk of them helps defining 'well controlled diabetes'. In everyday life, the issues of control and complications are intertwined in several ways and contribute to shape the complexity that the former implies.

In the first place, the way in which biomedicine addresses the problem of complications, substantially affects people's experiences and decisions about treatment. Most of the participants of this study were diagnosed around 10 years ago, when the management of diabetes was very different from now. Some of them had very clear memories of the terrifying picture that was coldly
presented to them at that time. It included a future in which they could get blind, amputated, or suffer from heart or renal failure. Their reactions to this were varied. Some of them assumed that given its inevitability, they would rather enjoy life while being healthy and did not follow the regime very carefully during the first years. Others took this as a motivation to be strict and tried hard to achieve the control that was expected. These attitudes changed throughout the years, but the fear of complications keeps playing a major role in people's choices regarding the present and influences their perceptions about the future.

On the other hand, the uncertainty linked to the possibility of having complications contributes to the perception of lack of control, and the frustration that accompanies it:

"You really don't know what is going to happen. Because there are people that have had type 1 diabetes for 20-40 years who were as uncontrolled as hell, because before we didn't have the technology that we have now, and they are perfect! Whereas there are people with diabetes for 3 or 4 years and they have nephropathy, retinopathy. I mean, it is very weird. I don't know. It is like being HIV positive and having terminal AIDS. One doesn't know what divides one side from the other. One doesn't know what or when is going to happen."

(Chillab, 27)

As it was previously shown, most of the participants experience this anxiety and fear when confronted with a bad number, when others make explicit comments about them, or when they feel symptoms. They partially deal with this by achieving some cognitive and practical control. With regards to the former, people protect themselves mostly by denial or avoidance (Schur, Gamsu et al. 1999; Gillibrand & Flynn 2001). In general, when participants referred to complications, they said that they try not to think about them and focus in the present. Some of them try to avoid reading or listening about them. During our interview, Rick referred to this in several occasions saying things such as: "...not thinking about the consequences all the time, thinking well, I just live once and I like to eat, I like to drink, so I just do that, actually", or "I don't wanna think all the time and I don't wanna hear the bad stories" and "I know enough about diabetes, I'm sure about that. I know how to
deal with it and know what the consequences are. But I don't think that it helps me when I hear more about the consequences because I know it already”.

Apart from sugars and routines, practical control includes the recognition of bodily sensations that might be associated with complications (i.e. not recognizing a hypo on time, feeling a weird sensation in your chest), and the performance of specific actions like consulting doctors regularly and taking all the recommended tests. Regardless of these precautions, the feeling of not being completely in control prevails for most of the participants:

I'm not a control freak but I like to have things in control. And that's what it means. When I have a wound or something, I’ve got it in control, I can see it, I can react on it, and when it is in my body [his emphasis], I feel I don't have any control about it... So I feel I don't have that in control at all. [Diseases in my body] (Rick, 27)

The fear of not being able to recognize some signs was shared by Chilib, who realized that complications can come insidiously. Not being able to do anything about this makes his concerns even bigger.

Moreover, controlling for complications overlaps and even conflicts with the need to master other things in life, such as professional goals, social life and performance. This implies that people are constantly struggling to keep a balance between their present and future, taking very tough decisions and learning to compromise. In turn, these trade-offs generate guilt, frustration and stress.

It is what they have always put into your head: complications. I don't know... Before I thought that if I was going to have them in the future there was no point in taking care. If I’m going to spend my life feeling frustrated, without going out or anything, only taking care of myself and at the end I’m going to have complications... Then I just live life, doing whatever I want because they are coming anyway. Then, at least I wouldn't have restricted myself from anything in life. Now I don't feel this way. You can take care of yourself a little; it is not carpe diem or nothing. Now I think that I can go out and have drinks and take care of myself as well. I try more for the balance. But I'm not going to stop doing the things I like because of diabetes. (Mara, 29)

The issue of complications was not an easy topic to introduce in the conversation. Complications are constantly mentioned in medical textbooks
and patient guidelines. However, they fail to acknowledge the important meanings attached to them, and the influence they have on people's lives. When I asked participants about this subject I felt like entering a carefully guarded territory. Sometimes, I felt as if I was being a sort of unwanted reminder, making people think about things that they were very often struggling to forget: "I think people don't really realize how much it affects you. Because I see you being fine and you're alive and so they don't really realize that whenever you see someone with a complication, you think 'that could be me in 5 years time'", Sarah told me.

Similarly, the freedom to execute certain plans or ideas for the future seems to be under the control of diabetes, which exerts a strong influence in the undertaking of certain decisions. For example, the question of whether to have children or not, was a concern for some of the female participants. Sasha said that at some point in her life, she had decided not to have children because of the risk of complications and of having a kid with diabetes. She changed her mind, and being in a very committed relationship she wants to have a bigger family in the future. She still fears the risks but argued that "the wish of having a child is stronger than the fear, so you can never let your life be controlled by fear". In regards to other types of decisions, Marleen commented that she thinks she is not really free to undertake certain projects in life. After changing her professional aspirations because of the condition, she still considers that she would be a better dancer if it was not for diabetes. Moreover, when she was younger, she wanted to do voluntary work abroad and was not accepted because of it. Chilib, in turn, said: "I think that there is nothing I can do, conscious or unconscious, that couldn't be influenced by this. I was 8 years old! So for me this is the life I've known, it's really the whole life!... Then, every decision I make is going to be influenced by it".

In short, the prevention of complications involves more than controlling the risk of certain diseases that can derive from diabetes. It involves the need to manage fears and anxieties, to deal with information and other people's involvement. Moreover, as in the case of life projects, it involves an alternative perception of control, in which the balance between present and future has to be constantly shifted. The choices involved in this process are completely
individual. For this, as for so many other aspects of diabetes, it is not possible to follow any standardized guidelines.
How do you think it would be to have really high blood sugars all the time? I would think it would be to not do things because of your diabetes. So if you really want to go on a trip and then you go 'Oh! I can't, I'm diabetic'. That's how I perceive it [not having it in control]. (Sarah, 21)

It is not possible - nor desirable - to look for a unique, stable definition of control in a life with diabetes. Doing so would be equivalent to strip it of lived experiences and overlook the daily struggles of those who deal with it on a daily basis. Different people experience control differently in different points of their lives, and the types of things that they might need or want to be in command of as well as their attempts to do so vary greatly. In the context of this research, all this takes place in the lives of young adults whose previous experiences, personalities, projects, plans, tastes and distastes, social lives and current activities (to name only a few), shape the way they feel, think and experience [lack of] control. It works in multiple ways; takes different paths and touches various spheres that are complexly interrelated. Therefore, control is dynamic, both inter and intra individual, multilayered, complex, constructed, achieved - or not- in a step-by-step process; in a daily struggle.

Having said this, the power of sugar control (the sphere of biochemical control) must not be underestimated. Diabetes - and metabolic imbalances- can undertake control and greatly affect other aspects of life by influencing emotions, moods, other activities (i.e. work, driving, traveling, social and leisure activities), future plans, social relations, practices and interaction, performance, body projects and the ability to manage time, be flexible and spontaneous. Similarly, because so many aspects of life are influenced by diabetes and are at risk of being overcome by it, people claim for the restitution of a certain degree (as much as possible) of control over them. In the end, for people, being able to be and do the things they want with no major interruptions and not letting diabetes rule, becomes a priority. In this sense, the struggle for metabolic control is used as the means to conquer those things lying beyond it.
Conclusions

Yet, it seems that these priorities are still being overlooked by the biomedical viewpoint. The concept of health has been re-formulated several times in order to make it more dynamic, comprehensive and suitable to different kinds of societies (Saracci 1997; Bircher 2005) and doctors constantly struggle to get closer to people’s needs (Newton, Connacher et al. 2000). In spite of these efforts, from this study it seems clear that there is still an important gap to be surmounted. There is a big distance between those statements and efforts, and the way biomedical consultations and treatment goals intersect with people’s life experiences. It would be important to conduct future research in which the health practitioners’ perspective and experiences of control could be contrasted with those of patients’. It is necessary to explore how these two actors negotiate their positions and viewpoints about it in the context of the biomedical consultation. It is there where the two worlds collide and the resulting misunderstandings increase pain and frustration.

Furthermore, the fact that people take control of treatment and practices challenges the power of biomedicine to dictate lifestyles, control behaviors and discipline bodies. People say that treatment practices become automatic with time. However, according to their accounts, the fear of being stigmatized and the emotions linked to those practices question how ‘automatic’ they are. It seems that its automaticity is more linked to the context in which they are performed and to how smooth diabetes goes. Here, ‘the rest of life’ becomes a central issue again, as it seems that practices are automatic to the extent that they do not interfere with it.

This research is not aimed at providing results that can be generalized to other people with diabetes, but to present a different focus from which to study and take into account the complexities that the condition entails; to show that the picture is broader, that there is more to deal with, that life with diabetes is not dramatic but is not unproblematic either. By looking at control as a dynamic, multilayered, embodied phenomenon instead of a one-dimensional or univocal concept, it is possible to get closer to diabetes as a human matter beyond metabolism. Likewise, it implies that diabetes control should be looked at in experiential terms, and not exclusively as concept attached to an objectified body that needs hormone regulation. Regardless of the fact that most of the struggle takes place behind the curtains, it is worth
Conclusions

trying to pull them back, bring as much elements to the scene as possible and contemplate those factors that give shape to what really matters in people's lives.
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Being Young and Living with Diabetes

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Being Young and Living with Diabetes

General Information and Justification

The present research project is being conducted as part of a master’s thesis in medical anthropology at the Universiteit van Amsterdam (Amsterdam Master's in Medical Anthropology AMMA).

It aims at understanding how young adults experience type 1 diabetes mellitus in their everyday life. Much of what doctors and the media have said about the disease, is focused on how to control it, how to prevent complications and how to cope with it. However, things in paper look much more different that in practice.

It has been generally overlooked that people who have type 1 diabetes are also young people who study, work, have future projects, go out and party, date, have a sex life, have food preferences, travel, etc. I consider that understanding the daily challenges of being young and living with diabetes is a necessary step in the effort to help dealing with and overcoming those challenges.

Practical issues

I am interested in contacting young adults (20 to 30 yrs old) who have type 1 diabetes and are living in the Netherlands or the UK.

- Participation in the project will consist in one or two conversations (in person or by internet video
The content of the discussion will be strictly confidential and subject to the consent of the participants.

- Their identities will remain undisclosed during the whole research process and presentation of results.
- Participants are free to leave the project whenever they feel like it.

This webpage will offer some additional spaces for speaking up. Discussions will be proposed and participants and other people are most welcome to join them. You are also invited to send me texts, pictures, images, documents or anything that you consider relevant at young.diabetes@gmail.com

For further information, please do not hesitate to contact me at young.diabetes@gmail.com or by filling in and sending this form.

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