Bodies in Balance: Tracking Type 1 Diabetes

Hélène Mialet
York University

Abstract
This article explores through the lens of Type 1 Diabetes what a body in fluctuation feels, and what kind of ecosystem has to be recreated to be able to survive, an ecosystem made of sensations, senses, sensors and more. It investigates the complexity of relying on sensations that appear or disappear, on other beings that have their own agendas, or on machines that could help or kill. It describes the fear of feeling estranged from one’s ‘extended body’ when it functions alone, it tracks the experience of low blood sugar through the memory of the body or the instruments left in its surroundings. It is a story about the fiction of bodily integrity, of the combat between life and death, and of the impossibility of controlling the texture of life.

Keywords
being-in-the-world, body-mind dualism, co-existence, experience, machine, sensations, Type 1 Diabetes

Diabetes is a dreadful affliction, not very frequent among men, being a melting down of the flesh and limbs into urine. The patients never stop making water and the flow is incessant, like the opening of aqueducts ... If for a while they abstain from drinking, their mouths become parched and their bodies dry; the viscera seem scorched up, the patients are affected by nausea, restlessness and a burning thirst, and within a short time, they expire.

–Aretaeus of Cappadocia

Corresponding author: Hélène Mialet. Email: hmialet@yorku.ca
B&S Online Forum: http://theoryculturesociety.org
In the second century, Aretaeus of Cappadocia eloquently describes a disease to which he has given a name (Tattersall, 2017: 4). Etymologically, diabetes means syphon, passing or going through. In Aretaeus’ terms, the body has become an aqueduct crossed by an incessant flow of water. With either lots or none of it, the body eventually dies consumed by itself; it ultimately ‘melts down’ or ‘dries out’.

Nearly 2000 years later, the disease is still a ‘dreadful affliction’. Once rare, it has become epidemic and has been split into two different types. Type 1, often called juvenile diabetes, is the one that interests me here. Part genetic, part environmental, its cause is still unknown, though from deadly it has become ‘manageable’. Indeed, thanks to the discovery of insulin, a once fatal disease has been transformed into a chronic one (Anderson and Mackay, 2014; Feudtner, 2003; Weisz, 2013). Insulin has become the indispensable actor that allows the person with Type 1 Diabetes (T1D) to survive while putting her at risk of being killed by what gives her the possibility to live: too much of it and she can die; not enough and her blood sugar rises and can create long-term complications. As a result, having diabetes means constantly monitoring blood sugar levels caught between two extremes. If low, she needs sugar immediately; if high, she has to give herself more insulin, knowing that if she gives herself too much, her blood sugar level may go too low. She thus has to be constantly vigilant to avoid or catch these two extremes, or to make decisions about the amount of insulin she will have to take in anticipation of what will happen to her body as she eats or exercises or just lives. To monitor her blood sugar, she has to be attuned to her sensations, and/or she has to delegate to her surroundings the capacity to tell her where her blood sugar is at. A number displayed on a machine, a gaze of a parent or friend, a paw of an hypoglycaemic alert dog poised on a leg: a ‘low’ or a ‘high’ – what they are, how they are produced, how they feel, how they are perceived or how they are measured – varies from one individual to another and from one device to another.

The patient’s competencies to manage the disease are thus (in part) delegated to her surroundings: human beings (e.g. parents who read their child’s reactions), machines (that measure blood sugar) or animals (that smell hypoglycaemia). All these actors (alone, or together) sense, feel, smell, see, read, measure, interpret, make visible, give feedback and/or alert to counterbalance the immediate threat of death,
if a hypoglycaemic episode is not treated, or long-term complications, if hyperglycaemia runs too long through the veins and arteries of the body.

The balance between relying on what the patient herself feels and/or on the humans (family, friends, doctors) and non-humans (machines and animals) that give her feedback, or alert her to danger, is a delicate question of trust. There is also a constant movement (and tension) between being in charge or relying on others. One is often tied to the other. This is the complex adjustment, balance, coordination and attunement between different actors (of which she is a part) that allows a person with diabetes to function 24 hours a day. She is what I call a distributed-centred subject (Mialet, 2008, 2012, 2019a, 2019b).

We are all mortal, but we often forget this inevitability. In the case of T1D, mortality is a tangible reality: it is close and far away, it could happen now or later, here or there, it could surprise her (and those with whom she is connected) at any point in time. And, because the body could fail, the mind must always stay alert and constantly ‘think’ about it. For this reason, T1D has often been called the thinking person’s disease, incarnating ‘the mind/body duality’, or the metaphor of ‘the pilot in his vessel’ so beautifully described by Descartes (1998). But, what does ‘thinking’ and ‘manageable’ mean in this context? And how is it done in practice? How can the thinking person ‘control’ the complex entanglement of unpredictable circumstances that make up the texture of life? In other words, how can life, assuming that it can be defined, be quantified? The person equipped with her sensations and/or all the prostheses to which she is attached has to rely on signs – half visible, half hidden, half reliable, half uncertain – that allow her to make judgements in anticipation of a state where she might lose the ability to judge. Thus, diabetes tells the story of a strange combat between mind and body. The patient has to think constantly, anticipate, calculate, be aware, attentive, focused, in control and on alert – ‘rational’ so to speak – to prevent or counteract a state where she might lose consciousness, volition, awareness, attention, focus and control. The forceful body could knock out the mind: mind against body, life against death.

This is not to essentialise the mind/body dichotomy, however. Far from it, I will argue that this duality is the product of the manifestations of the disease, as well as of the conditions imposed by its
management. Thus, on one hand, we will see that the competences through which ‘the thinking person’ manages diabetes are distributed in her environment (Mialet, 2012). Because permanent micro-calculations and multiplications of attachments to other humans and devices are crucial for an actor with T1D to live, we will be able to discern, as I previously showed in the case of Stephen Hawking (Mialet, 2012), the visible ramifications and organisation of attachments that produce ‘an individual actor calculating rationally’. In this regard, I propose to think about T1D through the lens of the paradigm known as distributed cognition (Goodwin, 1995; Hutchins, 1995; Mialet, 2012), which tries to understand how cognitive competences are delegated within complex environments of humans, artefacts and machines. However, I will not limit myself simply to the notion of cognition (which is often understood in this framework as the product of the manipulation of external representations), for I will also consider the importance of senses, sensations and feelings (Fox Keller, 1983; Myers, 2015); attachment (Hennion, 2015); and sensibility (Debaise, 2008). In phenomenology, sensing is taken to characterise the individual subject’s body par excellence. Here, by contrast, I will explore how senses, sensations, feelings and sensibility are also distributed in the environment. On the other hand, we will also ‘see’ the Cartesian subject in action, the one that Descartes himself criticised by telling us that if the body and the spirit were not intertwined, the spirit would be in charge of the body like ‘a pilot in his ship’. In this particular context, ‘The pilot in his ship’ reemerges at the specific moment where the person with diabetes loses control, or conversely, when she anticipates situations in which she might lose the ability to think. In both cases, ‘the mind/body dichotomy’ derives from the desire to maintain the boundary between being and mortality – between being alive and feeling one’s own life-on-the-edge-of-always-absent-present-death.

What does it mean to feel ‘low’ or ‘high’, to be ‘in’ or ‘outside’ one’s body, to accompany it or resist it, to be haunted by it or forget about it, to rely on what it feels like ‘now’ or what happened before, to project, imagine, or envision what one will feel later, to be ‘right on target’ or to be overtaken by one’s body?

This article explores the different manifestations through which T1D makes itself visible – and is made visible – through sensations, numbers, words, machines, unspoken signs and more. It also wants to
make tangible the complexity of experiencing a world through the lens of a body in fluctuation.

Although this article is based on interviews and ethnographic fieldwork conducted for a larger book project, it also relies on my hard won expertise as a parent of a child with T1D. My ethnographic investigations, informed by these personal (Denzin, 2013) and professional forms of expertise, make me particularly ‘sensitive’ to the different modalities of controlling, alerting, reading, interpreting and managing T1D. I, too, became a sensing machine.

**The Difficult Art of Balancing Highs and Lows**

The fear of someone who has diabetes is to lose control, to be overcome by her body, to be taken by surprise. Indeed, the person with T1D is always living on a mini earthquake: a ‘body-quake’. The danger is always present, running under the skin, ready to appear, to surprise, to unsettle, to destabilise or to kill. Caught between extremes of constantly moving blood sugars, of highs and lows, of hypoglycaemia and hyperglycaemia, the body can crumble and shut down at any moment. This is why everything that changes the state of the body (and thus the mind) can be a source of anxiety, a source of trouble. As Alexander, a young adolescent who has been living with T1D since he was two, says: ‘You don’t want something to fuck with your head, because even if I drink, I want to stay aware, or I make sure a friend takes care of me in case I pass out’ (Alexander, 2017). The mind must stay vigilant. As Camilla, who just turned 18, adds,

I think many people my age or younger have that whole indestructible complex, but once you have a chronic illness that is life threatening and potentially life shortening, that all goes away, you can’t really feel indestructible ... When I was growing up [she was diagnosed when she was 9] I would hear these stories of high schoolers doing heavy drugs [and] I was like no, no, no, (laughs) if I did heavy drugs I would forget to check my blood sugar and then I would die (laughs)! (Camilla, 2015)

The body might fail at any time – threatening to overwhelm the mind’s desire to fight and resist. This is why taking alcohol or drugs or anything that could alter consciousness can be so scary. Moreover, a hypoglycaemic episode can be doubly dangerous because though
one knows that it can kill, it can also be associated (when close to a coma) with a feeling similar to taking drugs: for the first time, one can relax and not ‘think’. Some diabetics liken this to living just beyond the fear and struggle of drowning – the moment of giving-in to an ethereal numbness, a kind of dream, a kind of nirvana, though one not always associated with a pleasant feeling (Alexander, 2017; McMahon and Wilbanks, 2019; Pickard and Rogers, 2012: 113).

Juliet, who has been living with T1D since she was 11, recounts an episode where she was walking with her partner in the desert in central Australia: ‘for one reason or another’, she says,

I was just hypo. I was just hypo after hypo after hypo ... by the time I’d finished [all the food], I was sort of thinking ... I’d be fine, but ... we were halfway, the turning back was two hours and I was hypo. Right? And, with no food! (Juliet, 2017)

‘There was no doubt in my mind’, she adds,

that I was going to die ... and I was completely fine (laughs). You know, the actual sort of feeling of it; there was no panic ... because I was sort of relieved of any mental processing. And it is, because in a sense, it sort of is a little death too, right? You are actually relieved from engaging, there’s no desire. You’re hungry, perhaps, but there’s no desire. I had no interest in either living or dying or anything like that. I’m removed from the world ... I’m sure it’s what some people might actually talk about as enlightenment, although it’s a fairly artificial form. (Juliet, 2017)

Then, she adds in a joyous laugh, ‘but as soon as my partner took off, American tourists came around the corner with bags of minties!’ One can glimpse here a certain beauty to life’s uncertainty: the inability to control life can hold bad as well as good surprises.

What she describes here corresponds to the end of the spectrum (close to a coma or death), but there is also the ‘in between stage’ where the mind still tries to regain control (while the blood sugar is falling and has not reached a ‘critical point’, or when the sugar intake has not acted yet). The mind here talks to the body as if it was detached from, or outside of it:

I understand that my body does its own thing ... But it shifts. ... When you’re already in a heavy hypo state, it’s very difficult. But the ‘in
between’ is so terribly fascinating, because I consciously apply my mind to managing ... something. So if I’m in a hypo state, and I’ve already had some juice or whatever, to kind of manage the hypo state, so I’m waiting, but ... I can’t always sit down and rest, right, because I’ve got something to do. And in that state, I’m consciously applying myself to the objects at every moment and ... it’s really quite intriguing because I will literally say: ‘PICK UP YOUR PHONE NOW’ to myself, in order to make myself do it, because my body won’t naturally do it ... Particularly if I’m lying in bed actually and I’m hypo during the night, ‘GET UP, GET SOME JUICE, DO THE BLOOD TEST’ ... I’m interacting in this instructive way with myself. Saying: ‘YOU MUST DO THIS’, ‘PUT THIS THERE NOW’, right? And it’s almost a robotic effect. (Juliet, 2017)

This ‘effect’ is also true when she has to process language. The mind, though, ultra-conscious, loses the capacity to know. Often, those seeing her in need will choose this moment to ask her questions to which she cannot respond. Her partner, who has become an extension of herself, will speak for her (Akrich and Pasveer, 2004; Mialet, 2003, 2012). Juliet says:

People are asking me questions. I can hear the questions. I can understand that they are asking me questions. I can even understand what they’re asking me word for word, but I’m always separating the words, right? But I can put them together. But I can’t work out what an answer to the question is. (Juliet, 2017)

It is being ‘hyperconscious’, but also less conscious at the same time: ‘It is one of the most heavily conscious times that I have. But having said that often, I forget things at those times, but I’m consciously applying my mind to each word’. As if the mind was trying to hold onto something tangible, objects or words, in order to stay attached to the world, as fingers might cling to a cliff.

One can see a link with Polanyi (2009 [1966]) here, when he shows that by being hyperconscious one loses the meaning of things, or Goffman (1959), who explains that the pupil who performs the role of the attentive listening student can be so taken by his own performance that he can’t understand or hear what his teacher is saying. In addition, Leder (1990) suggests that the body becomes visible in situations of pain or discomfort, what he calls dys-appearance; in this
context, it is consciousness that seems to dys-appear as if one could see it processing information in action.

Alternatively, the body also acts out; this time it is consciousness that seems to have disappeared. One becomes a stomach:

When my blood sugar is very low ... I get sometimes, not all the time, 
**insane** hunger. **Insane.** And it’s almost animalistic. Totally animalistic, and it’s the most satisfying feeling you could [have] ... I mean it’s the closest thing I think to being an animal ... the other ... would be sex ...
The satiation of the hunger even for that moment is so incredible that I imagine it is what animals feel. Nothing. No thinking. Don’t care. You know? I can eat, I can eat to the point where I can probably almost vomit and certainly because I don’t care. All I care about is the satisfaction of that hunger, at that time. Wonderful ... Terrible after though ... (Juliet, 2017)

In this combat between the mind and the body, hypoglycaemic episodes are articulated through different sensations, feelings or states of mind. Juliet goes from ‘the suspension of desire’, ‘a little death’, ‘and not thinking anymore’, ‘to seeing her mind shift and tell[ing] her body what to do’, ‘to hang her attention to a list of words to the point of not knowing what a sentence means anymore’, ‘to becoming a stomach, an animal which satisfies instinctual desires’.

Often the lower the blood sugar level, the higher its level will be later (and it is not always linked to the amount of food one eats). The blood sugar rebalances and rises. More insulin might be needed to correct the high blood sugar. It could eventually drop to a ‘normal’ level, or continue to fall.³ Caught between these unpredictable extremes can leave one feeling either ‘a little death’ or ‘as strong as an athlete’:

Because your body changes so fast ... the same capacity that I had two hours ago is not the same capacity I have now. And it may be **enhanced**, right? So if I wake up ‘high blood-sugared’ and [feel] sort of clumsy, sometimes, three hours later I actually feel like an athlete. You know? So I’ve sort of moved into this **healed** body. I’ve sort of rejuvenated simply by my blood sugar coming back to six.⁴ (Juliet, 2017)

Interestingly, the fluctuation of blood sugar dictates not only what one feels, but also who one is or becomes: a being not affected by
mental processes or desires – a free spirit; or a detached mind talking to the body attempting to force it to do something against its will, a consciousness that loses the capacity to comprehend the meaning of a sentence, a devouring stomach moved only by the satisfaction of its desires. This is the strange grammar of the body experiencing hypoglycaemia: a pure spirit, a bodiless body, a mindless mind, a pure body.

These feelings are more than feelings, however; they are also sources of information requiring action. These different states have to be perceived (if the person can still do this) as signs, or ‘clues’, upon which to perform (to defy coma or death). I am, precariously, alive, therefore I think – *sum ergo cogito*. Different people experience different sensations during hypoglycaemic episodes, and some are more attuned to their sensations than others. They can even lose this ability as their body acclimates to them. Or, they can regain it, often via the mediation of organic (Mialet, 2020) or inorganic (Mol, 2000) sensors.

Sensations can also be misleading. A ‘high’ can feel like a ‘low’, and a ‘low’ like a ‘high’. Indeed, feeling low when high and drinking juice to compensate can have dire consequences. Feeling high when low and taking insulin can result in a coma or death. This is why sensations are often used with or against other kinds of information derived from other sources (Mialet, 2020). Sensations and sensors of all kinds are used to check each other: sensations versus a blood glucose meter, or sensations versus a continuous glucose monitor (CGM), or sensations versus hypoglycaemic alert dogs and a blood glucose meter, or sensations versus the blood glucose meter and the parents, and so on. People with T1D mix and combine organic and inorganic prostheses in different ways. As with the cockpit described by Hutchins (1995), the information produced by one device is checked against another to prove whether it is ‘right’ or ‘wrong’. Finally, some do not feel anything or never rely on their sensations; they only rely on external devices. In this regard, people who have diabetes can be seen as the precursors of the Quantified Self movement (Ajana, 2018; Lupton, 2013; Neff and Nafus, 2016) as well as their astute adapters (Danesi et al., 2018; Mathieu-Fritz and Guillot, 2017). There is a difference, however, for them monitoring their bod-
ies is vital, they cannot stop. But, what does it mean to ‘trust’ a parent, a machine or a dog that sees things you do not see or feel?

Someone with T1D is constantly reminded of the possibility of mortality and of the fact ‘of having a body’. Indeed, the body appears in moments of discomfort or pain (Kingod and Cleal, 2019; Leder, 1990; Mialet, 2003, 2012; Williams, 1996). But ‘having a body’ can have various meanings. The sudden invasion of the body (this chemical imbalance) is experienced very differently and triggers interesting paradoxes. I describe here some of the manifestations of these imbalances: (1) The overwhelming presence of the body makes it disappear at the same time (one becomes a Yogi, a free spirit; it is the emancipation of the soul). (2) One talks to oneself as to another self or as if someone were someone else (the body is perceived as detached from the mind as something to control and guide – the pilot and the ship to recall Descartes’ metaphor). (3) The mind becomes hyperconscious and less conscious at the same time (the body affects the mind in such a way that it disables and troubles it; ‘it cannot think’). (4) One is taken over by instincts (the body becomes something whose intense desires have to be satisfied).

To anticipate or counteract these extremes, especially hypoglycaemic episodes, someone with T1D has to constantly anticipate and imagine what will happen to her ‘if’. Indeed, ‘her body’ seems always to pop up, as if it were at the corner of every decision to be made. Some express feelings of being prisoner of their own bodies. However, as we will see, there is always a lag between what the person anticipates – and how she imagines or projects herself – in different situations, and how she thinks her body will be affected, and how her body may react. But are we talking about the same kind of body?

**How to ‘Stay Constant’?**

In the case of T1D what embodied cognition teaches us, namely ‘one doesn’t think before one acts, one just acts’ (Dreyfus, 1972; Merleau-Ponty, 1962; Polanyi, 2009 [1966]; Quéré, 1997; Suchman, 2007), is put into question. In the case of the hypoglycaemic episodes described above, we saw how instead of just using her phone Juliet was acting as if she were becoming a mind telling herself what to do because her body was not responsive anymore (in this context ‘thinking’ is not conscious; it is a product of a hypoglycaemic episode). However (in
anticipation of this state), many actions imply an act of thinking, consciously enacted, in so far as ‘every single thing [outside the body] has to be processed in relation to how the body will react and what the body can do’ (Juliet, 2017). For example, food is often objectified and instantly transformed into information (in this case, numbers, a ‘carb count’) to be processed by the mind, a mind, that, if it belonged to a person not affected by the disease, would do this naturally each time she ate or drank. The choice of counting or not, for someone with T1D, has become a necessity and even second nature. As Juliet (2017) said,

Any food you put in front of me I can tell you the carbohydrate content long before we got this little thing that goes on the packaging, ... [food is] already measured in my mind.

If the transformation of food into information makes visible what the mind (and the body) of a human being not affected by T1D does naturally, the internal ‘calculation’ here is triggered by the functioning of the machines. Seeing food as numbers is the product of methods of calculation, and algorithms implemented through syringes and insulin pumps that people with T1D have to use.

What goes inside the body has to correspond to the number of carbohydrates acted upon by the insulin pump. Thus, the person has to test herself; based on the number the glucometer calculates, she implements the number of carbohydrates she thinks she is going to imbibe. Juliet assumes, for example, that the number she just calculated and inputted (what is reflected on her pump’s screen) is the same as the food in front of her. Both, she hopes, will match the amount of insulin calculated by the pump in accordance with the number she inputted along with her blood sugar level.

She has some leeway in agreeing or not with the amount of insulin the pump proposes. Later on, another blood test will show a ‘number’ which will once more ‘reflect’ the correlation between the two (the number of carbohydrates she imagined – she calculated – and the real food acting in her body) plus the amount of insulin she gave herself based ‘on where she was at’ and the number of carbohydrates. As we will see, this is a never ending and very complex, if not impossible, task.

Food is, thus, a sort of an object to process, because carbohydrates have to be counted in correlation with the right dosage of insulin that
will cover the impact of the ‘real’ food on the body.\textsuperscript{5} ‘But’, she says, ‘it’s every object ... it’s sort of everything: “a flight of stairs or a lift.” “Blood test.”’ Indeed, depending on the number appearing on the screen of her tester, she will have to decide what to do next:

Can I do the flight of stairs before I have to get to that meeting? Because I don’t want to arrive hypo, right? So ... every single thing has to be processed in relation to what your body can do. Yeah. And if you don’t do that, which I don’t do constantly ... you will \textit{endure} some kind of problems. (Juliet, 2017)

The problem for Camille, a student from UC Davis, who was diagnosed when she was 7, and who has recently joined the triathlon team, is what will happen to her when she exercises intensively. She wants to try to stay ‘as level as possible’ (Camille, 2015). But, between desire and realisation, there is a huge gap. On one hand, exercise works amazingly well at lowering her blood sugar, but she also knows that ‘it’s difficult to manage because it’s hard to prevent lows’. Relying on her experience, she has discovered, ‘that not to go low’, as she says,

I have to pretty much have all the insulin from my last bolus out of my system ... and I need to have [a] 20–30 gram snack if I am going to do hard exercise like swimming or running or biking. ... That’s been hard for me ... [because] ideally, I would like to \underline{stay constant} the whole time. (Camille, 2015)

What she hates most about diabetes are ‘the swings up and down and just to having to control that’. Conversely, to try to avoid high blood sugar when she eats, she has to calculate how long it takes her body to metabolise food in relation to how long her insulin takes to act: she thus boluses 15 minutes before she eats ‘so that the insulin and food will hit me at about the same time so my blood sugar will stay pretty level’. However, she found that with exercise ‘I need to let myself go up a little bit beforehand umm, so, ... it’s just makes it not as simple as just “oh I want to try to stay as level as possible”’ (Camille, 2015).

Professional athletes are known to mentally rehearse the course they will take, and even if they do not have diabetes, they will have to avoid hypoglycaemia, but for Camille there is another layer of uncertainty. As with Juliet, she might waver between ‘feeling clumsy’
and ‘feeling like an athlete’ by virtue of her blood sugar moving from one level to another, but she also has to push her own body as athletes normally do. In the same way that Juliet has to anticipate and picture herself in a meeting after she takes a lift or the stairs, Camille will have to do a thought experiment and project herself into different situations to anticipate what will happen to her when she is ‘running’, a form of distributed subjectivity (Mialet, 2012, 2019b). This is true for everyone – we constantly create scenarios to project ourselves into the future through embodied thought experiments (Latour, 1995; Mialet, 2011, 2014; Nersessian, 1992; Rotman, 1995) – but in the case of Camille, she will have to perform complex mental operations to make sure her body stays stable. As Mol and Law (2004) argue, ‘the body of the sports-person and the body of the person-with-diabetes are in tension’ (p. 56). She knows from experience that exercise is going to lower her blood sugar (something that she is striving for), but it could also lower her blood sugar too much and put her in danger (something that she fears). Thus, she has to make sure that she doesn’t have insulin acting in her body anymore (the salutary drug could act as a poison, a pharmakon). She has to compensate by eating carbohydrates (eating more than usual to create a buffer) that will raise her blood sugar a little too much (which is not always accompanied with a very pleasant feeling), but an unpleasant feeling is better than no feeling at all, and she knows that with exercise, her reading will go down and put her at ‘the right level’ for her ... because each diabetic has ‘a right level’ which can change frequently. Moreover, if she eats, she has to trick her body. She has to know how long it takes for her insulin to act and when the food will start raising her blood sugar in such a way that both will hit at the same time. Again, the way her body reacts to the insulin or the ways her body assimilates food is something that is unique to her, as it is for anyone.

Moreover, the way insulin acts in her body changes:

sometimes my insulin will work faster than other times umm, like in the morning I am generally more insulin resistant. Although, being at Davis, it’s actually changed quite a bit, because I am so active even in the morning I am already biking to school, so it has caused me to have issues with going low in the morning now. (Camille, 2015)

If she has to eat or perform later, she will have to rely on her own experience (how her body reacted in similar situations before), but
she also will have to gather information about her own body in situ. She used to rely on sensation alone, checking what she felt against what her tester said, but she recently acquired a sensor that reads her blood sugar continuously (a continuous glucose monitor). Thus, in addition to having an insulin pump, she has another ‘site’ as she calls it, linked to her body:

I think it’s worth it. I mean that’s me, I mean it is another site that you have to have and then it’s like ‘oh my gosh I have sites everywhere’ (laughs), but for me it’s totally worth it, because ... I like being able to feel in control, in complete control of my diabetes. (Camille, 2015)

To be in ‘complete control’ means going from what she used to do – frequently checking her blood sugar with her tester and trying to establish a routine anticipating what her blood sugar will do – to having a CGM that adapts to her ‘crazy life’. As she says, ‘my life varies so much day to day in college that it’s really hard to establish [a] routine ... And so’, she adds, ‘you know, this makes me feel that I don’t have to figure that out as much because I can see it all the time’. In other words, she feels in total control because, she adds: ‘I know what I am at any point, whether I am going down or going up’.

Before having a CGM, her capacity to treat her lows was based completely on her feelings: ‘I wouldn’t treat myself for a low blood sugar until I felt low because I wouldn’t know I was low until then. But now I can see myself going down’ (Camille, 2015).

Camille’s experience here recalls ‘processes of identification’ described by Ochs et al. (1994: 151) when they depict how physicists ‘journey across visual displays through talk and gesture (or in their imagination)’. As they argue,

they may construct themselves grammatically and somatically both as subjects engaged in interpretative activity and as objects of interpretation. Utterances such as ‘When I go below in temperature’ deconstruct the distinct social identities of scientist and scientific object, constructing in their place a blended, indeterminate identity. Like the image of the cyborg, this conjoined social identity conflates animacy and inanimacy and thrives in a liminal zone between here-and-now interaction, visual representation, and represented physical worlds, rather than in any single constructed world.
In this context, the physical phenomenon under study with which the subject blends is one’s own body.

If the question of ‘where you are at’ is always moving, identity is always moving as well. Catching a low blood sugar before it goes too low is a good thing, but only relying on the trend displayed on the screen of the monitor can also have negative consequences:

sometimes I will think I am going low so ... I will correct, but then it ends up that I was just about to level out anyway so I didn’t really need to correct for that low. Or sometimes, there will be an arrow going up and I think I am going up and I will give myself more insulin but I really wasn’t going to go [up] that much more, so I didn’t really need to give myself any extra insulin. (Camille, 2015)

Correcting a low too quickly can make you ‘high’, correcting a high too quickly can make you ‘low’.

She describes a low as feeling ‘shaky’, having a hard time focusing, having very low energy and feeling very anxious:

It really, depends, I’d say it kind of umm accentuates my emotions almost. Like if I am worried, I feel even more worried, but then ... sometimes it just makes me feel ... lethargic and like I don’t want to do anything until my blood sugar is up. (Camille, 2015)

However,

a high is harder for me to tell, which is also why I really like [the CGM] because ... I notice that when I am not on the sensor I really have a difficult time feeling. Sometimes if I get really high I start to feel really thirsty and just more tired. But if I am not that high, then I can’t feel it, so then I could be, you know, sitting up at 250 or something for a while before I check and notice that. And I’m like ‘oh my gosh I have to get myself more insulin’, whereas with this you can see like ‘oh I am, umm, I am going up from being at 250 for a while and I need more insulin’ but you catch it sooner. So ... then it goes back to what I was saying that can also work against you, but it ... has [also] helped me a lot. (Camille, 2015)

Here, the body doesn’t stop at the boundary of the flesh to incorporate the machines in its functioning (Mialet, 2003, 2012). Conversely, machines only ‘become instruments if the body can manipulate them
and incorporate them into its actions’ (Mol and Law, 2004: 51). Bodies and machines are enmeshed (Haraway, 1991; Hayles, 1999). But more than this, the machines make the body present as much as they comprise it. As I showed in the case of Hawking, ‘the machines enable him to mediate his relationship with his own body by excorporating or making visible the normally invisible functioning or dys-functioning of certain neurophysiological operations’ (Mialet, 2003: 593). Here, sensing machines allow the person to see what the body cannot feel though with an important caveat: sometimes they do not see what the body knows.

Juliet, for example, speaks about her relationships to instruments and machines and how they have reconfigured the boundary of her skin. She recounts how syringes have become an extension of her hands through a learned and continuously practiced ritual: ‘When you see ... a professional basket baller move the ball around, it’s like it is part of them, that’s what I feel, I have been with different mechanisms that I’ve got, they are just extensions of my hands’. Prolongation of her hands or her tongue, as mastering needles is similar to mastering a foreign language: ‘I was terribly fluent with the needles’, she says, or to playing with a toy – ‘a capacity to flip around the toys that I’m part of’ – or, even, to mastering an art: ‘I also took up fencing ... I think it is part of the same mastery, the sword and the needle were very related to me’ (Juliet, 2017; Mialet, 2012, 2019a). The association between needles and swords is not innocent. It is about playing with something that is sharp and can hurt you, a kind of a weapon. It is something that extends the body, but can also turn against itself. It has to do (in part) with breaking one’s own skin and dealing with the pain associated with this:

If you do it yourself you can do it slowly because you are actually feeling the pain at the same time that you are using your hands to put it inside, and you can take it out if it’s too much, so you can do it quite slowly and then you are holding it in there when you are actually injecting the fluid, and there is this sort of moment at which the pain is increasing or decreasing, it’s not clear ... the whole process is not a single event, it happens, it happens, you know, [during] a series of moments in which you feel different scenes, right. (Juliet, 2017)

These instruments and machines are indispensable actors without which one could not survive; at the same time, they are extensions of the body, of the eyes, of the hands, of the tongue, another language;
they are the toys with, around, and in which one plays and mangles, a sport, an art, a skill, another skin, a window, a site, they can also be ‘the other’; they can hurt, make mistakes, even kill.

‘Perfect control’ is impossible. As Juliet says,

this notion of the balance [between all these different elements, food, insulin, machines, etc.] is absolute nonsense, it’s everything you want, and you can’t possibly ever make it [...] it is part of all this calculating, and part luck, because there is a world that I cannot know – the [flight of] stairs, the anxiety about to arrive as I bump into a colleague who is about to heap another task on me, the cold that might be coming on, and then whatever else I do not know about: what I have eaten over the past few hours, etc.

She adds,

I blood test quite obsessively, it’s the kind of diabetic I am and in many ways it’s actually a check on who I am, constantly with the [numbers], but it is the ... accurate moment of the loop, ‘did I get it right’, ‘did I actually bring all these things together’ and bringing things together in a supposedly cohesive loop, you know this fantasy, this perfect way of bringing things together because it fails always ... I can have periods of time where I manage. These periods are hours ... at best ... because it constantly fails. (Juliet, 2017)

‘Failure’, ‘guilt’ or ‘shame’ come from the fact of not being able to control one’s body (Goffman, 1959: 56; William, 1996). Or, as Annemarie Mol (2000) argues, while the capacity for self-regulating the disease ‘frees’ people from professional (medical) control, it also opens them up to the accusation of irresponsibility: ‘Suffering is no longer attributed to “the disease” but to a failure in dealing with it’ (p. 21).

Juliet (2017) adds, with the loop

you have the possibility of things all coming together, in this kind of perfect way, there is a promise, it doesn’t matter how critical and how complex I am and how much I think about it, I still live for that promise, like actually, the idea that I can have perfect control, and put my diabetes aside for a particular amount of time, and just live my life, you know, if I could, in your terms, balance it, then I wouldn’t have to worry about it at all. On the other hand, ... the activity of balancing is precisely who I am so actually, to bring it together, it is
one thing but as soon as they are brought together, ‘I’ as I experience myself, I’m left out.

This is why the dream of the perfect loop – the closed loop – where the sensor and the machine speak to each other without human intervention is something she doesn’t want because, as she says,

for me, my own sense of intervention in that loop is crucial ... It would be like ... taking myself out of the loop and the loop is me, so I can’t entirely cyborg myself as I think about [it]. I don’t want the machines to decide ... because I feel that that activity ... is now who I am and I don’t know how not to be that. That testing the blood, that managing through the numbers, it’s part of who I am. (Juliet, 2017)

A strange balance between the dream of control and the control itself which, if it were to be attained, would make the disease disappear at the same time as it would spit the patient out of the loop whose identity has become, it seems, precisely the activity or the art of balancing. The thinking person’s disease, indeed ...

Creating Relations: Between I and the Other

T1D is, thus, to use Juliet words, ‘a persecutory God’, or to use my own, ‘a kind of Super Ego’, which never leaves the one it has touched alone. It asks for absolute dedication. It is unpredictable (blood sugar can change from one minute to the next), individualised (what works for one body doesn’t work for another), time dependent (what used to work doesn’t work anymore), invisible (no physical or intellectual stigmas are attached to it), and paradoxically, it is omnipresent (the person who has the disease has to calculate, adjust and think about it constantly to survive). 6 It is ‘the other’ with which one tries to enter into a relationship and satisfy in vain, at the same time as it is ‘oneself’. Juliet compares her relationship to diabetes to being pregnant: can we really talk about a ‘relationship’ with an embryo, she asks? Can we fabricate a relationship with something that is ‘you’ and ‘not you’ at the same time?

This echoes Danholt’s analysis. As he argues,

we may consider the problem of diabetes as being a matter of managing a relation between oneself and the condition instead of being about the
management of diabetes as an object. Hence, ... the productiveness of having an ambiguous and uncertain relation to oneself and the condition as a premise for engaging in an affective, interested relation with the condition. (Danholt, 2008: 41)

Juliet complicates this even further. It is not only a question of managing a relationship between herself and the condition, for diabetes itself is at the same time herself and the other, ‘it’ is part of her, made by and in symbiotic relationship with her (‘an embryo’), while having at the same time its own agency, which confronts her like ‘a persecutory God’. Sometimes feelings, body, diabetes, the ‘I’ function as a whole, sometimes they are disjointed by the very nature that the condition creates. This fluctuating body forces the person to develop a form of awareness or ‘control’; she can’t just choose ‘to enter into an uncertain relation with [herself] and the condition’: too much uncertainty or ambivalence might be lethal, and conversely it makes her feel controlled by what she cannot control. Yet, this doesn’t mean that diabetes is an ‘object’ whose appearance in the ‘body’ causes a ‘subjective experience’. Diabetes is distributed; it is managed and made visible through a complex attunement among different humans and non-human actors (Mialet, 2012). The fluctuating body, thus, produces a certain ecology made of a multiplicity of actors through which the disease is performed, while certain boundaries have to be enacted for this body not to disintegrate. This is where mind/body duality emerges. One can see here the distributed centred subject in action.

There is, then, a continuous tension between intervening ‘in’ the equation that makes one’s own body function, and feeling left ‘out’ of the equation when the body works properly on its own; between becoming the disease – it has become one’s identity through the permanent work of being (or trying to be) in a relationship with it – and knowing that one is so much more. As Juliet puts it, ‘All I am is diabetic, and yet it is not all I am [woman, mother, lesbian, feminist] ... Sometimes it is all I am however. It is colonizing’ (Juliet, email, 2017). There is a balance that one has to create through linking, translating and putting elements of different natures or orders (which often have their own autonomy and agenda) into the equation: food and numbers, feelings and numbers, projections and blood samples, and so on. All of this for the sake of taming a disease; a disease that
manifests itself in diverse and surprising ways, a disease that is at once oneself and the other, a disease that asks for permanent dedication and leaves you out when it is ‘controlled’ ... or not. Indeed, the uncertain feeling never entirely leaves the person. It stays present through the memory of (or actual) corporeal manifestations of unexpected lows and highs, or the objects that always ask for attention or have to be thought about: pumps going on and off, batteries to be changed, reservoirs to fill, stuff to buy ... Indeed, if the role and importance of specific infrastructures or arrangements make chronic conditions manageable by ‘minimiz[ing] certain types of work, such as remembering, collecting and gathering medication. (Danholt and Langstrup, 2012: 528), or, as we have seen here, by providing information upon which to act, they don’t go so far as to transform the environment of care into something invisible (Forlano, 2020; Mialet, 2012) or maybe ‘nonconscious’ to use Hayles’ (2017) vocabulary; rather they configure the disease as always present. They call for an ecology of attention (Citton, 2017).

To a certain extent, everyone lives, or aspires to live, in denial of mortality, pain, suffering and disease, when strangely, we instinctively look left and right each time we cross a road, we buckle our seat belts, we avoid passing under a crane, we have annual check-ups; we abide by rituals of all sorts, normalised or private, that become part of the tool set that we use to manage the quotidian risks that confront us.7 Instinctively, we navigate life, trying to create stability through routines and the construction of landmarks of all kinds, but our reflexes, our instincts, our whiskers, our guts and our noses (instinctual or highly trained) are there to alert us to danger; the imagination of bodily integrity is also inscribed in the houses that protect our life against the wind and the cold, and the materiality of the clothes that envelop us – they too, like machines and others, become part of our skin enmeshed in other layers of skins (see Mialet, 2017, 2019a, 2019b, and also Anzieu, 2018; Lafrance, 2009). But bodily integrity is a fantasy, an ideal and an archetype, something that allows us to function and makes us forget that we are all mortal. Diabetes makes this fantasy even more visible.

So what is T1D? ‘Diabetes is a languageless disease with too many numbers and not enough words’ (Juliet, 2017). Words. Multiplying words is what I have tried to do here; multiplying words to describe what it feels like to have lows and highs while coping with a moving
body, what becomes part of one’s own body (machines) and what becomes estranged from it (one’s own flesh), what it feels like to become old when young, what it means to be betrayed by one’s own body, what it means to talk to it as if it was something else, what it means to become an animal, to become a free spirit, to hurt oneself, to delay time, to project oneself, to count, ‘to be’ a number that is always fluctuating, at once to be in and out of the equation. Words. Half those of others, half my own, they are flowing from my hands which have also become fluent with needles and testing machines. They also know what it feels like to prick the skin of someone who is at once in and outside one’s own flesh, as a parent, as a mother. My own son was diagnosed when he was 2 years old. I, too, became a sensing machine.

Acknowledgements
I presented a version of this article at the Centre de Sociologie de l’Innovation at the Ecole Supérieure des Mines de Paris and in the Department of Anthropology at York University. I would like to thank the participants for their questions and comments. I would also like to thank all of my interviewees. Finally, I would like to express my gratitude to the Beggruen Institute in Los Angeles which provided me the time and resources to work on this article, and for the comments, suggestions and criticisms of Magali Molinie, Michael Wintroub, Hannah Landecker, Josh Berson and the reviewers for Body & Society.

ORCID iD
Hélène Mialet https://orcid.org/0000-0002-0693-3974

Notes
1. According to the Juvenile Diabetes Research Foundation (JDRF: 30 April 2020), ‘about 1.6 million Americans live with T1D, including about 200,000 less than 20 years old and more than a million adults’.
2. I underline my own emphasis and bold those of my interviewee.
3. The definition of ‘the normal level’ is fuzzy. There exists a distinction between a ‘normal level’ for the person and ‘the clinical standard’.
4. Juliet is Australian, so the ways of measuring are different than those used in the United States (where one uses milligram/deciliter).
5. People use product information listed on labels to determine carb values, weigh the item, or refer to tables and lists of common foods and carb values, or they may ‘eye ball’ – ‘guesstimate’ – the amount of carbs.

6. The work involved in the management of diabetes – emotional, mental, physical – often remains invisible to ‘outsiders’ (see also Mathieu-Fritz and Guillot, 2017; Forlano, 2020).

7. There is a possible link here between having diabetes and OCD. Rituals help cope with the anxiety created by living with the disease.

References

Ajana, Bihaj (ed) (2018) Metric Culture: Ontologies of Self Tracking Practices. Bingley, UK: Emerald Publishing.
Akrich, Madeleine and Bernike, Pasveer (2004) Embodiment and disembodiment in childbirth narratives. Body & Society 10(2–3): 63–84.
Anderson, Warwick and Mackay, Ian (2014) Intolerant Bodies: A Short History of Autoimmunity. Baltimore, MD: Johns Hopkins University Press.
Anzieu, Didier (2018) The Skin Ego (trans. Segal, Naomie). London: Taylor & Francis.
Citton, Yves (2017) The Ecology of Attention. Cambridge: Polity Press.
Danholt, Peter (2008) Interacting bodies: posthuman enactments of the problem of diabetes, relating science, technology and society studies, user-centered design and diabetes practices. Computer Science Research Report, Roskilde University, Roskilde.
Danholt, Peter and Langstrup, Henriette (2012) Medication as infrastructure: decentring self-care. Culture Unbound: Journal of Current Cultural Research 4: 513–532.
Danesi, Giada, Pralong, Mélody and Panese, Francesco et al. (2020) Techno-social reconfigurations in diabetes (self-) care. Social Studies of Science 50(2): 198–220.
Debaise, Didier (2008) Une métaphysique des possessions. Revue de Métaphysique et de Morale 4(60): 447–460.
Denzin, Norman (2013) Interpretive Autoethnography. London: Sage.
Descartes, René (1998) Discourse on Method (trans. Cress, Donald). Indianapolis, IN: Hackett.
Dreyfus, Hubert (1972) *What Computers Can’t Do: A Critique of Artificial Reason*. New York: Harper & Row.

Feudtner, Chris (2003) *Bitter Sweet: Diabetes, Insulin and the Transformation of Illness*. Chapel Hill, NC: University of North Carolina Press.

Forlano, Laura (2020) The danger of intimate algorithms. *Public Books*. Available at: https://www.publicbooks.org/the-danger-of-intimate-algorithms/ (accessed 14 August 2022).

Fox Keller, Evelyn (1983) *A Feeling for the Organism. The Life and Work of Barbara McClintock*. New York: Macmillan.

Goffman, Erving (1959) *The Presentation of Self in Everyday Life*. New York: Doubleday.

Goodwin, Charles (1995) Seeing in depth. *Social Studies of Science* 25(2): 237–274.

Haraway, Donna (1991) *Simians, Cyborgs and Women: The Reinvention of Nature*. New York: Routledge.

Hayles, Katherine (1999) *How We Became Posthuman: Virtual Bodies in Cybernetics, Literature and Informatics*. Chicago, IL: University of Chicago Press.

Hayles, Katherine (2017) *Unthought: The Power of the Cognitive Nonconscious*. Chicago, IL: University of Chicago Press.

Hennion, Antoine (2015) Enquêter sur nos attachements. Comment hériter de William James? *Sociologies*. Available at: https://doi.org/10.4000/sociologies.4953 (accessed 14 August 2022).

Hutchins, Edwin (1995) How a cockpit remembers its speeds. *Cognitive Science* 19: 265–288.

Kingod, Natasja and Cleal, Bryan (2019) Noise as dysappearance: attuning to a life with Type 1 Diabetes. *Body & Society* 25(4): 55–75.

Lafrance (2009) Skin and the self: cultural theory and Anglo-American psychoanalysis. *Body & Society* 15(3): 3–24.

Latour, Bruno (1995) The ‘pedofil’ of Boa Vista: A photo-philosophical montage. *Common Knowledge* 4(1): 145–187.

Leder, Drew (1990) *The Absent Body*. Chicago, IL: University of Chicago Press.

Lupton, Deborah (2013) The digitally engaged patient: self-monitoring and self-care in the digital health era. *Social Theory and Health* 11: 256–270.

McMahon, Andrea and Wilbanks, Lindsay (2019) Addiction to hypoglycemia. A case report. *Journal of Addiction and Recovery* 2(1): 1011.
Mathieu-Fritz, Alexandre and Guillot, Caroline (2017) Diabetes self-monitoring devices and transformations in ‘patient work’, new forms of temporality, reflexivity and self-knowledge relating to the experience of chronic illness. *Revue d’Anthropologie des Connaissances* 4(1). Available at: https://www.cairn.info/revue-anthropologie-des-connaissances-2017-4-page-k.html (accessed 14 August 2022).

Merleau-Ponty, Maurice (1962) *Phenomenology of Perception* (trans. Smith, Colin). London: Routledge & Kegan Paul.

Mialet, Hélène (2003) Reading Hawking’s presence: an interview with a self-effacing man. *Critical Inquiry* 29(4): 571–598.

Mialet, Hélène (2008) *L’Entreprise Créatrice, Le Rôle des Récits, des Objets et de l’Acteur dans l’Invention*. Paris: Hermès-Lavoisier.

Mialet, Hélène (2011) Réflexion sur une pensée diagrammatique. In: Jacob, Christian (ed.) *Les lieux de savoir*, Vol. 2. Paris: Albin Michel, pp. 922–944.

Mialet, Hélène (2012) *Hawking Incorporated: Stephen Hawking and the Anthropology of the Knowing Subject*. Chicago, IL: University of Chicago Press.

Mialet, Hélène (2014) The pugilist and the cosmologist: a response to ‘Homines in Extremis: what fighting scholars teach us about habitus’, by Loic Wacquant. *Body & Society* 20(2): 91–99.

Mialet, Hélène (2017) A singularity, or where actor-network-theory breaks down. *Subjectivity* 10(3): 313–328.

Mialet, Hélène (2019a) Becoming the other: the body in translation. In: Gruber, David and Walsh, Lynda (eds) *The Routledge Handbook of Language & Science*. Abingdon and New York: Routledge, pp. 375–384.

Mialet, Hélène (2019b) The distributed-centered subject. In: Bennett, Jill and Zournazy, Mary (eds) *Thinking in the World*. London: Bloomsbury, pp. 131–149.

Mialet, Hélène (2020) How dogs become instruments: care, attunement and reflexivity. *Humanities and Social Sciences Communications* 7(66). Available at: https://www.nature.com/articles/s41599-020-00539-2 (accessed 14 August 2022).

Mol, Annemarie (2000) What diagnostic devices do: the case of blood sugar measurement. *Theoretical Medicine & Bioethics* 21(1): 9–22.
Mol, Annemarie and Law, John (2004) Embodied action, enacted bodies: the example of hypoglycemia. *Body & Society* 10(2–3): 43–62.

Myers, Natasha (2015) *Rendering Life Molecular: Models, Modelers, and Excitable Matter*. Durham, NC: Duke University Press.

Neff, Gina and Nafus, Dawn (2016) *Self-Tracking*. Cambridge, MA: MIT Press.

Nersessian, Nancy (1992) The theoretician’s laboratory: thought experimenting as mental modeling. *Proceeding of Biennial Meeting of the Philosophy of Science Association* 1992(2): 291–301.

Ochs, Elinor, Jacoby, Sally and Gonzales, Patrick, (1994) Interpretive journeys: how physicists talk and travel through graphic space. *Configurations* 1: 151–117.

Pickard, Susan and Rogers, Anne (2012) Knowing as practice: self-care in the case of chronic multi-morbidities. *Social Theory and Health* 10(2): 101–120.

Polanyi, Michael (2009 [1966]) *The Tacit Dimension* (2nd edn). Chicago, IL: University of Chicago Press.

Quéré, Louis (1997) La situation négligée. *Réseaux* 15(85): 163–192.

Rotman, Brian (1995) Thinking dia-grams: mathematics, writing and virtual reality. *South Atlantic Quarterly* 94(2): 389–415.

Suchman, Lucy (2007) *Human-Machine Reconfigurations: Plans and Situated Actions*. Cambridge: Cambridge University Press.

Tattersall, Robert (2017) The history of diabetes mellitus. In: Holt, Richard, Cockram, Clive, Flyvbjerg, Allan, et al. (eds) *Textbook of Diabetes*. Oxford: Blackwell, pp. 3–22.

Weisz, Georges (2013) *Chronic Disease in the Twentieth Century: A History*. Baltimore, MD: Johns Hopkins University Press.

Williams, Simon (1996) The vicissitudes of embodiment across the chronic illness trajectory. *Body & Society* 2(2): 23–47.

**Hélène Mialet** has published widely on subjectivity, agency, innovation and cognition. She is Professor in the Department of Science and Technology Studies at York University. She is the author of *L’Entreprise Créatrice* (Paris: Hermès–Lavoisier, 2008) and *Hawking Incorporated: Stephen Hawking and the Anthropology of the Knowing Subject* (Chicago: University of Chicago Press, 2012). She is currently writing a book about Type 1 Diabetes, machines and dogs and the future of the human.