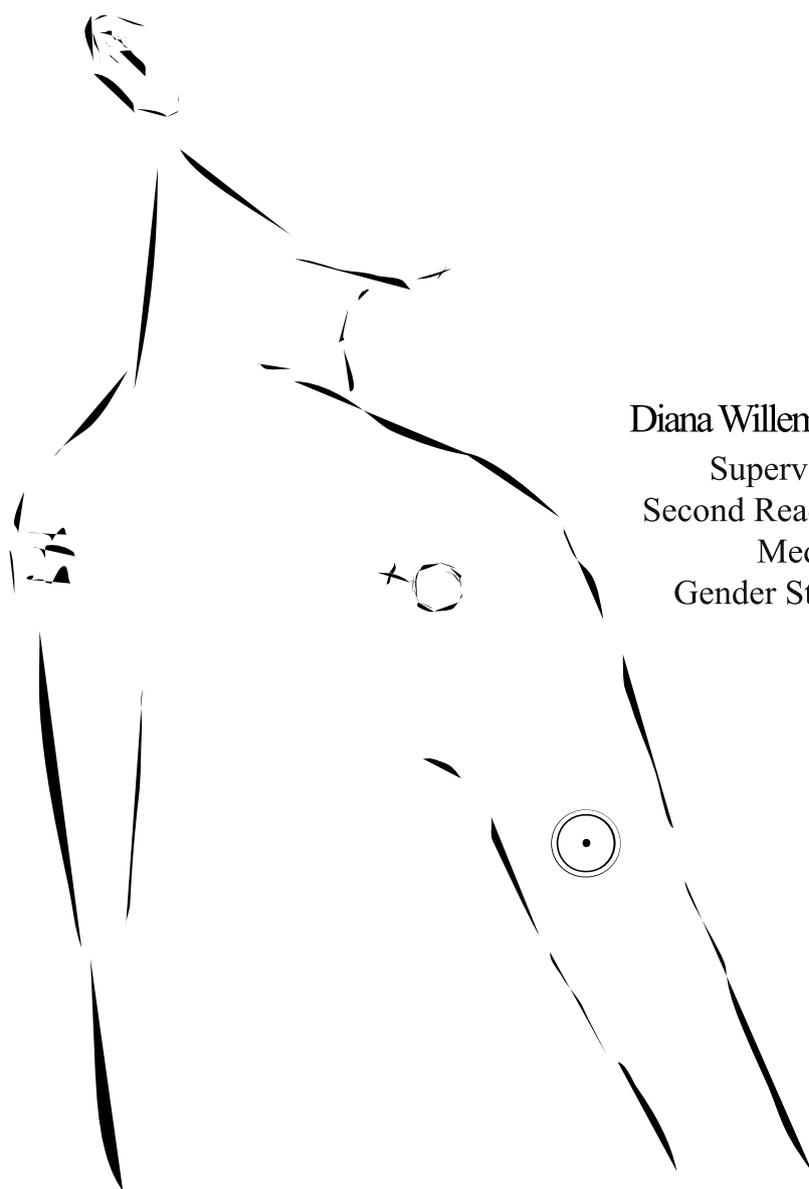


(Un)Stable:

A cripistemological queering of diabetes and dis/ability



Diana Willemijn Helmich (6863418)

Supervisor: Domitilla Olivieri

Second Reader: Heather R. Walker

Media and Culture Studies

Gender Studies Research Master

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**Utrecht
University**

Stable, *adj.* ¹

1.

a. Able to remain erect; secure against falling or being overthrown.

3.

b. of a system of bodies: having a permanent structure or constitution; not liable to disintegration

4. not liable to fail or vary

e. of a doctrine, theory, conclusion: securely established, not likely to be disproved or found wanting

f. permanent; of durable nature or quality

Unstable, *adj.* ²

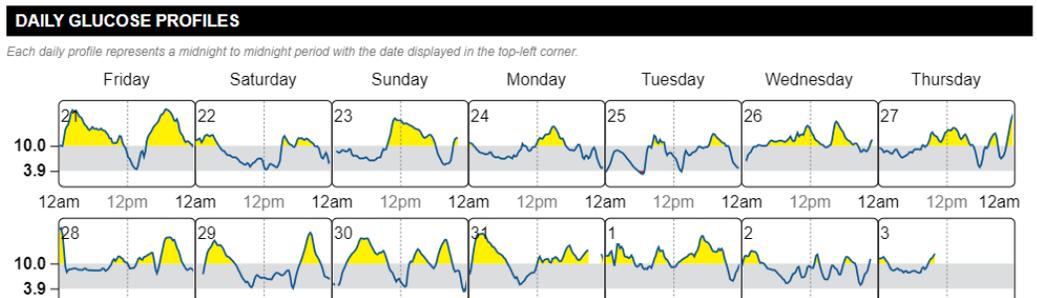
1.

a. not remaining steadily in the same place; apt to move or be moved about

c. of movement; unsteady; irregular

3.

a. not fixed in character or condition; exposed to vicissitude or change; apt to change or alter; variable



Source: Battelino, Tadej, et al. "Clinical Targets for Continuous Glucose Monitoring Data Interpretation: Recommendations From the International Consensus on Time in Range." *Diabetes Care*, American Diabetes Association, 7 June 2019. <https://doi.org/10.2337/dci19-0028>.

1. Daily Glucose profiles Diana - January 21- February 3 2022

¹ *Oxford English Dictionary*, s.v. "stable, adj.", accessed 25/01/2022.

<https://www.oed.com/view/Entry/188545?rskey=DCM1gL&result=3&isAdvanced=false#eid>

² *Oxford English Dictionary*, s.v. "unstable, adj.", accessed 25/01/2022.

<https://www.oed.com/search?searchType=dictionary&q=unstable&searchBtn=Search>

Abstract

In this thesis, I explore the ways that diabetes type 1 has been included and excluded from disability scholarship and discourses. This research project takes up Alison Kafer's remark in *Feminist. Queer. Crip.* (2013) that the largest group of people with disabilities, such as those with diabetes, do not consider themselves disabled or *crip*. I investigate the question "why diabetes can(not) be considered a dis/ability" through a mixed method approach of autoethnography, semistructured qualitative interviews, and textual and cultural analysis. Why is diabetes generally not seen as a disability from the perspective of the disability community and from those who are diabetic? What does that reveal about how diabetes *and* disability are viewed in scholarship and in society? And what does say about the values attached to normative (dis)abled embodiments? In four chapters that weave together theory and lived experience, I investigate disability discourse, disability/diabetes identity, neoliberal agentic subjectivity in diabetes care, and alternative, queer, and affective modes of kinship and care. Following Robert McRuer and Lisa Johnson (2014), I aim to create a "cripistemology" (or a crip epistemology) of diabetes type 1. Using queer, feminist, and disability scholarship, I contend that diabetes type 1 is scripted as a medical disease that is embedded in 'compulsory able-bodiedness' (McRuer [2006] 2017) which consequently leaves the lived, cultural experiences undertheorised. The hypothesis of the thesis is that personal narratives that highlight the (un)stable aspects of diabetes can offer an entry into destabilising, questioning, and queering categories of (dis)abled embodiment. Indeed, I offer ways of imagining (un)stable diabetic embodiment as a site of resistance that open up new potentialities for radical inclusivity (Keating 2013). Through a cripistemological queering of diabetes, I theorise towards dis/ability, which is an internal critique towards neoliberal notions of the (dis)abled body, or, phrased differently, an internal critique towards (st)able-bodiedness.

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‘Transformations occur in this in-between space, an unstable, unpredictable, precarious, always-in-transition space lacking clear boundaries’ – Gloria Anzaldúa³

³Anzaldúa, Gloria. 2009. ‘(Un)natural Bridges, (Un)Safe Spaces’. In: *The Gloria Anzaldúa Reader*. Ed. by: Keating, AnaLouise. Durham: Duke University Press. Pp. 243-248.

Introduction: “I never considered diabetes a disability”

I came to a disability consciousness in relation to my diabetes in the Gender Studies classroom. I remember the programme introduction, where I briefly mentioned that the sensor on my arm was diabetes-related, in case anyone was wondering. I did not see this as a public claiming of being disabled. It was not until I attended a session in a queer theory course, where we read queer/disability scholarship by Robert McRuer (2006) and Jasbir Puar (2017). I realised that my perspective of living with diabetes type 1 was a form of queer/crip embodiment. This realisation did not come into being because these scholars’ mentioned diabetes; if anything, I painstakingly observed that diabetes was often left out of discussions about disability (studies) the more I delved into both topics. I started to notice many exclusions in relation to diabetes and disability the more I critically reflected on these situations.

I noted a textual exclusion of diabetes in disability scholarship; either diabetes was briefly mentioned and then pushed to the side; diabetes was *not* mentioned; or diabetes was mentioned as an example of disability when convenient, even after a text had already made clear chronic illness was not disability (Swain and French 2000). It seemed like diabetes could not be configured in the paradigms, demarcations, and themes of discussions often related to disability; a lot of critical (queer) disability scholarship still bases itself in legible and public understandings of disability; those forms of embodiment that were either visually anomalous, or socially anomalous (chronic pain/exhaustion/mental illness/neurodivergence). I also noted a personal experiential exclusion; diabetes always seemed to exist in able-bodied narratives; diabetes always felt individual; I felt not “disabled” enough; I felt that my struggles were a symptom of not relating to my diabetes “correctly”; or, as charged by a new doctor I was seeing, I was not “understanding diabetes correctly”⁴. Diabetes care/management/public discourse seemed to be about being a neoliberal citizen; willing, capable, and able (Goodley 2014, 52). We assume that if someone is able to fulfil

⁴ And who, after I told him I was working on a research project that analysed the lived experiences of diabetes and disability under the umbrella of “gender studies”, wrote in my medical file that I was conducting research about “diabetes management and gender dysphoria”.

the demands and requirements for success in a neoliberal society, they are (st)able-bodied. In this way, diabetes – unless read in conjunction with other things that are not considered “successful” (e.g., diabetes and fatness) – is generally interpreted as an able body.

I wrote a paper about it. During the paper proposal discussion, multiple people said they “did not consider diabetes a disability”. A project was conceived: what began as a question of why diabetes is not really acknowledged in/as (feminist/critical) disability (studies) turned into a broader question: why can diabetes (not) be considered a dis/ability? What does this say about the way both diabetes and disability are positioned in society? What does this reveal about the values attached to normative (dis)abled embodiments? I follow Jeffrey A. Bennett’s (2019) observation that ‘diabetes [is] in a crisis of signification’ (9-11). I extend this statement to the categories of “disability” and “impairment”. Dependent on who you read and what you read, “disability” is more inclusive, others prefer “impairment”; some claim “chronic illness *and* disability”, others say “chronic illness *is* disability”.

The question of “why diabetes can(not) be considered a dis/ability?” takes as its hypothesis that theorising from (un)stable diabetes can be an entry into destabilising, questioning, or queering categories. I hope to trouble what is viewed as abled, disabled, and impaired, and how and where this can be read. The intervention of this thesis is thus both an epistemological mediation on inclusion and exclusion, and a queering of boundaries of categories. I work towards the potentiality that queering diabetes and dis/ability can offer: a way of relating differently to the self, to one another, and to the world. In the words of Margrit Shildrick, ‘if we are to have an ethically responsible encounter with corporeal difference, we need [...] a strategy of queering the norms of embodiment, a commitment to deconstruct the apparent stability of distinct and bounded categories’ (2019, 42).

Sometimes, the more I delved into Queer/Critical Disability Studies, this project felt frivolous; I did not feel like I experienced strong social oppression. I had access to medicine. I was able to live in various countries⁵, I was smart and had degrees. I worked in restaurants, cafes, lived a fast-paced life. But I still realised my body was different. As Mitchell and Snyder (2019b) ask, in their manifesto for the future of Critical Disability Studies ‘if we continuously pursue a concept of oppression and injustice as a matter of systemic exposé, how will we show what disability embodiment brings to us beyond our existing knowledges of the perpetrators or the carers or

⁵ Physically, not financially.

supporters [...] what can differential embodiment offer us that can exist so far ‘outside’ of liberalism’s conversations about reparations and yet involve so much suffering at the same time?’ (196-197). Indeed, how can we understand diabetes and diabetic embodiment better if we remain stuck only in analysing those bodies which are systematically oppressed the most? How would it then not become a project of reiterating categories rather than questioning them? And how can I recognise the implications of living dis/abled when only the abled aspects can be legible?

I explore these questions in a method/ology section followed by four chapters. The method/ology recognises how such a project would not have been possible without feminist, queer/crip ways of doing research, and explains the choices I have made to answer the research question. Chapter one lays the theoretical groundwork for why diabetes can(not) be read as a disability. Chapter two questions the possibilities and limitations of diabetes/disability identity, and proposes approaching diabetes through a queer perspective to offer ways to step outside the binary ways of thinking about diabetes/(dis)ability. Chapter 3 questions how diabetes is embedded in a neoliberal subjectivity of management and control, which further troubles how diabetes can be read in a disability context. Chapter 4 offers an imaginative framework of thinking diabetes and dis/ability in an *otherwise*: how can diabetes be made differently legible through the use of queer temporalities, humour, and ambivalence? And how can affect offer alternative forms of identification that lead to anti-capitalist, anti-neoliberalist community, solidarity, and kinship? Throughout, I position the unstable diabetes type 1 perspective as a site of radical resistance against normativity, offering a cripistemological reading of being with diabetes.

A note on the language of dis/ability, disability, and (dis)ability

In Dutch, the term “disability” translates to “invalide”; the term “beperkt/beperking” (impaired/impairment) is common nomenclature instead⁶. Yet, when speaking in Dutch about the field of disability studies, the English term “disability” is used.⁷ Therefore, I use the term disability and disabled rather than impairment. Adding a slash in dis/ability, moreover, more aptly reflects

⁶ “beperkt” is also the term used by the interviewees; I still choose to describe their experiences as disability, as I believe that translation is about capturing the meaning rather than literal translation. I myself, even when speaking Dutch, prefer to use the English term disabled too, for, as I show here, it best incorporates my dual feelings of being both abled and disabled.

⁷ See Van Hove, Geert, Alice Schippers, Mieke Cardol, and Elisabeth Schauwer, editors. 2016. *Disability Studies in de Lage Landen*. Antwerpen/Apeldoorn: Garant.

the fluidity of ability and disability that are part of chronic illness (Wendell [2001] 2017; Samuels 2017). I am inspired by Sara Ahmed's style of playing with language, and using language not as binding in meaning but rather as a fluidity, to show language's transformative potential. You will notice that my use of ability, disability, disabled, (dis)abled, (dis)ability and dis/ability are context specific to make a point of how "disability" as a category in itself is (un)stable and multiple. The slash also recognises how 'we are entering a time of dis/ability studies, where both categories of disability and ability require expanding upon as a response to global politics of neoliberalism and capitalism. Disability is re-sited as [...] radically challeng[ing] the preferred desire to be non-disabled. Crip and disability politics are combined as dis/ability politic' (Goodley 2014, ix).

Notes on Method/ology

The aim is to produce a qualitative study that focuses on experiences in order to question why diabetes can(not) be read as disability. This project uses mixed methods, in line with Ada S. Jaarsma's argument that 'transdisciplinarity of methods puts pressure on the fidelity of research methods, therefore undoing closed loops by which the 'we' is produced' (2020, 17). According to Jaarsma, mixed, transdisciplinary methods can produce an open-ended 'we' that 'undo[es] the grip of knowledge-in-advance' (16) and keeps Critical Disability Studies moving. Moreover, the mixed method/ology of my project aims to focus on 'problematization' rather than 'the false problem' which keeps the inherited logics of a discipline intact (Jaarsma 17-18). Jaarsma argues that problematization 'attunes us to problems in ways that compel creative rather than pre-determined responses; it prompts us to engage with the conditions by which problems emerge, instead of relying on disciplines to supply us with ready-made problems and methods for resolution' (16). Mixed methods in itself can be seen as a queering of methods or a queer methodology, which Hannah McCann defines as 'a more experimental method that is resistant to expected results [...] [which] resists settling on the methods of a particular field, and draws upon various methods for the production of knowledge' (2016, 234-235).

The mixed methods I use are autoethnography and semistructured interviews combined with textual, visual, and cultural analyses. I make use of autocritical discourse analysis, (Bolt 215, 2021) and "cripistemology" (McRuer and Johnson 2014) which both value personal disability perspectives in analysing and producing epistemology. The slash in method/ology reflects how theory and experience are closely entangled.

I treat autoethnography as 'intentionally trying to contribute to, extend, and/or critique existing research and theoretical conversations' (Adams, Holman and Jones 2014, 37). As a type 1 diabetic, I am able to provide a specific insider's knowledge which, when critically reflected on, and related to other experiences, can provide alternative insights into diabetic embodiment. Adams, Holman and Jones argue that 'experience, not objectivity, becomes an epistemological point of departure and return' (22-3). Secondly, I follow Adams, Ellis and Bochner in the idea that autoethnographic accounts 'must consider ways others may experience similar epiphanies' (2011, 276) and I have chosen to do this by the incorporation of qualitative, in-depth interviews.

I conducted semistructured interviews (Hesse-Biber 2006), or rather “conversations”⁸, with three Dutch women (Felice (25), Sille [pseudonym] (25) and Brechtje (26)) with diabetes type 1 that experience their diabetes as unstable, like I do. In order to not have cultural differences, infrastructural differences and unaffordable medicine factor into experience, I chose interviewees in the same nationality⁹, age, and gender demographic as myself. I found the participants through my personal network (Felice is a friend of a friend), and a call that I posted on my Instagram story¹⁰ which was then shared by some of my (feminist) follower circle. The Instagram call stated that I also have unstable diabetes and I was looking to “go into conversation” to map lived experiences. I received twelve responses, and selected two people who best fit the criteria. Before conducting the interviews, I explained the nature of feminist research valuing lived experience as evidence (Scott 1991); how the incorporation of personal experiences is not utilised to make universal or “truth” claims, but rather focuses on ‘how, and in what form, self-understandings and experience are produced’ (Cerwonka 2011, 66). I also emphasised feminist reflexivity about the relationality between researcher-researched (Hesse-Biber 2014; Faharani 2010) and the idea of ‘seek[ing] those ruled by partial sight and limited voice – not partiality for its own sake but, rather, for the sake of the connections and unexpected openings situated knowledges make possible’ (Haraway 590, 1988).

The location of the conversation was determined by the participant, and was recorded using an iPhone so that the conversations could take place as organically as possible. The semistructured interview style means that I had predetermined themes that I would touch upon during the interview (diabetes and the self, diabetes and social/medical relationality, and diabetes as disability). In the words of Hesse-Biber, ‘[the research agenda] is not tightly controlled and there is room left for spontaneity on the part of the researcher and interviewee’ (2006, 116). The semistructured interview allowed a circulation of insights from both parties, which, in turn, created greater horizontal dynamics during the conversations.

⁸I prefer the term ‘conversation’ because it more accurately reflects the horizontal exchange of information that took place during the interviews.

⁹ Consequently, the interviews were conducted in Dutch: all translations incorporated in the thesis are mine. The original transcripts of translated parts can be found in the appendix of this thesis.

¹⁰ A temporary 24-hour post that does not appear on your Instagram feed but appears as a “bubble” on the top of your followers Instagram home pages. People can click on the bubble to see the message; common practice is that the story gets screenshot by followers and is reshared on their Stories. Depending on who posts the story to their feed and their follower count, this can have an endless reach. I was lucky enough that the head of a popular Dutch political feminist NGO reposted my story which influenced who reshared my call. Because my account is a personal account as opposed to a business account, I do not have insight in the actual engagement my post garnered.

I stored the data conform to Utrecht University's research participation guidelines¹¹, and transcribed the interviews manually, paying attention to recurring themes, affective tones, and emerging topics. I drew on my own responses in the interview too, which have been the source for (some of) my autoethnographic accounts. Any information included in the thesis that was relayed outside of the recorded conversation (such as Felice's tattoo analysed in chapter 4) has been approved by the participants through personal communication.

The women whose voices are woven through this thesis – my own included – are cis-gendered, white, working/middle class, and not deemed “fat”¹² by (Dutch) society standards¹³. Whilst I would have wanted to offer a more intersectional study that included a less homogenous group in terms of race and class¹⁴, my reach for the scope of this research was limited. I recognise that ‘giving presence to the lived realities of some bodies over others risks hasty generalizations and reckless universalizing’ but ‘the same can be said for conglomerations of data, abstract theoretical terms, or scientifically essentialized categories’ (Bennett 2019, 27). I yet again stress that our experiences are situated knowledges (Haraway 1988). Mitchell and Snyder (2020) refer to the inclusion of disability perspective as ‘non-normative positivism’, that ‘serves as a site for

¹¹ Outlined in [‘Instruction Document For Drawing up an Informed Consent’](#), further elaborated on in Teams meeting with J.P. Flores from the Research Data Management Support department. In line with Utrecht University's protocol on research participation, I included a description of the research and its purposes in an informed consent form that the participants signed – all were given the option to approve transcription before it would be used for the study – two participants used this. All were given the option of using a pseudonym (approved by the person); only Sille is a pseudonym.

¹² This is an important distinction to make because of the relationship between fat embodiment and diabetes in the public sphere (Bennett 2019; Walker and Frazer 2021). Fat embodiment in combination with diabetes (could) lead(s) to double oppression and discrimination. Because we are not considered fat, we are more susceptible to be read as ‘victims’ as opposed to ‘deserving of this outcome because of [...] overconsumption’ (Bennett 2019, 13).

¹³ This is also the primary visible group within diabetes frameworks in the Netherlands: when you Google image “diabetes Nederland”, most depictions feature white and skinny bodies.

¹⁴ There are no exact statistics available about diabetes type 1 and different class/race demographics in the Netherlands. *Diabetesfonds* (Dutch diabetes foundation) has a page called “diabetes in cijfers”, with a subsection that lists statistics about “people with a migration background” (“migratie-achtergrond”): it is stated there that people from Hindustani-Surinamese backgrounds are the most common demographic to get diagnosed (not clear if type 1 or 2). People from Turkish, Moroccan, or Surinamese backgrounds are 2 out of 3 times more likely to get diagnosed. Children from Moroccan backgrounds are at a higher risk to be diagnosed with diabetes type 1. Children from Surinamese and Turkish backgrounds have a lower risk to be diagnosed with type 1. In 2019, 109.100 people had diabetes type 1 in the Netherlands; the average age of diagnosis is 35. More men than women have diabetes type 1. (this is a translated short synopsis of some of the statistics, for their more detailed (Dutch) overview, see: https://www.diabetesfonds.nl/over-diabetes/diabetes-in-het-algemeen/diabetes-in-cijfers?gclid=EAIaIQobChMIj6bU74Dk9QIVVeR3Ch2onwAVEAAYASAAEgL40fD_BwE)

alternative ethics’ for disability, and ‘how we might revise, reinvent and transform narrow normative practices, beliefs and qualifications of who counts’ (183) ¹⁵.

The methodological framework of this thesis is largely informed by, and would not have been conceivable without, feminist and queer theory. By shifting the focus from the approximation to cure and medical advances to day-to-day life with diabetes, I aim to complexify and expand the existing framework around diabetes type 1. Reading our experiences alongside Jack Halberstam’s (2011) concept of “queer failure”, I aim to produce a ‘cripistemology’ (McRuer and Johnson 2014) of diabetic life as always already queer through its failure to attain a stable, continuous approximation to the norm of neoliberal success (Halberstam 2011), normalcy (Garland-Thomson 2017), and (cap)ability (Goodley 2014). I follow Sedgwickian ideas of queer theory as ‘probing beyond the bounds of normativity, taking on the load of rejection, resistance, negativity, indiscretion, quirkiness, and marginalization’ (Chen 2012, 68)¹⁶. I position the diabetic body as queer in relationality to itself, fixed categories, its (temporal) surroundings, normativity, and able-bodiedness. This thesis contends that queerness can both be a useful analytical tool and method to trouble neutralised concepts, and that ‘critical examinations of compulsory able-bodiedness and compulsory able-mindedness are queer and crip projects, and they can potentially be enacted without necessarily flattening out or stabilizing “crip” and “queer”’ (Kafer 2014, 17)¹⁷. Indeed, ‘*The Queer* means telling a story about being half in and half out of identities, subject positions,

¹⁵Whilst my thesis is not rooted in new materialism(s), I wanted to include this methodological approach developed by Mitchell and Snyder. They argue that ‘non-normative positivism’ in relation to Critical Disability Studies is an extension of new materialist methodology of ‘multimodal materialist analysis of relationships of power’ developed by Diana Coole and Samanta Frost which ‘open up the matter and materiality of embodiment as exceeding its social scripts of limitation, and, via this opening, one may better recognise’ the transformative and vulnerable trajectories of embodiment (Michell and Snyder 2020, 182).

¹⁶ I acknowledge that the use of “queer” is widely and continuously debated in activist and academic spheres; I do not want to diminish sexuality’s importance in relation to queer (theory) and the epistemological-political implications of doing so.

¹⁷ Whilst it is outside of the scope of this thesis, diabetes and sex(uality) are always already queer in how diabetes influences sexual encounters: for example, the influence that sexual activity has on your blood sugars, often leading to hypos. Or the (non)disclosure of diabetes to strangers that you meet in one-off sexual encounters; the unpreparedness for a hypo when you stay over at a strangers’ house and feeling like you are dying for hours, hoping and trusting on your body’s reserves to maybe raise your blood sugars enough when those strangers do not have (fast) carbohydrates in their house. Kafer (2013) places this anticipatory interaction in queer temporalities; more on anticipation, disability, and queer interaction in chapter 4.

Secondly, there is also the aspect of the influence of (un)stable diabetes on sexual reproduction for women; until late 2019, one of the conditions under which you could get the Flash Glucose Meters covered by health insurance was if you had a pregnancy wish (I briefly considered faking this wish). Brechtje, during our conversation, also brought up her anxieties about reproductive abilities, questioning both how she would be able to maintain stable blood sugars during pregnancy or care for a child with such an unpredictable condition. Of course, this intersection between gender and diabetes is interesting and necessary, but beyond the scope of this study.

and discourses and having courage to be fluid in a world relentlessly searching for stability and certainty' (Adams and Jones 2011, 117).

Chapter 1: “Invisibility”

The problem of diabetes and/in disability discourses

Introduction: (dis)placing diabetes in disability theory

In this chapter, I hope to lay down the theoretical groundwork in order to complexify the position that diabetes type 1, and chronic illness more broadly, hold within feminist/critical disability studies¹⁸. I encountered feminist/critical disability studies during my studies, and reading from a positionality of a person with type 1 diabetes, it felt like perspectives of diabetes (both type 1 and 2) are still largely missing. I argue that a reading of feminist/critical disability studies theory from a situated diabetes type 1 perspective can enliven current debates and reassess what we do (not)/can(not) imagine as a disability. Concurrently, I also argue that a different approach to the way diabetes type 1 is seen, both in academic, individual, and public discourses, can push the paradigms of the way disability is thought and talked about. Disability studies is said to be in its ‘third phase’ (Kent et al 2019, 4) which is posited as a meta-reflection on the ‘tensions and conflicts’ (Rachel Adams qtd in Kent et al 2019, 4) within the field itself. I identify this perspective of diabetes type 1 as dis/ability as part of this move that tries to reify and expand on these tensions and conflicts from a situated perspective. Through an approach of carefully reading seminal texts within the field, this chapter aims to trace the challenges, paradoxes, and contradictions of trying to place diabetes type 1 experiences within disability frameworks, what it means to claim dis/ability, and ways to envision the potentialities of such inclusions and exclusions. This quest

¹⁸ I consciously choose the term feminist/critical disability studies (and not the more broad “disability studies”) to signify that this line of thinking is part of the broader field of critical theory, where disability is not just seen as a matter of being able to participate in society as it stands, but rather to use disability both as an entry-point and an analytical lens to uncover the ideologies of modernism, neoliberalism, and colonialism embedded in the way we view “humanness” and “the body” (Garland-Thomson 2002 363). In 2019, Garland-Thomson wrote that ‘the definition I offer is that critical disability studies is an interdisciplinary academic field that expands the understanding of disability from a health science perspective to consider it as a civil and human rights issue, a minority identity, a sociological formation, a historic community, a diversity group, and a category of critical analysis in culture and the arts’ (12). Moreover, Dan Goodley argues that using the prefix “critical” ‘... denotes a sense of self-appraisal; re-assessing where we have come from, where we are at and where we might be going’ (632). Indeed, “feminist/critical disability studies” marks the attempts at open-endedness and fluidity that many of these scholars endeavour on. I use the prefix “feminist”, marked by a slash, because not all theorists I enlist specifically refer to themselves as feminist researchers, though I find that a lot of the cutting-edge interventions in critical disability studies have feminist theory/approaches as their foundation.

also forms the broader framework of my research. As the word ‘(dis)entangling’ in Dan Goodley’s cartographic essay ‘(dis)entangling disability studies’ (2012) suggests, this is not necessarily a linear or chronological tracing of disability studies. Feminist/Critical Disability studies is a much-varied field with many different voices, arguments, and lines of thinking – which reflects how disability is not a monolithic, hegemonic, nor stable concept or analytical tool. I will begin by outlining the relation between chronic illness and disability in activist and academic discourse; I will then explore other ways of making sense of the possibilities and potentials of breaking out of these discourses; after, I discuss the contradictions and paradoxes of diabetes type 1 as disability; lastly, I turn towards Alison Kafer, David Bolt, Robert Mcreuer and Lisa Johnson to discuss queer and feminist approaches to write disability epistemologies (or cripistemologies) *differently*.

On the (im)possibilities of chronic illness and/as disability

Diabetes type 1 is a chronic illness, and in my experience, not often thought of specifically as *disability*. Feminist/Critical Disability scholars have much concerned themselves with the causes, effects, and (im)possibilities of catching the complexities of chronic illness and impairment within the field of disability studies over the past few decades. While there have been many models developed to look at disability, the medical and social model remain most persistently referred to in (feminist/critical) disability scholarship. David T. Mitchell and Sharon L. Snyder (2015) note that ‘Barrier removal and bodily limitations have been the two poles between which disability studies research has primarily shuttled since its founding moments in the 1970s. The former (barrier removal) has claimed the lion’s share of the field’s attention, while the latter (impairment effects) has continued to evolve as a key component of scholarship on disability embodiment’ (1).

The course of correction in the field of disability studies primarily comes from feminist interventions, which Mitchell and Snyder argue comes through feminist theorists’ advocacy of ‘a more visceral engagement with bodies’ (1) as opposed to merely placing disability as a problem of the surroundings. In the words of Susan Wendell, ‘theory [of disability] should be feminist [...] because feminist thinkers have raised the most radical issues about cultural attitudes to the body’ (Wendell 1989, 243). Questions of embodiment, bringing the body back into discourse, and first-hand experiences from marginalised positionalities are moreover a feminist approach to producing epistemology, where the conventions of what knowledge is and what *counts* as knowledge are continuously questioned. In Rosemarie Garland-Thomson’s seminal essay ‘integrating disability,

transforming feminist theory' ([2002] 2017), she makes the argument for how an integration of disability into feminist theory can transform the paradigms of feminist theory, and vice versa. She argues that 'a feminist disability theory presses us to ask what kind of knowledge might be produced through having a body radically marked by its own particularity, a body that materializes at the ends of the curve of human variation' (373).

In 'Unhealthy Disabled: treating chronic illness as disability' ([2001] 2017), Susan Wendell traces how disability and illness have a difficult history in the medical model, where illness and physical forms of disability have been conflated. The medical model posited disability 'as an individual misfortune, and people with disabilities are assumed to suffer primarily from physical and/or mental abnormalities that medicine can and should treat, cure, or at least prevent' (160). Dan Goodley (2012) argues that indeed, by using the social model of disability, the disability rights movement was also able to show how disability is not just an issue of personal misfortune, but a problem of society and societal barriers which leads to the exclusion and oppression of people with disabilities (634). Wendell points to how this medical perspective historically led to the institutionalisation of people with disabilities, where the basis of "treatment" was a way to exert control over disabled people's lives (161). A move from "medical" to "social", thus, was a political project about gaining agency.

Driedger and Owens, in *Dissonant Disabilities* (2008) locate the split between chronic illness and disability in the (Canadian) disability rights movement, where people with physical disabilities were consciously distancing themselves from the "sick role" that society, through a biomedical approach, had delegated to them. Sickness, Driedger and Owens argue, signifies a sense of weakness, passiveness, a personal failure to get well – it places the realm of disability on the individual, whereas disability activists felt impaired by society. In their words, 'being sick is not viewed as a valuable social role' (6). It makes sense then, if the aim of the disability justice movement was to distance themselves from signs and signals of weakness to move towards an approach to show that disabilities are not negative, to position the limitations of the disabled body as caused by spatial and social discrimination. This eradicates the exclusion and consequential oppression people with physical disabilities face, and the disability justice movement shows how and why they too should be included in (capitalist) society – or to be 'valuable in the social world' (Driedger and Owens 2008, 6). This position also provided a common overarching cause for people with a variety of different disabilities (Kent et al 2). Simultaneously, the social model of

disability does not offer a radical change to the workings of society; demands inclusion. However, as Mitchell and Snyder argue, ‘neoliberal inclusionism tends to reify the value of normative modes of being developed with respect to ablebodiedness, rationality, and heteronormativity’ (2)¹⁹.

While the social model held and holds many possibilities for social inclusions, this approach causes rigid exclusions with those whose dis/ability is not *only* compromised by social and physical barriers. As Wendell notes, ‘some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate’ (2017, 161).

Wendell’s project uses the terminology of “healthy disabled” and “unhealthy disabled” as a way to read chronic illness as disability (also noting the fluctuating meanings of sickness and health in the process): a healthy disabled person is someone whose health is not necessarily impacted by their disability, and their disability is constant and predictable ‘for the foreseeable future’ (Wendell 2017, 162). Their life expectancy is also not compromised in comparison to ‘any other healthy person their age’ in the way that it is the case for those who are “unhealthy disabled”. Wendell does note the leakiness of such a categorisation, as some “healthy disabled” people do suffer sickness or other health complications as a result of, or in conjunction with, their disability, or will do so in the unforeseeable future (and, as many disability scholars point out, the able-body state is not a static position of being either²⁰). Whilst Wendell never gives a strict categorisation of what is counted as “unhealthy” disabled, it can be deduced that she is indeed referring to all whose life expectancy and/or functioning is compromised through chronic illnesses, which she lays out as taking a variety of forms and shapes from lupus and diabetes to schizophrenia,

¹⁹ It should be noted that most discussions about the development of the social model of disability are rooted in British and US-based contexts; the British social model is rooted in Marxism (Goodley 2012), whereas the U.S. social model mostly used the signifier ‘people with disabilities’ to mark it as a minority group (Shakespeare & Watson 2001). In *Manifestos for the Future of Critical Disability Studies*, a ‘relational model of disability’ developed instead of the social model, which shares many semblances to the social model, but also acknowledges the situational nature of disability as well as how categorization of disability is oftentimes arbitrary (Kent et al 2). They refer to disability studies scholar Tom Shakespeare who notes that in the Nordic model, activism less heavily influenced academia when it comes to disability, and the researchers were (largely) non-disabled. Whilst my research and own positionality is situated in the Netherlands, I still think a discussion of the social model and (bio)medical model is important because it offers much of a framework for the (mis)understanding of dis/ability and the epistemologies that come from such frameworks – specifically, my first (and most encounters to this day) are still knowledges produced in British/American contexts.

²⁰ The words of Rosemarie Garland-Thomson, written in 2002, loom around many disability texts: ‘disability is the most human of experiences, touching every family and – if we live long enough – touching us all’ (363).

depression, MS and HIV/Aids (161-162). Most of these illnesses are marked by their treatability through medicine.

The use of terminology of “healthy” and “unhealthy” disability brings with it its own problematics. As Eli Clare (2017) notes, ‘today inside white Western medicine, health ranges from individual and communal body-mind comfort to profound social control. Between these two poles, a multitude of practices exist. Health promotes both the well-being sustained by good food and the products sold by the multi-million-dollar diet industry’ (14). Jasbir Puar, in ‘The Cost of Getting Better’ (2017) quotes Lauren Berlant in saying that the concept of health has been politicised as a form of successful normativity (12). People with diabetes also tend to distance themselves from the “sick narrative” (Walker and Litchman 2021; 915) when, in Wendell’s argumentation, they would be part of the “unhealthy” disabled²¹. Even though “health” is thus a problematised concept in itself, there is also a very useful dimension to its use in order to show how chronic illness does (not) configure within disability activism, especially when discussing disability pride²² and, for example, the less contested place that cure holds when you are “unhealthy disabled”.

Disability activism, Wendell poses, is much centred around how disability is a valuable form of difference or human variation, which should be celebrated and be seen as something to be proud of. The emphasis on the dimension of health points to this internal contradiction: ‘compare “Thank god I’m not disabled” with “Thank God I’m healthy”, and you see the difficulty of applying disability pride to a chronic illness’ (170). Wendell’s article expertly demonstrates, without perhaps directly making the argument, that indeed disability, chronic illness, and impairment is a question of both a sameness and difference, something that she has pointed out is a feminist issue and topic of debate relevant to disability activism, studies, and public perception.

Secondly, the topic of health, treatability and cure within disability activism and scholarly work has been widely debated: in *Brilliant Imperfections: Grappling with Cure* (2017), Eli Clare focuses on the much politicised, ideologised position that “cure” holds” within disability registers and lives. Clare notes that by researching the ideology of cure, he ‘... landed inside a knot of

²¹ I follow Berlant (2011) and Puar (2017) in saying that health and unhealthiness in the contemporary moment has been politicized and entrenched in neoliberalist meanings and practices of personal responsibility and narratives of success/failure of the individual person.

²² Tobin Siebers conceptualizes disability pride as a way ‘to reverse the negative connotations of disability’ (316). He argues that ‘it will be necessary to claim the value and variety of disability in ways that may seem strange to people who have little experience with disability studies. But it is vital to show to what extent the ideology of ability collapses once we “claim disability” as a positive experience’ (316)

contradictions. Cure saves lives; cure manipulates lives; cure prioritizes some lives over others; cure makes profits; cure justifies violence; cure promises resolution to body-mind loss' (2017, xvi). Eli Clare and Susan Wendell make reference to one another in how their notion of cure in relation to their research on disability existence is in contradiction with one another – indeed, there is no simple answer other than that it shows how deeply loaded, contradictory, messy and difficult disability and/as chronic illness is. One disabled person's grapple with cure can be the other disabled person's light at the end of the tunnel.

The focus on ideologies of cure and their complication in feminist/critical disability studies also could make people with diabetes feel excluded or misunderstood in their place within dis/ability. A lot of diabetes activism focuses on the need for cure and innovative in management strategies, because the long-term complications such as limb amputations and blindness (brought on by “ineffective management”) of diabetes *are* what is more commonly recognised as disability. The long-term complications supplant the day-to-day disabling effects in public discourse, arguably because it is the horizon of a physically disabled future through diabetes that seems more feared. This in itself reinstates the ‘compulsory able-bodiedness’ (McRuer 2006) surrounding diabetes – the contemporary disabling effects are superseded by the long-term *real* disabling effects of diabetes. In trying to imagine diabetes type 1 as a disability in a way that it should fit in a disability studies framework, the predominance of the cure narrative in diabetes discourse, not the notion of cure itself, is perhaps the issue. Cure focuses on medical and technological advances, as opposed to embodied experiences – showing again how difficult it is to not talk about chronic illness outside of medicalisation.

Eli Clare mentions diabetes sparingly in his book about grappling with cure; one instance is a conversation he has with a diabetic friend who says they would choose to be cured from diabetes tomorrow if they could. Clare notes that he ‘can hear your stream of thoughts: the daily insulin, the tracking of blood sugar levels, the shame, the endless doctors, the seizures, the long-term unknowns. You don't hate your body-mind, nor do you equate diabetes with misery’ (54). Even though this seems like an acknowledgement of how and why cure for diabetes is a logical desire, it also oversimplifies and displaces diabetes as a disability or its everyday unpredictability as disabling. Continuing with the words of Susan Wendell, ‘many of us with chronic illnesses are not obviously disabled’ (2017, 164); the insulin shots and the blood sugar levels and the doctor visits in Clare's text are indeed not posed as disabling, but rather as an inconvenience that can be

resolved by cure. This approach to diabetes also foregoes any complex engagement of life with diabetes beyond the tangible, visually interpretable aspects. As the example of Eli Clare's discussion of his friend with diabetes amply shows, the disabling embodied a/effects of diabetes are often forgotten or brushed over. It is precisely this focus on medical intervention (be it cure or being kept alive by insulin) which works as an alienation within disability discourse, as 'we have to remind people frequently of our needs and limitations' (164) beyond the fact that diabetes is curable, treatable, and only potentially disabling in the long-term.

Moreover, if you have to be the agent in relating to other people that you are in that moment impaired, questions of doubt arise – are you really disabled if it is not legible? This invisibility complicates the notion of "identification" with disability further. Susan Wendell discusses these doubts and complications under the notion of "suspicion", present both in relational spheres within the disabled subject, and in their environment – 'suspicion surrounds people with chronic illness – suspicion about how ill/disabled we really are, how or why we became ill, whether we are doing everything possible to get well, and how mismanaging our lives, minds or souls may be contributing to our continuing illness' (169). It can be said that this suspicion – about wanting to call attention to your disability when it is not directly apparent – is what leads to stigma and an invisibilisation of (un)stable diabetes.

In a society where, as McRuer (2006) argues, subjects are assumed to be able-bodied unless otherwise visibly queered through disability (400), and the ease with which this is possible for someone with diabetes, it seems logical that passing as able-bodied is desirable. This thesis specifically focuses on women with diabetes who fail to approximate the norm through the fact that their diabetes is experienced as hard to manage, but are still held to the standards of compulsory notions of approximating such norms (of "manageable diabetes"): it is precisely this gap that could make the able-bodied ideal of diabetes unstable. Interestingly, 'many people with diabetes simultaneously accept that diabetes identity and reject disability identity, along with any association of sickness. This paradox of identifying as a specific type of sick, but not as generally sick, may present limits on what a theory of diabetes identity can do' (Walker and Litchman 2021, 915). We should also remember that having a compromised or invisibly disabled body is not immediately and always read/felt as subversive in the same way that drag performance is not always necessarily a subversion of normativity (Butler 2011, 85).

We can start to see exactly why diabetes type 1 does not lend itself to be positioned within a disability studies framework not only because chronic illness and disability are not considered one and the same, but also because diabetes seems to be distanced from both the narratives of “illness” and “disability” entirely. Arguably, the public face of diabetes type 1 has run parallel to many of the movements of disability in academic and public discourse – in that it has tried to prove that despite having diabetes you are not limited and should not be excluded. But through such moves, diabetes has somehow positioned itself in order to fit into the frame of “neoliberal inclusion” (Mitchell and Snyder 2015; 2020). Through this positioning, and the mostly invisible nature of diabetes, people with diabetes are visually able to be seen as able-bodied – the number of times I have heard people say they “never considered diabetes a disability” only further reproduces this idea. Mitchell and Snyder argue that ‘integration practices within neoliberalism largely short-circuit opportunities for more meaningful apprehensions of disability subjectivities that involve ways of experiencing and being disabled in the world’ (2-3), and indeed it seems that diabetes type 1 has mostly been successfully integrated: its positioning as ‘a specific type of sick’ separate diabetes from the notion of sickness as incompatible with capitalist productivity (Hobart and Kneese 2020, 4). The fact that diabetes is often not thought of as disability or a deficiency (nothing that medicine and technological advances cannot fix!) means that “neoliberal inclusionism” (Mitchell and Snyder 2015; 2020) has been achieved successfully²³. This inclusion, however, invisibilises any experience of diabetes outside of this discourse – “neoliberal inclusionism” sees disability as something that can be integrated into capital and “the normal” (Mitchell and Snyder 2015; 2020), rather than be used to question the category of the (st)able-bodied human and human variations.

On diabetes type 1 and the problem of visibility: paradoxes and contradictions

The question of whether diabetes type 1 should be seen as a disability and included in disability frameworks is both paradoxical and full of contradictions. Diabetes type 1 poses a problem for

²³ Jeffrey A. Bennett argues that the language of management and (self-)control further emphasises how embedded diabetes is within neoliberal conceptions: he claims that ‘the disciplinary tendencies that accompany diabetes highlight the degree to which management has been couched in and grounded by neoliberal conceptions of agentic subjects and their relationship to biopolitical performances of governmentality. That is, undergirding the logic of diabetes care regimens, there is an assumption of a person who has the ability to make particular, if undefined, choices in order to achieve an abstract goal of control’ (15) which is arguably why diabetes type 1 is generally not seen as disabling (it can be controlled) and what has allowed for the narrative of diabetes (type 1) to be accepted in neoliberal inclusionism. More on this in chapter 3: “Control”.

frameworks of disability, namely, how to be recognised as disabled when your disability is – mostly - invisible? How to recognise the disabling factors of diabetes when such factors have been invisibilised through the able-bodied public face of diabetes? How then to recognize oneself as part of disability studies, when diabetes experience is illegible within most of the discourse in the field?

Firstly, and perhaps most obviously: diabetes is a medical disease. It can be diagnosed through “hard data” of urine tests and blood tests. Diabetes, unlike chronic pain, is not a contested condition – you either have diabetes or you do not. Tangible, societal changes in terms of spatial access are not going to change whether a person with diabetes is disabled or not. In that sense, diabetes seems both neutral and apolitical. This position also makes it very difficult to talk about diabetes *experience* without slipping into a medical register. But, as Eli Clare notes, ‘diagnosis can become a cover for what health care providers don’t understand; become more important than our messy visceral selves; become the totality of who we are’ (2017, 42).

Secondly, there is the confusion between diabetes type 1 and diabetes type 2²⁴. Type 2 can be (but is not always) curable, and can be caused by environmental and social circumstances (as Alison Kafer argues in the introduction of *Queer. Feminist. Crip.* (2013)), type 1, on the other hand, is classified as a chronic disease – causes are unknown²⁵. However, the continuous confusion between the two makes it complex to include within disability studies, especially from an outsider perspective. Even though Kafer rightly points out that diabetes type 2 is caused by social and environmental circumstances (Kafer 12), she never specifies that it is type 2 diabetes that she is referring to: for a critical evaluation of diabetes (both type 1 and type 2) within feminist/critical disability studies, an obvious beginning is to make very clear distinctions between the two, without falling into the trap of hierarchising one over the other as “worse”. Aside from this, there are

²⁴ In reality, there are more types of diabetes, but in public understandings diabetes is usually divided into type 1 and 2. Treatments for type 2 vary, and because I consider type 1 and type 2 to be so vastly different, and the whole point of this thesis is that it is so difficult to fully *understand* a disability from the outside without (re)producing simplifying, convoluting, or ignorant knowledges, I will not go (too much) into type 2 diabetes. I do want to note, however, that there is a current discussion on diabetes awareness platforms to emphasise that you are not only insulin dependent when you have type 1, but can also be insulin dependent with type 2 diabetes. In other words, even the boundaries between type 1 and 2 are more fluid than they are posited.

²⁵ And not (merely) genetic, as most people assume. I asked my interviewees if anyone in their (extended) family had diabetes, and the answer was no. I am in the same boat. When I worked as a waitress in Melbourne, customers would often ask about my diabetes and sometimes say something smugly about how they could not get diabetes because it does not run in their family, to which I would respond that it did not in mine either, so you could technically wake up tomorrow and find out you, too, are diabetic (enjoy your breakfast!).

different gradations of the manageability of diabetes – thus, not only is the clear distinction between type 1 and 2 necessary, this difference within diabetes type 1 experience should also be recognised: a move towards a multiplicity positionality within the category of “diabetes type 1” is much less discussed but very much long overdue.

Thirdly, until the invention of insulin in the 1920s, diabetes was a fatal disease. Obviously, diabetes type 1 was not cured, but instead of inadvertently leading to death, it now became a disease “manageable” by the use of medication. Jeffrey A. Bennett, in *Managing Diabetes: The Cultural Politics of Disease* (2019) notes that the discovery of insulin led to ‘the “happily-ever-after” account of life with diabetes that circulated widely and that did not accurately reflect the daily realities of management’ (192). He argues that with the invention of insulin – a tangible solution that prolonged the life of people diagnosed with diabetes, ‘Public narratives extolling the ease of management quickly supplanted the fatalism that characterized medical anecdotes about diabetes treatment, care, and longevity’ (182). It would be easy to say that, perhaps reductively, the invention of insulin caused the pendulum to swing the other way: from fatalism to liveability (or from “failure” to “success” on the scale of death/life).

There is definitely some truth to this: I am not complaining about the fact that insulin exists and I am also not trying to claim that I do not owe my life to insulin. I am indeed able to (mostly) fully participate within society (whatever this means). Diabetes type 1, in this way, inadvertently falls into the rhetoric of “able-bodiedness”. As Robert McRuer argues in his seminal essay ‘Compulsory Able-Bodiedness and Queer/Disabled Existence’ ([2006] 2017), ‘even though the language of “the normal relations” expected of human beings is not present in the definition of able-bodied, the sense of “normal relations” is, especially with the emphasis on work: being able bodied means being capable of normal physical exertions required in a particular system of labor’ (399). Thus, this obscuration causes diabetes type 1 to “successfully perform” the hegemonic mainstream identity of the compulsory able body: McRuer says that ‘the cultural management of the endemic crises surrounding the performance of heterosexual and able-bodied identity effects a panicked consolidation of hegemonic identities. The most successful heterosexual subject is the one whose sexuality is not compromised by disability (metaphorized as queerness); the most successful able-bodied subject is the one whose ability is not compromised by queerness (metaphorized as disability)’ (400). Disability, McRuer argues, is ‘often understood as somehow queer’ through the way disabled bodied are interpreted through asexuality/hypersexuality (400).

By emphasising diabetes embodiment as able-bodied, diabetes type 1 identity becomes “normative”, and in this sense, diabetes type 1 is both not conceived as disabled nor queer, taking diabetes out of the disability equation. Diabetes in this way can easily perform as an able body, not as having a lack, but as a whole (with the help of additional supplements).

However, as Bennett notes, this “happily-ever-after” narrative overrides and obscures the difficulties of “management” and day-to-day hardships, despite the fact that insulin exists and keeps us alive. Indeed, I place this into an able-bodied rhetoric because, as ‘suffering caused by the body, and the inability to control the body, are despised, pitied, and above all, feared’ (Wendell 1989, 112). There seems to be no room for a discussion for what such a life might look like, because such discussions might indeed reveal the scary, unstable dimension of how diabetes can never fully approximate the norm of the able-body or expose ‘the failure of science and medicine to protect us all’ (116).

Because of the continuous improvements and advancements in technology for diabetes management in the last 100 years, such as synthetic insulin, and after that the insulin pump and the flash/continuous glucose monitors (also called “sensors”), diabetes type 1 digs itself deeper into fitting this “able-bodied” definition. I argue that the public face of diabetes type 1 since the invention of insulin is immersed in and continuously seeks to prove its proximity to the able body, to show how people with diabetes type 1 are really like “everyone else”. For example, Theresa May has been able to lead a nation with diabetes type 1 – as a matter of fact, Theresa May’s diabetes never even seemed to be a point of discussion unlike with Supreme Judge Sonia Sotomayor in the United States ten years prior²⁶.

The strong emphasis on “manageability” with diabetes takes away the dimension of disability that displays the ‘fragility and unpredictability of embodied entities’ (Goodley 2012, 639). That is, people with diabetes can not only live “happily ever after” now, they are posited as agential subjects about, and have personal control over, the course of their disease which completely obscures the disabling effects in the present. I will go further into the able-bodied character of diabetes throughout the thesis, but it is important to continuously emphasise it because

²⁶ See ‘4. Containing Sotomayor: Narratives of Personal Restraint’ in *Managing Diabetes: The Cultural Politics of Disease* for a very enlightening discussion on an intersectional analysis of the (re)percussions of the public face of diabetes management.

this is indeed so foundational about why the acknowledgement of diabetes in/as disability (studies) is so complex.

The complicated relationship of people with diabetes to their illness is twofold: both because of the able-bodied rhetoric surrounding diabetes, but also because of the truly abstract idea of being sick “chronically”: what does this even mean, and how should one envision this? How does one embody such a temporality? The difficulty in trying to figure out how to position oneself with diabetes – arguably even further complicated through the able-bodied dimension of diabetes – looms over people with diabetes type 1. Indeed, it is precisely this “grey area” position that presents tension in the inclusion of diabetes type 1 within feminist/critical disability discourse, showing that the problem of exclusion and (not) wanting to be included comes from both sides. Alison Kafer (2013) also echoes this when she urges for the inclusion of diabetes in feminist/critical disability studies, but also acknowledges that

this forging of crip communities, means accounting for those who do “have” illnesses or impairments, and who might be recognized by others as part of this “disabled we,” but who do not recognize themselves as such. This group would include the largest proportion of disabled people: [such as] those folks with [...] diabetes who, for a whole host of reasons, would claim neither crip identity nor disability. [...] indeed, I think it is the hardest group for disability studies and disability rights activism to address. Given my (our) focus on disability rights and justice, on radical queercrip activism, on finding disability desirable, how am I (or how are we) to deal with those who want no part of such names? (13-14)

Rosemarie Garland-Thomson (2017) urges those who are able to pass as non-disabled to reconsider what this means, because ‘by disavowing disability identity, many of us learned to save ourselves from devaluation by complicity that perpetuates oppressive notions about ostensibly “real” disabled people’ (375). Able-bodied notions about diabetes seem to be deeply internalized, where, as Walker and Litchman (2021) showed, diabetes oftentimes not even seems to be recognized by diabetics as a “sickness”, let alone a “disability”. This is a move in itself which can be explained by how sickness is a stigmatised position within contemporary neoliberalist Western society (Berlant 2011, 95; Goodley 2014, 92) – but also because disability often still has a subtext of static embodiment. No matter the political status of disability, doubtful questions of the fluctuating nature of the disabling factors of chronic illness make it hard to fully relate to a disabled position as it currently stands (Driedger and Owens 2008, 8).

Arguably, this calls for an analysis and reconsideration over terminology of healthy/unhealthy, sickness, ability, and disability – which is an ongoing debate in the field of Feminist/Critical Disability Studies. As Margrit Shildrick said, ‘we need to remind ourselves that the embodied self is always vulnerable, and that the normative parameters of the embodied subject as defined within modernist discourse are based on illusion’ (2019, 42). I argue that thinking through diabetes differently, namely a ‘critically queer, severely disabled’ perspective (McRuer 401-2) through those who struggle with diabetes’s (un)stability, allows us to think through dis/ability differently, and vice versa.

Towards a relational, cripistemological approach in feminist/critical disability (studies)

The main voices often cited in feminist/critical disability studies have already moved long beyond the question of the social or medical model of disability, and attempting to include all kinds of disability has become one of the base requirements for the field. Alison Kafer (2013), for example, proposes a ‘political/relational model’ of disability, where ‘the problem of disability no longer resides in the minds or bodies of individuals but in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being’ (6). In trying to define the political/relational model, traces of the social model can still be found – disability is still conceived outside of the individual and historically situated. However, the main distinction that Kafer makes is that, unlike within the social model, she is not strictly against medical intervention. She adds the critical layer where she recognises that ‘medical representations, diagnoses, and treatments of bodily variations are imbued with ideological biases about what constitutes normalcy and deviance’ (6).

A similar move happens in David Bolt’s *Metanarratives of Disability* (2021) where the premise of the research focuses on how disability experience should not be merely located in the embodied, personal experiences, but continuously placed in the context of the metanarrative of disability, which is shaped by the cultural, normative frameworks that enables assumed authority derived from a normative social order which (re)produces stigmas and ableism. Thus, metanarratives move outside of the social model through its integration of a kind of oppression and discrimination that is embedded in ‘the normative social order’ (Bolt 2021). In other words, people in an outsider position often derive a form of authority about people with disabilities, shaped by tropes, stereotypes and myths formed through medical and cultural representations of

disability, in which the authoritative form takes shape in (not always in ill will) advice about what the disabled person *ought to do*. David Bolt argues for a move towards ‘autocritical disability studies’ (xviii) because he argues both that disability is incredibly multifold and diverse in its experiences, and also because any form of outsider’s perspective of a disability will inevitably fall into the trap of the existing metanarratives around disability.

In this sense, Alison Kafer’s “political/relational model” and David Bolt’s concept of “metanarratives” mark a critical move that allows to make room for those who have chronic illnesses through the fluid, inclusive boundaries of their approaches; they both emphasise the need for (crip)epistemologies that are produced from situated perspectives to not (re)produce common (mis)interpretations about a disability/chronic illness. Their approach includes the materialized, embodied notion of living with a disability, but also locates the way disability is *experienced* as a negotiation within the body and between the body and the discourses and surroundings of medicine, culture and society. Kafer and Bolt’s edited volume recognising the political and ideological dimension of the field of medicine and medical treatment opens up new doors to approach medical chronic illnesses such as diabetes. Reliance on - and access to - medicine does not equate to not being viewed as disabled.

The concept of ‘compulsory able-bodiedness’ (McRuer 2017) similarly tries to move away from or beyond the binaries of the question whether disability should be seen as medical or social; of course, the theory of compulsory able-bodiedness resides within the social construction of naturalising certain ways to be as biological facts of life. At the same time, McRuer’s text still (subconsciously) centers a demarcated idea of disability²⁷. My first reaction to reading compulsory able-bodiedness was a sense of alienation, not understanding how I could be ‘severely disabled’ (402), which McRuer conceptualises as a form of resistance that ‘loudly call[s] out the inadequacies of a given situation, person, text or ideology’ (402). The examples that McRuer uses to illustrate the concept of being “severely disabled” all reside within the visually legible versions of having an impaired body too. These tangible forms of disability only complicated how I felt that I could (not) identify as disabled and use my disability as a resistance. The only way to visibly be “severely” disabled with diabetes, on the surface, is by pointing to the visible, long-term complications of diabetes (as is already happening in current diabetes activism). This approach

²⁷ Diabetes is mentioned once in all of the texts included in this thesis by Robert McRuer, and only in the context of being challenged by students who wrote diabetes as a form of alternative corporealities (2006, 161).

displaces disabling diabetes experiences temporally – namely, as a futurity – and thus also does not take diabetes type 1 out of the able-bodied rhetoric it seems stuck in (even if this able-bodied status is, as is shown through long-term complications, temporary). Another way would be to have visual aids, such as a glucose sensor, insulin pump, or even insulin injections, though this usually leads to an interpretation of the manageability of diabetes. This, thus, does not lead to calling out the inadequacies of compulsory able-bodiedness in the way that McRuer envisions, and it does not adequately lead to a deeper understanding of how diabetes type 1 is disabling. As Ellen Samuels (2017) points out,

the focus on specularity and visible difference that permeates much disability theory creates a dilemma not only for nonvisibly disabled people who wish to enter the conversation but for the overarching concepts of disability and normalization themselves. Passing, closeting, and coming out become vexed issues that strain at the limitations of the discourse meant to describe them (346).

Thus, even if critical disability studies has successfully moved beyond residing in the social/medical model, it also proves that it remains very difficult to fully materially realise more inclusivity.

Since McRuer's conception of compulsory able-bodiedness, he has more broadly developed a *Crip Theory* (2006), indeed also moving beyond talking about 'disability' as such; McRuer and other feminist/critical disability studies scholars²⁸ have adopted the term "crip" both as a verb and a noun (McRuer 21-22). The term crippling is borne out of the convergence of disability studies and queer theory, and thus in itself is hard to give a neat, contained definition. It rather signifies by 'what it might potentially become (as a process) than by what it is' (McRuer 2018, 22). The term also signifies a further inclusion of all kinds of dis/abilities, aims for coalition and solidarity between those that are "able-bodied" and people with disabilities and uses disability identity politics while also disavowing these "deindividuated disability identities" (McRuer 2006, 72)²⁹. This (dis)identification is illustrated through an example of McRuer coming out as HIV-positive, whilst leaving it ambiguous whether he *is* HIV-positive (53-57). Intuitively, I feel like the word "crip" still assumes two positions: an acknowledgement of diabetes type 1 as a disability both culturally and epistemologically, which as it currently stands is not the case. Secondly, I have trouble with the term because "crip" also still signifies – despite its open-ended undefinedness – a

²⁸ Including Kafer, who positions herself as 'Feminist. Queer. **Crip.**'

²⁹ This is one of the five aims listed in *Crip Theory: Cultural Signs of Queerness and Disability* (2006)

very legible way of being disabled. To me, those two issues are entangled by the way diabetes is scripted in ability. Disclosing that you have diabetes rarely leads to being read as disabled how to “claim crip” despite this? Yet, paradoxically, theorising and analysing diabetes through a queer/crip position might open a world of possibilities.

In 2014, McRuer and Johnson co-authored an introduction to a double-fold issue of the *Journal of Literary & Cultural Disability Studies*, in which they coined the term ‘cripistemology’. Cripistemology, a play of words on crippling epistemology, poses that ‘neoliberal disability epistemologies are highly lucrative [...] disability identity is now part of capitalism’s array of target markets; a “crip economy” akin to the globalized queer pink economy’ (128). Their critique on the neoliberal conception of knowing disability is a much refreshing, and very clear move, away from the medical/social binary of disability. They very specifically point to the inclusion of disabilities that are not particularly legible. They point to the ‘knowing and unknowing of disability’, the ‘making and unmaking of disability’, and ‘challenging subjects who confidently “know” about “disability”’. We were questioning, in other words, what we think we know about disability, and how we know around and through it’ (130). They are also careful not to automatically perceive the disabled person’s perspective as epistemically privileged, though they do say that ‘Lorde [in *The Cancer Journals*] and many others do foreground the ways in which disability experience *in relation* produces new/different/better knowledge’ (141), which shows that there is still a subtext of exceptionalism (specifically by using the word “better”) for the person with disabilities. However, in a way they forego this type of exceptionalism at the same time by saying that ‘disability knowledge – embodied and relational – is *about* disability [...] and extends *beyond* disability’ (141). Disability, much like gender, race, sexuality, and class, is an axis of identity that grants a particular way of relating to the body, the precarity of life/death, and culture more generally and should be integrated as such.

The move towards relationality as I understand it both acknowledges how some disabled people are dependent on medical intervention, but it simultaneously de-neutralises and politicises the medical-industrial complex and its ideologies. In this way, the emphasis on relationality makes critical disability studies much more inclusive – with the recognition that these *cripistemologies* need to come from the “inside” (or to make disability studies “autocritical”). It opens up possibilities for thinking diabetes type 1 as disability, because it does not disavow its status as a disability simply because you use medicine; it does not disavow its status as disability because it

is not easily legible; if anything, it makes diabetes legible by showing how any experience of disability is always relational on a variety of levels. In the case of diabetes, I know these disabling experiences intimately: it is the relationality of the constant fluctuation of your blood sugars affecting your brain capacity, the paranoia that comes with (un)stable blood sugars (which can be affected by innumerable identifiable but also infinite inexplicable abstract causes), the debilitating low blood sugars, the debilitating high blood sugars, the unpredictability of how much glucose/insulin you should take to fix those (which you have to think about rationally when you are already in a debilitated state, mind you), the varying recovery times after those critical medical situations (which can last from 10 minutes to two hours to sometimes an entire day) plus the actual space you have to recover, and how to configure all of the above in everyday functioning. Moreover, it opens up space for the acknowledgement and analysis of “positive affirmative” yet still very ableist remarks such as “diabetes is so manageable these days” (which come from outside *and* inside the disability community) to the even more ableist subtexts (“you are in a high risk group so it makes sense that you take this COVID-vaccine that I am so wary of, because for your already compromised body, it is different”).

Chapter 2: “Self”

Finding subversive dis/ability identity between shame/pride and (un)acceptance

Introduction: between shame/pride and (un)acceptance

I have always struggled with the notion of how to (publicly) relate to my diabetes, specifically in relation to my own identity. In the introduction of this chapter, I will use two illustrative examples to explore diabetes and disability identity. These examples highlight why it was and is so difficult to think about diabetes identity, diabetes and disability (identity) and relating to diabetes. From the moment I was diagnosed at the age of 6, I participated in a host of variety of events aimed at children with diabetes – from fun day activities to the diabetes camps or trips organised a few times a year. I went to diabetes camp twice. When I reflect back to those events, what stuck with me most is the difficulty I had relating to others – I felt like the fact that we *all* had diabetes did not make us the same. We had different carbohydrate intake allowances, we had different technological tools for our diabetes, we used different terminology to talk about diabetes, we had different fast carbohydrates of choice for when we had hypoglycaemic episodes. I also remember extremes: people who (seemingly) had no issues with their diabetes and were well regulated, and people who threw their insulin pens in the hotel bins as a form of childhood resistance against diabetes. I could not relate to either of them: I was neither a “happy diabetic” (I had way too many issues with diabetes regulation regimes and management for that), nor did I ever feel the need to resist treatment to make a statement. I also never felt the need to place diabetes at the forefront of my life.

I hated those camps. What I maybe hated most about them was how diabetes was so front and centre. As if diabetes was the human connector that made us relate to one another³⁰. Indeed, as Anzaldúa argues that the reason she disidentifies from a disability identity in relation to her diabetes is because, *‘the disabled category is a particular form of “Otherness”*; all such western notions of “Otherness” are exclusive and hierarchical, and tend to homogenize, deface, and

³⁰ Ignoring, for example, different socio-economic and cultural backgrounds (though those camps were expensive, so the participation was not extremely diverse in that regard); secondly – and this might be my distorted memory – there were mostly girls, and most of them were white, middle class, and blonde. Even before I was diagnosed with diabetes, this was not particularly a group of people I strongly identified or “felt at home” with.

compress a large number of people under one particular form of “Otherness”, allowing issues of class, cultural diversity, ethnicity and gender to be ignored’ (2009, 304, italics added).

I often got accused of being “ashamed” or “unaccepting”³¹ of my diabetes (even though to me the ultimate portrayal of such unacceptance was throwing insulin pens in hotel bins). Any representation I saw about diabetes seemed to take place on either side of the binary, whereas the lived experience seemed much more unstable. These binary framings seemed to offer a narrative framing of *knowing* and intelligibility of an embodiment which in reality felt much more abstract and complex³². Due to the – to me – defamiliarising binary and moreover terrifyingly simplifying way of thinking about living with diabetes as pride/shame and acceptance/unacceptance (which both place the “problem” of diabetes within the individual), I disidentified from anything diabetes outside of my own.

When I was maybe 12 years old, I asked my doctor how to wear my insulin pump without everyone noticing, because I was tired of being stopped in the street or at the local swimming pool by people asking what I was carrying on me. I was once giving a presentation for an open day at school, and when the kids in the audience could ask questions, they were all about the insulin pump in my pocket. Well-meant, sure, but these moments were exhausting and often packed with ableist subtexts. I was tired of always being singled out by my marker of “difference”, about something people kind of *knew* something about but also not really, and the tireless remarks following it. My doctor told me I was ashamed of my diabetes. I hated that my entire being seemed to be predicated on having diabetes whenever something diabetes-related was visible. The insulin pump, aside from its annoying visibility, came with other inconveniences too, such as the type of clothes I could wear (they always had to have pockets, which women’s clothes notoriously often do not have). Otherwise, there were dysfunctional bands that I could put the pump in, in case I wanted to wear a dress (that always sagged from my child body, straining the infusion-thread, sometimes causing

³¹ Heather Walker (2021) points to how in the medical world, patients with diabetes are encouraged to “accept” diabetes ‘into one’s self-concept’ because it would improve self-management, leading to a conceptualization of diabetes identity placed within the individual, and making it an individual pursuit. She distinguishes between an identity in diabetes versus diabetes identity, claiming the first version is a de-politicised form of diabetes identity whereas claiming diabetes identity has as a condition that you ‘must also reckon with the history of abuses others with diabetes have faced’ (283-284). Whilst I recognise that this political move is necessary and valuable, I rather aim to question the demarcations of identity boundaries more generally, to question what individual experiences of alienation from broader diabetes narratives might offer us in terms of alternative epistemes and disability paradigms.

³² I recognise that for some people, such narratives are a way of coping with the reality of living with a chronic illness. After all, in the words of the late Joan Didion opening her essay ‘The White Album’ (1979) we need stories to make sense of life and the things around us in order to *live*

the infusion set to come out prematurely). I was also told that I could stuff the pump in my bra (long before I developed breasts)³³. I felt like being attached to a machine at all times limited my freedom instead of increasing it. Because of the visible marker of a medical aid which people interpreted as a device that could make you lead a “normal” life, it always felt like discussions on the restraints of such devices were foreclosed by their supposed usefulness.

When, in 2016, my doctor suggested that I could start using the glucose sensor³⁴, I had long negotiations with myself weighing the pros and cons of whether I was willing to expose myself again to strangers without diabetes who felt the need to make authoritative³⁵, but well-meant, remarks about my diabetes and how I should or could be managing better (or even tips to cure it!). These days, my diabetes is invisible most of the time, unless I am wearing sleeveless tops that reveal the glucose sensor attached to my upper arm (and even, often when exposed, people think the sensor is a nicotine patch). These aspects contribute to the fact that my diabetes is not read as a disability or as disabling: the only visible marker is one that signifies a form of management (whether it is “managing” blood sugars or a smoking habit). This is how people can make sense of diabetes: they can perceive what is on the outside, and what is visibly legible from the outside are those attributes that help with “management”. Aside from that, ‘the fact that type 1 is largely invisible – both interpersonally and in the public sphere – likely contributes to the idea that it can be casually managed’ (Bennett 2019, 11). Diabetes in disability scholarship (and more specifically in disability scholarship about identity³⁶), I argue, is often disregarded because of this

³³ Sky Cubacub’s essay “Radical Visibility: A Disabled Queer Clothing Reform Movement Manifesto” in *Disability Visibility* (2020) made me realise that this was not my stubbornness of wanting to wear specific types of clothes, but that clothes are mostly designed for able-bodied people, and that this is a disability justice issue.

³⁴ Which, at the time, became more commonly used. The glucose sensor only became covered by health insurance for all insulin dependent people from 10/12/2019, unless you met certain requirements (see: <https://www.diabetestype1.nl/onderzoek/behandeling/68-vergoeding-van-de-freestyle-libre-waar-staan-we-nu>). I will explore the contradicting and gendered nature of these requirements more fully in chapter 3.

³⁵ David Bolt starts the prologue of *Metanarratives of Disability: Culture, Assumed Authority, and the Normative Social Order* (2021) with this example: being out and about as a disabled person, and being corrected by people on the street, people at work, or essentially anywhere where there is social contact (xvi). Bolt contextualises this as ‘a primary example of normative arrogance cloaked in helpfulness and [it is] often accompanied by virtue signalling’ (xvi). He argues that it is part and parcel of being included, but that it diminishes the voice and agency of disabled people. Personal narratives of people with disabilities are displaced by the ‘received wisdom of the normative social order’ (xvi) which is derived from myths, tropes, and stereotypes in various media and cultural landscapes. In the edited volume, Bolt points to something that is – I argue – still not given enough attention in disability scholarship; namely, how (re)presentation of disability gives able-bodied people a sense of authority and right to comment upon disability, still othering it, from what Bolt calls the ‘normative social order’, which in turn also effects your embodied experience of having diabetes.

³⁶ For example, I quote Rosalyn Darling in *Spoiled Identity: Self and Disability in a Changing Society* (2019) on the first page of the introduction to her book about self-conception and disability: ‘clearly, a person with an impairment

trope of ease. The emphasis lies on the existence of medical aids that both single out your difference but at the same time put people at ease because it shows how your difference can be contained. It is also precisely this trope that I am trying to trouble here: the casualness of diabetes – especially the way diabetes “management” and thus, living with diabetes, is portrayed as being about regimes rather than unpredictability (diabetes can be cured by cinnamon³⁷, a diet of brown rice³⁸, not eating sweet things³⁹, lifestyle management, just check your blood sugars!).

On top of that, the assertion that I was not doing diabetes right because of “bad results” in the doctor’s office and my disdain for the shame/pride politics of visibility, combined with the narrative that “diabetes is not so bad”, often makes its instability feel like a personal failure (rather than an attribute of having a disability). I knew I could not be the only one who felt the same difficulties and internal contradictions – and to supplement this different way of thinking of living with diabetes that does not rely on people who identify with “pride” or “shame” when thinking about their relationship to their diabetes, I set out to find them. I am lucky to have found three women, who were struggling with regulation and their relation to their diabetes⁴⁰: Felice, Brechtje, and Sille⁴¹. Whilst Felice, Brechtje, Sille and myself all feel disabled by diabetes in different ways, none of us strongly positioned ourselves as having a *diabetes* or *disability identity*.

Queering diabetes: failure, knowledge, and identity

I want to, instead of dismissing our reluctance to identify with such frameworks as internalised ableism, shame, or unacceptance, question what this reluctance says about diabetes, disability, and identity more generally. In this sense, I follow Kim Q. Hall in ‘Queer Epistemology and Epistemic

such as asthma or diabetes may experience some limitations in life activities but probably will not encounter the stigma and social exclusion experienced by an individual with cerebral palsy who uses a wheelchair and a speech synthesizer’ (1). Whilst I appreciate where she comes from and the point she is trying to make, such statements can cause feelings of exclusion when thinking about how diabetes is disabling, because it has a subtext of “not being disabled enough” through the (assumed) proximity to the able-bodied world.

³⁷ This is something I saw commented on in meme-form on social media the other day. Likely spread through misleading headlines such as: <https://www.healthline.com/nutrition/cinnamon-and-diabetes>

³⁸ A personal anecdote

³⁹ A common misconception, especially because diabetes in the Netherlands is also referred to as ‘suikerziekte’ or ‘sugar disease’.

⁴⁰ See ‘notes on method/ology’ for a more elaborate discussion on the participants and method and methodology.

⁴¹ And, once you start delving into this “failure”, you end up finding that this failure is more present than it initially seemed – Félice forwarded me a post by diabetes meme Instagram-account @insulin_and_tonic, and through algorithms, I ended up at meme account @dankdiabetismemes, in which this failure and unknowing is much more on the foreground of diabetes experience. I had never been suggested such accounts or before this. More on this in chapter 4.

Injustice' (2017) that 'attention to the risks entailed in the use of identity categories, attention to what or whom they include and exclude, can be a source of queer epistemic resistance that denaturalizes dominant narratives and reconceptualizes, rather than rejects, identity' (2017, 161). Through positioning our resistance as queer/crip, I am not attempting to claim a holistic, catch-all theorisation of being with diabetes type 1. I also do not aim to argue that everyone with diabetes type 1 has the same frustrations that me and the interviewees struggle with⁴². Walker and Litchman (2021) argue that, due to medical research highlighting how tight management of diabetes could lower your risk of complications, a "pull yourself up by the bootstraps" mentality developed in diabetes care. This mentality creates a level of shame that could also contribute to the reluctance for some to portray or discuss the unstable nature of diabetes (2). As Felice pointed out towards the end of our long conversation, my research could be seen as controversial by some people that are part of the diabetic community who identify with a more able-bodied or neoliberal positionality of living with diabetes⁴³ (for those whose bodies do not respond unpredictably⁴⁴). I argue that is also reflected in the public face of diabetes – the focus on management, as Bennett (2019) puts it – (re)produces the narrative that diabetes is liveable and not disabling, which seems to foreclose the discussion on the complexities or the messiness of the disease⁴⁵ in favour of "neoliberal inclusion".

I also recognise the political move of portraying a "positive disability identity"⁴⁶ (as it leads to our inclusion in everyday practices), but it simultaneously almost inadvertently flattens the dimensions of living with diabetes, leading to various (public) misconceptions and misrecognitions – especially because of diabetes's invisibility, a public diabetes identity does not necessarily resistantly defy notions of compulsory able-bodiedness. I argue that, on one part, the difficulty of conceiving of a "diabetes identity", or even a "disability identity" is by the way that, even if it strategically uses identity politics, invisibilises a large group of people who do not fit into the

⁴² Though I do find that this project is a form of consciousness raising to myself and my own relation with and to diabetes, so who knows what I might achieve with this research for others?

⁴³ Félice, Interviewed by Diana Willemijn Helmich, Amsterdam, 1/10/2021.

⁴⁴ Some responses I received to my (Instagram) call for participants, interestingly, were from people who did not have issues with predictability. I hope to make clear that I am not trying to posit some extreme form of a stereotype, nor an us-versus-them mentality – I am merely looking for a specific experience.

⁴⁵ Arguably, this is because of the strong imposed medical regimes that argue that not achieving stable blood sugars is a result of "poor management".

⁴⁶ As Tobin Siebers argues for in 'Disability and the theory of complex embodiment' (2017), a positive disability identity is a political move to offset the negative connotations and the ideology of ability which creates a fear of disability, and which signifies disability as a loss (2017). I will elaborate on this further later in this chapter.

“characteristics” of how diabetes/disability is seen in these politics. I do want to acknowledge Heather Walker’s remark that ‘bringing diabetes into [her] self-concept has been a political act requiring unlearning and unconditioning’ of “self-exceptionism” against other diabetics, internalised ableism, and navigating the “blame game” of how your diabetes came about (2021, 282).

I do not want to position myself as an all-knowing, neutral figure with diabetes who is exempt from internalised ableism and biases; nor do I want to position myself as knowing the answer or “right” way forward. This is a cripistemological attempt to *queer* knowing and always *knowing*, be it in the form of management and control of diabetes, or the way you can position yourself towards diabetes. The point of cripistemologies, as Halberstam points out in the virtual roundtable discussion ‘proliferating cripistemologies’ (2014), is to acknowledge how it is about knowing, unknowing, and failures to know (152). As I stated in the introduction of this chapter, I have a hard time configuring how to relate to diabetes in terms of identity, and I do not think this difficulty should be disregarded as a simple ignorance or misunderstanding of my own positionality. This difficulty is shared by the three people I interviewed: I specifically picked people to talk to about diabetes who did not have an overt diabetes type 1 social media presence, because I felt that it was this group who is underrepresented in diabetes discourse: not the proud diabetic, nor the unaccepting diabetic

I trace the three conversations I had alongside my own experience with negative affects of “failure” in diabetes to expose the gaps of and the way we can think of and about identity and how diabetes configures in this. I differentiate this negative affect and failure from throwing away insulin pens by positing that all four of us take our diabetes seriously, but despite our best efforts, seem to “fail” to meet the conditions of management, controllability, and, through certain refusals, are not seen to “properly relate” to our diabetes. The use of “failure” as a heuristic is borrowed from Halberstam’s *The Queer Art of Failure*⁴⁷ (2011), where the crux of the argument is that there are ‘subjugated knowledges’ or ‘counterhegemonies’ in analysing this failure. Halberstam follows failure in optimism and silliness, but also ‘turn[s] the meaning of failure in another direction, at the cluster of affective modes that have been associated with failure and that now characterize new directions in queer theory’ such as ‘futility, sterility, emptiness, loss, negative affects in general,

⁴⁷ Both Margrit Shildrick (2015) and David Mitchell & Sharon L Snyder (2019) make use of Halberstam’s work, which suggests that thinking through queer failure opens up different or new directions in thinking about disability.

and modes of unbecoming’ (2011, 23). Halberstam contends that these more negative associations of failure point to a sense of unbeing, and that ‘these modes of unbeing and unbecoming point to a different relation to knowledge’ (ibid). I argue that through the binary framings of shame/pride and (un)acceptance of diabetes, those that fail to fit these frames of being with diabetes are in a state of unbeing. Their positionality is overlooked or not taken seriously through the personal failure ascribed to them. Failure forms the entry-point in this chapter to offer a counterhegemony to the trope of *knowing* that takes up much of public diabetes discourse – whether through the emphasis on biopolitical tools of measurement (such as blood testing, insulin pumps, glucose sensors), to knowing what and how you feel and relate to the messiness of diabetes, to claiming visually and visibly that you have diabetes and are (not) disabled.

The three conversations, alongside a tremendous amount of self-reflective thinking about my own relationship to diabetes type 1, uncover a form of messy embodiment, one that is not contained within “neat” forms of a legible diabetes or disability identity both to oneself nor to the outside world. Even though I insist on breaking outside of the strictly medicalised discourse around diabetes, I wanted to point to how this messiness is beautifully illustrated by the blood glucose graphs obtained through the glucose sensors⁴⁸: “good diabetes management” is reflected in straight, stable lines. “Bad diabetes management” is reflected in a chaotic up and down spikes and drops of glucose measurements “out of target” (accompanied by dramatic arrows $\uparrow \downarrow$  ). The lines turn from black to bright red when someone with diabetes has a hypoglycemic episode⁴⁹. My graphs usually look like (I climbed) a mountain range, and the embodied experience feels like this too, in the way that these fluctuations are exhausting to body and mind. What I am trying to illustrate with this example these graphs constantly confront you with the messy and unstable reality of diabetes in a visual way through.

(Un)willful passing: interpreting legible dis/ability

In this section, I wish to explore the notion of “passing” with an invisible disability, not to disavow or avow “passing into normalcy” as a deliberate act of assimilation when having diabetes, but

⁴⁸ Which are now very commonly used in diabetes treatment in the Netherlands.

⁴⁹ A dangerously low blood sugar experienced by people with diabetes: I now consciously make the effort to refer to low blood sugars as “hypos” (the layman term for hypoglycemia) because of the amount of times I have been met with responses from people without diabetes who told me they “too had low blood sugars”.

rather to examine the processes of identification and disidentification that come into being when you (un)willfully pass as “abled”. The concept of “passing” allows for an examination of the way that we think about disability (identity) and the sociocultural aspects of diabetes. Often, there is a negative connotation to not *visibly* coming out as being part of a certain identity group.

Indeed, doing research about disability *and* diabetes identity reinforced the notion that I was a “bad diabetic” or suffered from “internalised ableism” because I would not continuously and overtly discuss or show my life with diabetes. This reverts back to the story I started this chapter with. Instead of dismissing these feelings of failure, questioning my political commitments or my own self-understanding and relation to the disabling chronic illness that I have been living with for 21 years, I think it is more productive to explore what cultural logics are attached to passing. Passing is often linked to “hiding” something: indeed, to be ashamed, to have a wish for a “normal” identity (Swain and Cameron in Samuels 2017, 346) which also reinforces the (un)acceptance framework. Otherwise, it can be read as not “accepting” that you are disabled, which forms a paradox simultaneously because of how chronic illness is often not read as a disability (Wendell 2017). However, passing can also be a form of survival mechanism, not necessarily in a form of assimilation, but to make life liveable – to dodge unsolicited advice or questions. Either you are met with confusion and ignorance about your specific disability (Wendell 1989), or people build on metanarratives (tropes, stereotypes, cultural myths) about what you should to treat/cure your disability: I would argue that this is also a differentiator between “passing as straight” and “passing as nondisabled”.

Felice talks about how people find it odd that she does not want to put “her diabetes on display”⁵⁰: they attribute a certain stigma to the fact that she is *choosing* not to put her diabetes on display, that she is trying to hide it. Felice mentions that stigmas such as shame and a deliberate choice to hide it are attached to non-visibility. She attributes to the way diabetes (and maybe disability) identity is thought of more broadly: either you are proud with diabetes and display that to the entire world, or you are ashamed about it and therefore choose to hide it. She notes that she has been living with diabetes for 23 years, that you can ask her anything and she does not mind answering questions. Felice feels good with/about herself (for as much as diabetes allows that), and she never actively chooses to hide it, but also never actively feels the need to put diabetes on display. In this sense, the notion of a “diabetes identity” has created a different “metanarrative”,

⁵⁰ Félice, Interviewed by Diana Willemijn Helmich, Amsterdam, October 2021.

to use David Bolt's (2021) concept, and one that still has negative influences: namely that you have ulterior motives if you do not display your diabetes. People who do not have diabetes still feel the need to authoritatively make assessments and assumptions about these motives and what your relationship with diabetes is. It is the able-bodied world telling you what acceptance or unacceptance of your disability looks like (we live in a visual world, marked by visual platforms such as Instagram and Facebook – if your identity is not legible, you must be “hiding” something).⁵¹ Felice makes clear that her refusal to fall into this legibility of having diabetes is a refusal to fall into the binary narrative of diabetes pride/shame, as she emphasises self-confidence and openness to discuss diabetes whenever people have questions.

Two public figures that I would also briefly like to turn to further complexify “passing” with diabetes are United States Supreme Judge Sonia Sotomayor (through a section of Jeffrey A. Bennett's intersectional analysis about her in *Managing Diabetes* (2019)) and ex-prime minister of the United Kingdom Theresa May (through a short interview published online). Both women are publicly known to have diabetes type 1. In the case of Sotomayor, her diabetes (and how tightly it is regulated) was used and propelled into the dominant public narrative about her when the Obama administration appointed her as a Supreme judge, to show a narrative of transcendence and overcoming. The political elite asserted that ‘Sotomayor's diabetes was largely a non-issue and, if anything, accentuated her determination, control, and fortitude’ (Bennett 2019, 127).⁵² Thus, even though Sotomayor is publicly known to have diabetes, she still passes as able-bodied to an extent in this way⁵³. One of the most striking things in Bennett's discussion of Sotomayor is that during the confirmation process, pictures show Sotomayor with two glasses in front of her. Not uncommon, notes Bennett, apart from the fact that one of the glasses contained Sprite in case Sotomayor had a hypo. Bennett reads this as a way that this glass gives presence to the invisible

⁵¹ In ‘Metanarrative of Blindness in North America’, Devon Healey and Rod Michalko analyse the metanarrative of blindness in two films, *Scent of a Woman* and *Weights*. In their analytical discussion, they discuss how one of the ‘key aspects of the metanarrative of blindness’ is loss: when the main character in *Weights* does not conceive of his blindness as a form of loss, he is told by his (sighted, able-bodied) councilor that he does not understand or accept his blindness. I argue that this runs parallel to not wanting to make your diabetes legible to your entire environment: there is the assumption that this is about shame and perhaps wanting to pass as able-bodied, therefore suggesting that she does not accept or even maybe *understands* her own diabetes: paradoxically, stigma is assigned to *not* wanting to make your disability legible, because of the strong politics of disability visibility that currently exists.

⁵² This is part of a much more dimensional intersectional discussion that also discusses the perception of diabetes in relation to class and race in the United States, which I unfortunately do not have space to go into here) – Bennett's argument is also not that Sotomayor is portrayed as able-bodied, but the fact that diabetes is placed in a narrative of (individual) overcoming does displace the disabling aspects of diabetes stood out to me.

⁵³ Especially in the interpretation that disability is about exclusion from social and institutional places.

disease, but also to the control Sotomayor seemed to publicly portray over her diabetes (assuming she did not need to treat a hypo). What I wonder, though, is how visible this actually is: Sprite is the same colour as water. Sprite is also drunken by people without diabetes.

Something similar happened in an interview in an interview with Theresa May (*diabetes.org.uk*), where she discusses how during a meeting in the Chamber, she ‘had a bag of nuts in [her] handbag and one of [her] colleagues would lean forward now and then, so that [she] could eat some nuts without being seen by the Speaker’ (*diabetes.org.uk*)⁵⁴. The disabling aspect of diabetes – the hypos they could experience which would temporarily put them in a state of disablement – is hidden quite literally. The disruptive act of eating or drinking a substance not commonly accepted in the spaces they found themselves in is also obscured⁵⁵. This complicates the notion that “passing” with diabetes goes beyond hiding that you have diabetes – both women are commonly known to have diabetes. It does show, however, how beyond the public reclamation of having diabetes, there is also still a lot that is not understood about diabetic experience. It is revealing in what realms and dimensions diabetes can/is understood in the public. Not invisibilised, and acknowledged through speech acts, but limited in how its disabling and unstable aspects are allowed to be portrayed.

People still think there is a strange desire to wish for, or instate, the non-normalcy status of “disability” when thinking about diabetes. It is a phrase that I have heard repetitively since starting this project and told people what it was about. This could be seen as a product of the ideology of ability (Siebers 2017; Walker 2021) that runs strongly in society. This way of unimagining, to pose that I am writing diabetes type 1 “into” disability, as opposed to diabetes already existing *as* disability, shows the lengths and successes of the ability to pass as able-bodied when you have diabetes. It also shows an implicit assumption of what is generally perceived as a “disability”, a visually marked body of difference. Ellen Samuels (2017) and Susan Wendell (1989; 2017), both writing from a chronic illness disability perspective, point out that passing happens (un)willingly when you have an invisible disability/chronic illness. Wendell argues that

⁵⁴ “Theresa May: “Type 1 Doesn’t Change What You Can Do”,” Diabetes UK, 07/11/2014, https://www.diabetes.org.uk/about_us/news/balance-interview-with-theresa-may

⁵⁵ Annemarie Mol (2008) places traces this taming of behaviour back to Christianity and the conception of the ‘bourgeois citizen’; to ‘tame the beast inside’. She coincidentally uses the space of a meeting to illustrate her point; ‘take the situation so typical for the celebration of our citizenship: the public meeting. [...] while the meeting lasts, you will not shuffle, fidget, yawn, sleep, scream, or scratch yourself. Your body is supposed to be able to postpone its needs for food, beverages and toilet breaks (not to mention sex). Meetings require us to be physically present, but our bodies have to simultaneously be absent’ (39).

it is especially difficult to recognise the category of young and middle-aged people who have a chronic illness, because they are the most difficult demographic to fully make legible or to understand as disabled: too young to be ill for the rest of our lives, but at the same time not expecting recovery; death is not in near proximity; there is a pressure to be productive in this age category – we are not close to retirement age and appear able-bodied (Wendell 2017, 163-164). Notice how, in this example, identity and identification are again placed in the relational realm of visual legibility – how a disability needs to be interpretable and understandable in a certain framework in social contexts. This becomes especially challenging when it is difficult to articulate your needs when the disabling factors of diabetes are both unpredictable and not legible as “disability” (needing to drink sprite to treat a hypo is not quite the same as sometimes needing a walking stick).

A common experience echoed by my interviewees is that we could be doing the exact same thing two days in a row – eat the same, do the same activities, and yet our insulin needs and glucose measurements could be wildly different. I always perceived this as a failure of my own acting – specifically because diabetes is purported to be about regimes and routine and “knowing what you are eating”. I was surprised to hear this sentiment echoed by my interviewees. Bennett discusses how he is a man of routine, and this does not lead to tightly managed diabetes (2019, 5). Not every hypo feels the same. Additionally, not every hyper feels the same. A hyper feels different if it has been going on for four days: Brechtje talks about excessive headaches as a result from this, for example⁵⁶. Sometimes I cannot read and write and speak when my blood sugar is slightly high, but I also defended a master’s thesis with a glucose measure of 20 and did well⁵⁷. Felice sometimes cancels plans to go on nights out if her blood sugars have been high for an extended period, to her friends’ surprise⁵⁸. Sille’s sleep is so affected by diabetes that the most disabling factor about diabetes for her is that she is too tired to enrol in school or maintain a job⁵⁹. I might seem to stray away from the concept of “passing” with these illustrative examples given here, but I would argue that it also troubles the “static” notion that you either pass or you do not – in this case, diabetes is a much more fluid state of disablement.

⁵⁶ Brechtje, interviewed by Diana Willemijn Helmich, Rotterdam, 5/11/2021

⁵⁷ A non-diabetic person’s blood sugar is four times lower than that, to illustrate my point.

⁵⁸ Félice, interviewed by Diana Willemijn Helmich, Amsterdam, 1/10/2021.

⁵⁹ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021

In their introduction to *Disability and Passing* (2013), Brune and Wilson contend that ‘the meaning of passing varies widely according to context and can represent a challenge to power rather than simply an acceptance of oppression and stigma’ (5). I do not read my passing as unwillingness to identify with this form of identity as a case of internalised stigma or as having ableist ideology of diabetes embodiment. Rather, I see it as an open questioning of the liminal sense of “in-betweenness” I have always had – between abled and disabled, but also through living with diabetes but simultaneously not feeling like that made me identify with other people with diabetes.

In ‘My Body, My Closet’ (2017), Ellen Samuels also discusses other subversive dimensions to passing: for example, she quotes Elaine Ginsberg’s work – which focuses on passing in relation to race – in saying that passing uncovers the flaws in cultural logic that the physical body is the locus of ‘identical intelligibility’ (351). The issue with disabilities where it is easier to make them invisible (you can make your insulin pump or glucose sensor as visible as you want, of course), is that it comes with accusations of shame or unacceptance because of the ‘cultural logic’ that Ginsberg and Samuels point to. Brechtje, Felice, and Sille all quite clearly stated that they were not ashamed that they had diabetes; they were not deliberately hiding their diabetes (aids); but they were also not deliberately putting them on show all the time. When people asked, they answered frankly (“yes, I have diabetes, yes, it is a struggle”). If you look at my personal Instagram profile, you can identify the glucose sensor on my arm on many photos if you look for it. There is a nuanced grey space between hiding and overtly, constantly reinstating and making visible that you have diabetes. Samuels also underlines how passing can function as an act of subversion, ‘and how the passing subject may be read not as an assimilationist victim but as a defiant figure who, by crossing the borders of identities, reveals their instability’ (351). Indeed, passing, and not defiantly putting diabetes at the front and centre of your being and your identity offers a specific perspective that can question the limits of ascribed identities.

In line with Felice’s refusal mentioned at the start of this section, I also see not openly publicly constantly reinstating my status as having diabetes as a way to subvert other people’s feeling of authority. In this way, passing allows for a sense of control over social situations – passing can be interpreted not as “hiding” something, but rather as a way to create and control the sense of authority others can feel once they know you have (some) form of disability. I argue that passing with diabetes also functions as a tool to subvert notions and blur the lines of what ability

and disability is. This is, of course, not always without pitfalls: it runs at risk of reinforcing the notion that “diabetes can be casually managed”, and consequently reinforces the able-bodied representation of diabetes that I am critiquing.

Complicating diabetes and disability (dis)identification

In Disability Studies, the notion of a “disability identity” is a recurring topic; the question of how identity is approached, however, is rarely ever really delved into. Visuality and visibility (in the literal sense) seem to be an unescapable rhetoric when talking about identity: from the overemphasis on physical disabilities to “being in the closet” (which builds on the negation of visible identity) to McRuer’s (2017) examples of ways to be ‘severely disabled’ that I highlighted in Chapter 1, I would argue that this is a result from the strong hold that the social model still has over (especially more classic) disability studies, where social and institutional exclusion and access are still main focus points for disability justice and scholarship⁶⁰.

Moreover, the category of belonging to a certain identity has demarcations. I was struck by these demarcations of identity especially in Tobin Siebers’ seminal text ‘Disability and the Theory of Complex Embodiment’ (2017). In this essay, Siebers argues to conceive of a positive disability identity (one that defies the ideology of ableism). The ideology of ability (or ableism, as it is also often referred to) runs through society, and is what ‘makes us fear disability’ (315). The thesis of the argument is that disability creates ‘theories more complex than the ideology of ability allows’ (ibid), and very crucially brings the body back into theorising both ability and disability (saying that when someone is able-bodied, they are not really aware of their body – the body only becomes noticeable when something ‘goes wrong with it’). Siebers argues for an identity politics through the claiming of a positive disability identity, as a way to fight social injustices against the minority identity of disability. He states that disability is a form of complex embodiment, one that defies the logics of ableism and something that offers a different ‘crucial understanding of humanity and its variations’ (2017, 315). He conceives of disability identity through minority identity, which is marked through: identifiability (the ability to distinguish a group); differential power status (not a

⁶⁰ See chapter 1 of this thesis, or refer to Mitchell and Snyder 2015, 2019; Goodley 2013; Wendell 2017 for elaborate critiques and reasons to move beyond this. From the field of feminist/critical disability studies, incorporations of poststructuralism (Shildrick 2012), queer theory, affect (Shildrick 2015; Mitchell and Snyder 2015, 2019), and/or posthumanism (see Shildrick 2015; Mitchell and Snyder 2015, 2019; Goodley and Runswick-Cole 2016, 2018) are moves to push such paradigms.

numerical minority); differential treatment; group awareness ('awareness is not merely self-consciousness but an epistemology in group identity status'); and the ethical test (for example, neo-Nazis are not a minority group) (320-322).

Minority/disability identity approached in this way indeed can make strategic use of identity politics in order to gain a social recognition, to show how disability is not a weakness but rather a form of human variation, and how it offers a more complex embodiment. Simultaneously, this form of positive disability identity presupposes that the disabled in question are automatically positioned as weak (2017, 318), something which (especially younger, able-bodied presenting) people with diabetes are not necessarily viewed as. Secondly, Siebers argues that 'identity must be representable and communicable to qualify as identifiable. Identity serves social purposes, and a form of identity not representable in society would be incomprehensible and ineffective for these purposes' (2017, 319). Indeed: Siebers' theory is showing the difficulties of actually conceiving what a "diabetes identity" exactly looks like – how can diabetes be made representable as a minority group if it is mostly interpreted through its close proximity to the able body? Moreover, in many discussions about chronic illness and invisible disabilities, it is noted that identifying as a certain disability requires a constant (re)instatement of one's identity, which can work alienating as you constantly verbally have to pull attention to chronic illness or disability (Wendell 2017; Samuels 2017).

The question of identity (politics) is also widely discussed in feminist theory. In 'Beyond Intersectionality' (2013), AnaLouise Keating writes from the observation that identity politics runs at the risk of creating separatism. She argues that we identify each other through markers, which have built-in assumptions that seem 'factually accurate, unchanging, and homogenous' (36). She argues that these assumptions are actually what *create* these identity categories – she uses the example of race, but notes that 'similar statements could be made about [...] other identity categories that we (often automatically) used to try to make sense of our world. Trapped by labels, we cannot fully engage with one another' (35-36). Indeed, it seems that Keating poses that identity is read through relationality ('we identify each other through markers') as well as through individual assessment (presumably we also count ourselves as part of an identity group through such markers?). If identity is built on certain assumptions – which purports staticity, how does this work when your disability is not recognised as a disability because it does not fit the demarcations?

When the disablement is an aspect of your body's functioning rather than created through social and institutional barriers? When you go through fluid states of ability and disability?

Siebers argues that the 'theory of complex embodiment' that he conceives with the notion of disability identity infused with positive affect, supposes that 'the body and its representations [are] mutually transformative. Social representations obviously affect the experience of the body [...] but the body possesses the ability to determine its social representations as well, and some situations exist where representation exerts no control over the life of the body' (2017, 325). Indeed, this approach of transformative effects of the visibility of the complex embodiment of disability allow for such transformations – they allow to affect social representations. At the same time, what seems to be at stake is how difficult it is to exactly determine and change the social representations of diabetes when the disabling day-to-day factors (the irregular blood sugars, but also the tiredness, the paranoia, and required continuous alertness) are difficult to make legible. Some of these disabling aspects, as Susan Wendell points out, could also not be eliminated through social justice (2017). Moreover, a lot of social media presence focuses on the visible markers of diabetes: the insulin pumps, glucose sensors, the graphs, the countless Instagram accounts of people running marathons or cycling long distances *despite* having diabetes. It is what makes diabetes legible, but also reinstalls the focus on the aspect of "management" and "overcoming barriers", foreclosing the more abstract complexities of day-to-day life with diabetes as an embodied experience.

I want to briefly turn to queer feminist Chicana scholar Gloria Anzaldúa. Gloria Anzaldúa suffered from diabetes type 1. Gloria Anzaldúa passed away from complications of diabetes type 1. During my two years of reading Gloria Anzaldúa, this fact was never discussed⁶¹. In general, Gloria Anzaldúa's work does not specifically focus on having diabetes⁶²; however, if one closely engages with her work, you find discussions of her talking about having diabetes. I would like to look at the short chapter 'Disability & Identity', an email exchange between Anzaldúa and Keating published posthumously in *The Gloria Anzaldúa Reader* (2009), which gives one of the rare

⁶¹ Bennett points out how, because diabetes type 2 affects communities of colour for various socio-economic reasons (2019, 118-119), people often assume Anzaldúa had diabetes type 2 (showing how the outside world feels the authority to make sense or explain something they do not necessarily possess knowledge of).

⁶² McRuer does name her 'the late cripp theorist' (2006, 37) posthumously; again though, no mention of the fact that she could "claim cripp" because she had diabetes.

insights in Anzaldúa's relationship to having diabetes and how Anzaldúa does (not) conceive a diabetes/disability identity as such.

In this chapter, Anzaldúa says that 'I don't identify myself as disabled or as a diabetic (preferring to say I have disabilities & that I struggle with diabetes) [...] for several reasons: 1) "disabled" would reduce me to an even more partial identity than chicana, feminist, queer & any other genetic/cultural slices-of-the-pie terms do. & 2) Diabetic would make me a victim' (2009, 299-300). She also distances herself from the term diabetic and chooses "person-first" terminology, in order to create separation from her person to her diagnosis (or to not be a 'victim'). However, she asserts that this should not be reductively read as that she 'feel[s] distanced from [her] "disability".' (2009, 300). Indeed, she actually points to how diabetes type 1 is continuously present in different formations, be it either through constant worry and paranoia about the future complications or the day-to-day continuous fluctuations of blood sugars during mundane activities: 'I feel an in-my-face, up-front-and-personal relationship with diabetes & its disabling complications. I can't escape it. I am concerned with my eyesight when I read, write, watch TV, or go to the movies. I have to pay attention to my blood sugar levels when I eat & exercise, when I stay up all night, when I socialize, & when I travel to do speaking engagements. [...] When I forget some of these my body reminds me, sometimes painfully' (ibid). Anzaldúa articulates the various disabling aspects of diabetes, its omnipresence in day-to-day life, and the high level of uncertainty that comes with it beautifully. With this, she also illustrates how inadequate the framework of (un)acceptance is. As Anzaldúa points out, it is hard to deny having diabetes: it is 'in-[your]-face' all the time. How do you contain and convey the messiness of living with diabetes into a legible form of disablement through which diabetes can be read as neither "casually managed" nor "fatal", neither as a matter of shame/pride, and how does diabetes or disability identity (politics) negate or play into this?

Indeed, Anzaldúa has issues with being made legible as disabled because she feels like it is a reductive identity strategy that overlooks other forms of oppression and difference such as class, race, gender, and ethnicity (2009, 302). Moreover, Anzaldúa argues that while disability justice through claiming a disability identity might work in the short-term, she is worried that it might reinstate and reproduce hierarchising difference, because 'our identification is based on an oppositional distinction from another group, the "normal" [...] we get locked into the binary abled/disabled, us/them.' (ibid). Where does all of this then leave diabetes and "diabetes identity"?

I am arguing both for a cripistemological queering of diabetic/disability/normative embodiment to recognise the varieties of being within a certain category that does not reinstate boundaries but rather opens them up, to broaden understandings; and question dominant and hegemonic norms and perception about diabetes forced upon us through both the inside and outside. In this way, I hope to argue for a more nuanced understanding of diabetes and how it functions as both ability and disability.

Beyond shame, pride, and (un)acceptance?

I want to look at Analouise Keating's politics of inter-relationality to achieve a radically inclusive approach (2013, 30) to formulate different forms of making sense of oneself and the disabling effects of diabetes. Keating argues that 'all too often, feminist and other social-justice scholars remain trapped in what [she] calls "status-quo stories": 'worldviews that normalize and naturalize the existing social systems, values, and standards so entirely that they prevent us from imagining the possibility of change' (35). "Status-quo stories" consist of "core beliefs" that people have about reality and the world – based on 'feelings and imaginations', reinforced through 'words and deeds'(ibid). The example of feelings of shame being attributed to Felice not publicly carrying her diabetes identity could be attributed to the status-quo narrative of diabetes and disability more generally. That is, unless you publicly talk about these things (with pride), you must be ashamed about them.

Keating asserts that it is a facet of Western logic to evaluate and assess each other through these status-quo stories. The concept of status-quo stories as way to make sense of the world can be read alongside the metanarratives of the normative social order, or indeed that status-quo stories are riddled with metanarratives – they rely on tropes, stereotypes, and myths ascribed to people with disabilities. In this way, 'status-quo stories both rely on and reinforce the separatist framework and a metaphysics of difference. Status-quo stories are divisive, teaching us to break the world into parts and label each piece. These labels solidify, and we read them as natural descriptions about reality' (35). The issue with status-quo stories, Keating argues, is that they police boundaries of individual and group identities. In this way, looking at identity through identity labels and markers is not an effective tool for change, but rather inhibits it (because it excludes, discounts, undoes). Secondly, status-quo stories create separatism instead of solidarity, between and across different peoples/groups. To achieve the notion of inter-relationality that

strives for a radically inclusionary approach, Keating has discerned three lessons she learnt through the publication of *this bridge*⁶³ (2013, 38): making connections through difference; positing radical interrelatedness; and listening with raw openness.

The radicality of Keating's approach is that it strays away from the limiting demarcations of identity labels as such to incite change; the three lessons are all marked through a connectivity between differences through affective strategies. These strategies rely on recognising the common struggles and oppressions in the present. It should be marked that difference within, amongst, and beyond mark an important aspect of this affective form of identification: they, however, do not form barriers. Keating attempts to use affect and empathy, the 'heuristics of love' to borrow a term from Chela Sandoval, to move past these barriers (2013). Indeed, both Félice and Sille had a strong praxis of this radical openness of their differences with friends; Félice says that if you have known her long enough, you have seen the struggles, and you understand⁶⁴. Sille talks about how, whenever she meets new people, she shares her 'life story'⁶⁵: she details how, when the radical openness is reciprocated in response, they are immediately 'on the same wavelength'. When I talked about the misunderstandings and misconceptions in my surrounding regarding me and my diabetes, she also urged me to be more open and look for connections with people who accept this raw *crip* openness. I am still trying to find a way to navigate the ableist world and how to convey something so abstract and unpredictable as diabetes embodiment within the ableist system of viewing ability and disability, but I think about Sille's remark a lot.

Conclusion

As I have tried to demonstrate in this chapter, my issue with "identity" as such is that it relies on demarcations, boundaries, identifiable markers – a certain sense of "knowing" about what this part of your identity is that does not allow for the unstable, but also having to meet certain conditions

⁶³ A sort of "sequel" to the feminist anthology *This Bridge Called my Back: Writings by Radical Women of Color* (1981) edited by Gloria Anzaldúa and Cherríe Moraga, *this bridge we call home: radical visions for transformation* (2002) edited by Gloria Anzaldúa and AnaLouise Keating. The chapter 'beyond intersectionality' that I refer to here is a pedagogy conceived by Keating from the lessons she learnt both through the reception of *This Bridge* (1981) and the project of working on a sequel 20 years later.

⁶⁴ Félice, interviewed by Diana Willemijn Helmich, Amsterdam, 1/10/2021

⁶⁵ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021
Sille is "multiply disabled": from our conversation, I gathered that she has diabetes, that she is deaf in one ear, has epilepsy, has vision issues, and PTSD.

in order to feel “at home” in the identity ascribed to you. Both my interviewees and I have experienced being told that a regime or a specific medical aid worked for others, so it should work for us too – in this sense, normativity still persists even within the category of diabetes, which leads to disidentification both from diabetes and disability. The element of personal failure moreover makes it hard to recognise yourself in/as disability/ed. By using queer, queerness, and queering as a lens, I question the productiveness of thinking through identities in such a way, and question identity limitations. Relating to each other through sameness in difference (such as finding Felice, Brechtje, and Sille through our “difficult relationship to your diabetes”) can open up different forms of relating to each other that can give us a different insight into being that move between, across, and beyond categories and markers.

I recognise the importance in McRuer (2006; 2018), Siebers (2017), and Walker (2021)⁶⁶ work of claiming an identity is a way to provide a horizon for (political) commitments and a collective meaning. These two identity projects are, however, not mutually exclusive processes. I turn to Anzaldúa once more:

I'd like to create a different sense of self (*la nepantlera*)⁶⁷ that does not rest on external forms of identification (of family, race, gender, sexuality, class, and nationality), or attachments to power, privilege, and control, or *romanticized self-images*. But can we talk about ourselves in ways that do not rest on some notion of identity when identity is the means by which we (both as individuals and groups) attempt to create a sense of security and belonging in the midst of a fast-paced, ever-changing world? We mourn (here is where *LaLlorona* comes in) the loss of the “healthy” abled, integrated self, a self we may never have possessed. I can never go back to the way things were before I lost my “health” or home or whatever (2009, 301-302).

Anzaldúa here opens up ways for the complications for the very concerns occupying this thesis project, how to embody a (de)(st)abilised identity, and the very challenges and possibilities in doing so. In the next chapter, I will explore the neoliberal character of diabetes and health, with a

⁶⁶ Walker specifically writes about a diabetes identity as a way to politicize diabetes – at the moment, prices of insulin are continuously skyrocketing and slogans advocating for ‘insulin as a human right’ are becoming more ubiquitous in the United States; people are dying because they are either rationing insulin or do not have access to insulin because they cannot afford it. Such issues are slightly different in the Netherlands because everyone is by law obliged to have health insurance, and insulin is covered in the “basic package”. While I am careful not to use the U.S. health system as a deflection to not talk about the plethora of issues within the health care system in the Netherlands (this deflection is a common strategy to avoid addressing local issues), the political stakes are quite different, and arguably more tied to livability rather than survivability – it became clear in self-reflection and the dialogues that it is mostly dealing with social stigma, misconceptions, and misrecognition (thus, the issue is more cultural rather than strongly political, especially in this chapter). Yet, it is still political in the sense that neoliberal agentic subjectivity influences concepts of health, health care, and the navigation of personal responsibility. More on this in the next chapter.

⁶⁷ From ‘(un)natural bridges, (un)safe spaces’: ‘Bridges span liminal (threshold) spaces between worlds, spaces I call *nepantla* [...] most of us dwell in *nepantla* so much of the time it’s become a sort of “home”’ (2009, 243)

specific focus on what arose in the interviews. I will more deeply analyse how this further complicates the position of “claiming crip” as a diabetic through the shame and blame – who/what bears responsibility of its disabling e/affects? How do neoliberal notions of management and control play into this? And how could failure and diabetes be read outside of “neoliberal inclusionism” (Mitchell and Snyder 2015; 2020)?

Chapter 3: “Control”

Problematizing neoliberal subjectivity in diabetes care

Introduction: neoliberal thinking/feeling

In this chapter, I focus on the influence of neoliberal registers on personhood and subjectivity in lived experiences of diabetes. With this, I mean that I am not focusing on neoliberalism in relation to economics and politics of the state, but rather on the way that it governs our everyday life through thinking and feeling (Ehrstein, Gill, and Litter 2020, 197). Ehrstein, Gill, and Litter posit that neoliberal subjectivity calls into being subjects who are ‘rational, calculating, and self-motivating: subjects who will make sense of their lives through discourses of freedom, responsibility and choice – no matter how constrained they may be (e.g., by poverty or racism)’ (ibid). Walker and Litchman (2021) argue that despite the influence of inequities on diabetes care and control, ‘diabetes care has been emphatically reliant on self-governance (for medical compliance) on the part of the patient’ (913). This neoliberal thinking/feeling is shaped through medical research conducted in the early 2000s, which showed how tightly managed blood sugars would reduce the risk of complications (Walker and Litchman 2021). Consequently, the standards of care shifted forms of empowerment within diabetic embodiment to the idea of self-regulation (ibid); this approach instated a norm that if you just *tried* hard enough, your diabetes would not be(come) a disability. Such a notion promotes the false promise that long-term complications are within individual control. The concept of agentic subjects in diabetes places ability and disability in the realm of self-regulation by measuring, administering, and counting carbohydrates⁶⁸.

Bennett contends that ‘undergirding the logic of diabetes care regimens, there is an assumption of a person who has the ability to make particular, if undefined, choices in order to achieve an abstract sense of control’ (2019, 15) which is grounded in ‘neoliberal conceptions of agentic subjects’ (ibid). This undergirding produces a specific governmentality both within people with diabetes as well as in public interpretations of diabetes (“should you be eating that?”). I argue

⁶⁸ On one of the days where I was writing this chapter, I had eaten breakfast at 10am and then got so immersed in writing that I did not eat for the next 7 hours – in that time, my blood sugar went down and up multiple times without any intervention.

that this is because of diabetes's perceived proximity to the able-body, which embeds itself in 'ablest society which upholds the *imaginary* autonomous, self-sufficient, whole functioning citizen; promotes signifiers of ableist achievement, mastery and competence in symbolic culture' (Goodley 2012, 186). Consequently, this 'denounces those who fail to match such ableist images and signs [as] *really* uncivilised, dis-abled, fragmented, dis-coordinated shells of humanity' (ibid). This chapter analyses how neoliberal terminology and attitudes towards diabetes manifest a certain subjectivity within the experience of living with diabetes. I argue that the emphasis on control and management – specifically in the promise to not become *further* disabled – focuses on (re)producing a phantasmatic neoliberal citizen, one that is focused on (re)productivity. Shifting the narrative of diabetes from management and control to the unattainability thereof allows for a reading of diabetes that, because of its resistance to 'compulsory able-bodiedness' (McRuer 2017), is always already queer, producing 'alternative ways of knowing and being that are not unduly optimistic, but nor are they mired in nihilistic critical dead ends' (Halberstam 2011, 24).

This chapter explores lived experiences of diabetes using (auto)ethnography, and through performing a feminist discourse analysis on my conversations with Felice⁶⁹, Brechtje⁷⁰, and Sille⁷¹. Feminist Discourse Analysis is a useful tool to 'show up the complex, subtle, and sometimes not so subtle ways in which frequently taken for granted gender assumptions and hegemonic power relations are discursively produced, sustained, negotiated, and challenged in different communities' (Lazar 2007, 142). In order to attend to pervasive narratives of control surrounding diabetes management, the chapter stays with the negative affects of failure. Through focusing on personal narratives about diabetes that is experienced as unstable, I hope to further complicate diabetes embodiment in alternative registers than those of tightly managed blood sugars. I aim to uncover where and how the difficulties of diabetes and dis/ability are sometimes (falsely) located, and question how these perceptions can be shifted. Neoliberal ideals of self-regulation and control within diabetes management are not only present and performed in the interactions between doctor and patient, but reach far beyond these spaces. It influences how you experience day-to-day life with diabetes; it influences how you experience the disabling aspects of living with diabetes; it influences feelings of isolation and loneliness in dealing with diabetes;

⁶⁹ Felice, interviewed by Diana Willemijn Helmich, Amsterdam, 1/10/2021.

⁷⁰ Brechtje, interviewed by Diana Willemijn Helmich, Rotterdam, 5/11/2021.

⁷¹ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021.

it shapes public discourse about diabetes and contributes to the exclusion of diabetes in disability scholarship. I focus on aspects of living in such registers and aim to critique the neoliberalisation of care discourse that builds on personal responsibility and self-regulation.

What/Whose health?

Susan Wendell (1989) points that from a disabled perspective, you hear the subtext of moral virtue when health and physical rigour are discussed (113). Lauren Berlant (2011) argues that ‘health itself can [...] be seen as a side effect of successful normativity, and people’s desires and fantasies are solicited to line up with that pleasant condition’ (106). As is evident in cultural perceptions on fatness, health is something that can be witnessed and interpreted through constructed social norms. In the contemporary moment of neoliberalism, capitalism, and consumerism, health is positioned as something that can be achieved and maintained by the choices we make (regardless of, for example, (infrastructural) access, wealth, genes, etc). In reality, ‘health is always partly a matter of luck and therefore beyond our control’ (Wendell 1989, 113). Yet, the influence of neoliberal ideals within how well-managed diabetes (and thus, the attainment of being “healthy” despite having diabetes) is achieved remains pervasive. The conception of health as a symptom of successful normativity forms an entry-point for the explanation of why the unstable lived experiences of diabetes are underdiscussed (as it is undesirable).

. In ‘Self-exceptionism and its Counternarrative’ (2021), Heather Walker reflects on how neoliberal approaches of individual responsibility to diabetes caused her to use “good management” as a form of self-exceptionism from other diabetics and to disprove pervading stereotypes of the lazy diabetic ‘unwilling to do what it takes to see species-typical blood glucose levels’ (283). Indeed, the regulation and management of diabetes tends to have a “pull yourself up by the bootstraps” narrative, which consequently suggests that ‘those who try hard earn health, and its antithesis, those who do not try hard reject or do not deserve health’ (Walker and Litchman 2021, 914). This leads to multiple forms of stigmatisation, such as that people with diabetes are ‘adjudicated for every micro-decision around food, exercise, and health behavior (e.g., blood sugar monitoring, injecting insulin, taking oral medication) because diabetes management is understood to be controllable by the individuals inflicted with it’ (ibid). We see similar discourses with discussions on fatness, where fatness is attributed to the inability of a person to be agential about

what they consume, rather than to see fatness as a form of both bodily variation and a product of social and environmental circumstances⁷². Agency provides a sense that we can exert control over abstract variables. It places (dis)ability on the medical aids, or rather: (dis)ability is read through the existence and workings of such devices

The (neoliberal) fantasy of being in control

Susan Wendell (1989) argues that ‘suffering caused by the body, and the inability to control the body, are despised, pitied, and above all, feared. This fear, experienced individually, is also deeply embedded in our culture’ (113). She continues saying that ‘feminist theories have probed the causes of our patriarchal culture’s desire for control of the body’ – but she also contends that ‘[t]he consequences for disabled people are less often recognized. In a culture which loves the idea that the body can be controlled, those who cannot control their bodies are seen (and may see themselves) as failures’ (Wendell 1989, 114). Even though Wendell originally made this argument in 1989 (where she pleads the case of disability as a feminist issue), I would argue that the fantasy of being able to attain control of the body is still under-exposed, especially in relation to diabetes. It makes sense in a catch-22 type of way. Medical companies need to overstate the amount of control and consequent improvements of the ability to “manage diabetes” in order to sell their products (this is simply how consumerism works)⁷³. Simultaneously, the importance and need for these devices needs to be overemphasised by those with diabetes in order for the equipment to be considered as necessities to get them covered by health insurance⁷⁴. This, too, leads to a (public)

⁷² For an elaborate discussion on the biopolitical dimension of such rhetoric on obesity, see ‘Slow Death’ (2011) by Lauren Berlant. (Berlant uses the term ‘obesity’ in her analysis, while I adhere to the more recent political move from Fatness Studies to use the term ‘fatness’, to break out of the pathology of such embodiment).

Of course, it is not surprising that similar rhetoric exists between “controlling” fatness and diabetes; culturally, the two are intertwined, as there is an increased risk for diabetes type 2 with fatness. This cultural association and consequent authoritative control outsiders maintain over the actions of people with diabetes is very foregrounded in U.S. publications about diabetes (type 1) and culture (see Walker and Frazer (2021), Bennett (2019), Walker (2021)). However, this correlation seems to be less strong in the Netherlands, or at least not a common accusation my interviewees and me receive (for we appear white, thin, and healthy looking). Diabetes in the Netherlands is in layman terms referred to as ‘suikerziekte’, which does create the misunderstanding that you either ate too much sugar; you are not allowed to have any food with sugar (often disregarding the fact that carbohydrates are sugar); or you are not allowed to have carbohydrates.

⁷³ This is beyond the scope of this chapter, but for an enlightening discussion of this issue, see: ‘Chapter 2: Customer or Patient?’ in *The Logic of Care: Health and The Problem of Patient Choice* (2008) – Annemarie Mol, or ‘Chapter 6: Cyborg Dreams’ in: *Managing Diabetes: The Cultural Politics of Disease* (2019) – Jeffrey A. Bennett.

⁷⁴ There was a long road of lobbying for Flash Glucose Sensors to be covered by basic health insurance, and this was only achieved in December 2019. See: <https://www.dvn.nl/nieuws/nieuwsbericht/hoera-fgm-wordt-vergoed>

ideal of the idea that diabetes can, with the right equipment, be *controlled* through such technological advances, and their inadequacies could be attributed to individual management regimes rather than the fact that control of the body in itself is an abstract, neoliberal fantasy.

The use of advanced technological tools feigns the sense of agency; they produce a (public) affect that health and body are within personal control; thus, it is easy to interpret the instability of our diabetes despite such aids as carelessness or inadequate management. This interpretation renders my experiences and those of Felice, Brechtje, Sille, and probably countless of others invisible: I cannot overemphasise enough that we care. This is precisely why I argue that management and control in the way that it is purported in diabetes care is an inept framework for interpretation, which consequently produces misconceptions and misrecognition. The purpose of this chapter is not to disavow medical aids, or to be ungrateful for technological advancements; rather, I hope to find more nuance in the notions of management and control, regulation, and personal responsibility.

Internalising Blame and Shame

In theory, the sense that you have control over your disability could be seen as a source of empowerment. In lived experiences, the emphasis on control actually has the adverse effect of creating internalised blame and shame; if your diabetes is unstable, irregular, unpredictable, it is easy to interpret this as a fault of your own mishandling. The contention that neoliberal subjectivity creates internalised blame and shame – even within those I have interviewed – sounds like a contradiction with what I argued in the previous chapter about the insufficiency of the framework of pride/shame or (un)acceptance. However, the framework of pride/shame and internalised blame and shame are distinguished by their relationship to management. Pride/shame as discussed in the last chapter is shame related to *having* diabetes, unrelated to how that diabetes is managed or controlled. Internalised blame and shame related to management and control is directly related to the affective experience of not meeting the conditions of the neoliberal/ableist ideals of self-management and control. By focusing on Halberstam's notion of failure and negative affects, I question how looking in different places than the neoliberal and normative medical logics of caring, self-regulation and personal responsibility can serve as a productive means to create different ways of thinking about diabetes and (dis)ability.

In Walker and Litchman's (2021) qualitative research about "diabetes identity" online, they 'found that, most frequently, interviewees distanced themselves from descriptors of being out-of-control (e.g., variability in glucose, disabled, sick, and prolonged hypoglycemia). Sickness was almost exclusively rejected as a signifier' (918). The combination of the in-control narrative and the rejection of any ideas of sickness also (re)inforces the diabetic to be read as a (mostly) able-bodied 'neoliberal citizen [...]: willing, capable and able' (Goodley 2014, 52). This is also generally how I experience(d) narratives about diabetes: the obscuration of out-of-control-ness reinforces that there is some shame in this experience of having diabetes. The location of control through the personal responsibilities of interactions with medical aids, counting carbohydrates, and living "healthy" produces negative affects of internalised blame and shame.

In *The Cultural Politics of Emotion* (2004), Sara Ahmed discusses the affective life of shame as a concept. Ahmed's analysis focuses on political expressions of nation-wide shame about historical injustices conducted by colonising countries – which is wildly different in scope and focus from my thesis. However, her discussion of 'shame as a lived experience' can offer a useful interpretation of how and what internalised blame and shame can do to the way that people with diabetes relate to themselves, to health care regimes, and to each other.

A few effects of shame emerge in Ahmed's discussion. Shame, following Silvan S. Tomkins, is identified as a 'negative affect' (103). With this, Ahmed tries to make clear that the experience of shame is 'an intense and painful sensation that is bound with how the self feels about itself, a self-feeling that is felt by and on the body' (103). The sensation of shame is tied to the identification that the self has done something bad. When my mum and I recently went through her archive of notes that I wrote to her as a child, we found a note from when I was maybe about 7 or 8. I chastised myself in my childlike handwriting about my unstable blood sugars, saying it was my own fault. During that time, I was under a very strict diet/insulin ratio regime – I remember feeling like I was given all the tools to control my body, so any sign of unstable blood sugars was a matter of internalising blame.

Ahmed makes sure to also differentiate the experience of shame and guilt; guilt is interpreted as a failure of internal law, a sort of punishment, whereas shame is 'about some quality of the self' (Nathanson qtd in Ahmed 2004, 105). Guilt relates to action, whilst shame 'implies that some quality of the self has been brought into question' (ibid). In the context of neoliberal subjectivity, which relies on a self-governing built on the principles of calculating, self-motivating,

and rationality as I outlined earlier, the “mismanagement” of diabetes, or undesirable outcomes of fluctuating blood sugars, can be seen as a failure of qualities the self should possess. In this context, I read blame and shame as one and the same; through the assertion of personal responsibility, the blame of unstable blood sugars falls on the individual, which leads to a form of internalised shame about not being able to attain ‘species-typical blood sugar levels’ (Walker 283). In a way, internalised shame can be read in relation to Walker’s notion of “self-exceptionism”; in the same way one can feel good about staying “in target”, one can feel ashamed about not being able to attain such goals.

A consequence of shame, or experiencing shame, is that it both feels like an exposure – a vulnerable expression or admittance of self-failure – but it also ‘involves an attempt to hide, a hiding that requires the subject turn away from the other and towards itself. The very physicality of shame – how it works on and through bodies – means that shame also involves the de-forming and re-forming of bodily and social spaces, as bodies ‘turn away’ from the others who witness shame’ (Ahmed 2004, 103). I am trying to explore how the neoliberal subjectivity created through the concept of self-regulation, management, and control forge isolation through shame, which forecloses the potentiality of a community feeling.

In order to show how shame, blame, and the illusion of agency and control as a result of neoliberal ideals influence diabetic experience, I turn to the conversations with Brechtje, Felice and Sille. These conversations reveal the dissonance of lived experience and expectations of perfect management, as well as how internalised shame emerges in different forms. These are honest and vulnerable conversations about the messiness of lived reality with diabetes that show how neoliberal subjectivity manifests in affective registers and the desire for control – to admit this shame, I argue, was only possible because we shared a mutual recognition of the feeling of “out-of-control” diabetes.

A short disclaimer before I continue: I am trying to show the difficulty of ‘translating medical ideals into lived praxis’, and how ‘failures tend to be attributed to individuals and not the internal contradictions of management’ (Bennett 2019, 28). This, in turn, could displace the way diabetes is read as a disability: not in long-term complications or the use of medical aids, but rather in its unstable character. I do not experience injecting insulin up to ten times a day as disabling. I have never regarded the prospect of maybe going blind as disabling. What is disabling is the brain

fog. Or when my blood sugar quickly drops or goes up. Or the interrupted nights of sleep. Or always and constantly having to attend and be attuned to our bodies.

I am not hoping to give the impression that just because we show symptoms of being “out-of-control” (by discussing our unstable blood sugars, bouts of hypoglycaemia, different forms of management), our “health” is necessarily poorly managed. We get annual full medical checks of all the things that could show signs of (potential) long-term complications, and as far as I am aware, we are not showing any of these symptoms (yet). Approaches and attitudes towards management are always fluid and ongoing negotiations. Just because ours can be regarded as unconventional, and does not fit the image of diabetes as fully controllable, or a matter of self-regulation, does not make it invalid. It does make it invisible.

I am also not interested in identifying how one method of caring for oneself is more “effective” than other forms. Rather, I am curious about the effects of normative, neoliberal interpretations of what good care (should) look(s) like. Rather than purporting that there is “one way to do diabetes” that is the good way, I locate agency in diabetes embodiment in figuring out, and taking seriously, the experiential knowledges of what works for someone. Indeed, as Dana Leigh Combes in argues about her experiences with sarcoidosis in *Metanarratives of Disability* (2021), ‘... my illness experiences could qualify me to some level of authority on living with what I do. This should bestow upon me some ‘credentials’ which my doctors treating me, however well-educated and experienced in their observations they may be, will never have’ (201).

I start with Brechtje, who shares her experience of being diagnosed with diabetes at the age of 18, when she just started studying.

B: when I first got diagnosed, I had a dietician and a nurse, and I used to visit my endocrinologist often. The emphasis was always on “measuring is knowing” and “count everything” and things will be fine. But even when I did that, writing down every little thing I did and ate for weeks on end, the carbohydrate-insulin ratios, nothing came out of it. One moment my blood sugars would go up with 4mmol/L⁷⁵, and the next day, after the exact same meals at the same time with the same amount of exercise, my blood sugar would drop. After a while you become despondent, it created an aversion for the counting and “getting things under control”. I still don’t count carbohydrates – because I got so annoyed because it was like “measuring is knowing and after that control will follow” which just did not happen. After I while it did make me feel like “*maybe it was my own fault, because I do what they tell me to, but I still can’t get it under control*”. I think this could be a point of improvement for the hospital, because after a while I got the feeling that because I was a student⁷⁶ and I was doing this wrong, that wrong. Whereas with some people, it really does not matter how much you

⁷⁵ A non-diabetic’s blood sugar would be an average of 5mmol/L.

⁷⁶ Brechtje disclosed during the interview that her doctor said her diabetes was hard to control because she was a student

do, your diabetes can still remain unpredictable. That's not due to the individual, but due to how your body responds.⁷⁷

While there is a clear acknowledgement and knowledge within Brechtje that she has tried to do everything “according to the books” and followed medical advice on how to “gain control”, it does not seem to work. Brechtje is aware of this, yet simultaneously feels like it uncovers a failure of the self, as she wonders if “maybe it was her own fault”. Such strong insistence on management and formulaic ways of gaining control of your diabetes, through trying to make everything quantifiable, creates a strong dissonance both between doctor and patient, but also between Brechtje and the experience of the self. Whilst she can acknowledge that in general, bodily variation exists (“it's not due to the individual”), this does not fully eradicate internalised feelings of individual blame and shame (“maybe it was my own fault”). Whereas it has also been shown that even if she follows the strict regimes, the desired outcome does not happen. The question of carelessness – the fact that she does not count carbohydrates⁷⁸, which is often seen as “bad practice” – is actually far more common than we are made to feel. Like Brechtje, I have been on both sides of the spectrum: under tight regulation, weighing everything I ingested, counting and keeping track of every carbohydrate and activity, and working with insulin-carbohydrate ratios. I have also had periods in my life when I did not do this; the outcome was not wildly different. It then becomes a question of whether not counting carbohydrates is a matter of carelessness (it is often interpreted this way by health care professionals) or of not wanting control, or whether it is an alternative form of care. Care that focuses on the liveability of diabetes: to accept that counting is an obsessive practice that feigns the sense of control but in some cases simply is not worth the mental pressure because it does not have the desired effects (it did not regulate Brechtje's blood sugars better).

Felice, like Brechtje, also does not work with carbohydrate-insulin ratios, because in her experience, her diabetes acts erratically and it does not work to use such formulaic regimes. On

⁷⁷ Brechtje, interviewed by Diana Willemijn Helmich, Rotterdam, 5/11/2021. Translated from Dutch by the author.

⁷⁸ This, of course, does not mean that Brechtje is in the dark about carbohydrates; the phrase ‘not counting carbohydrates’ refers to the practice of estimating, instead of dissecting your entire meal to find out how many carbohydrates each component consists of. Estimating also relies on building on past experiences and seeing how your body responds to specific foods and estimating your insulin needs according to that. With some things, it is easier to figure out the carbohydrates without consciously counting (all food that has nutritional information on the label shows the carbohydrates). Estimating is, of course, far from an exact science, and doctors do thus not encourage people to do this. Yet, even strictly counting is a balancing act of attaining control of your blood sugars and living life: eating out always involves estimating, if someone cooks for you it always involves some sort of estimate, etc.

top of this, during her teenage years, Felice developed an eating disorder through the fact that she was monitoring every single thing she ingested. Felice argues that tightly managed diabetes for her did not at all improve her quality of life. She chooses to listen to her body and uses this sense of governing to manage her diabetes; this requires a continuous attention whilst not feeling too restricted or engaging in actions that have a negative effect on her (mental) well-being. Simultaneously, her unconventional style of managing diabetes inadvertently leads to self-blame and shame. In treating a hypo, Felice talks about the following experiences:

F: I would prefer to eat something tasty when I have a hypo, although I feel like I should not “reward” myself – *because it is often my own fault*, but you also think ... [mumbles] I don’t know...

D: because you get the feeling that the hypo shows you have not “regulated it well”. I completely understand it, but I want to explore this a bit more. We use terms such as responsibility and blame, but I think this is a very individualistic way of looking at how diabetes is managed, and how choice and responsibility play a part in this.

F: That’s really the case. Every choice you make has consequences for how you feel, and what you carry out. I strongly feel that whenever I have a hypo, because you know, say you ate something and you overestimated the amount of insulin you needed, you think – see! *I was too confident with my estimations, and now I feel like shit and I can’t study like I was supposed to be doing today. Because you are responsible for the choices you make, so that automatically creates a feeling of shame and blame.*

[...]

F: and you keep arriving at the question of blame, because who is to blame? *Where do you put the question of blame? You can put it everywhere, but it often gets put on us.* I don’t think that’s fair. But also, I do it too.⁷⁹

Bennett argues how ‘paradoxically, hypoglycaemia is something that transpires *because of control*, not in spite of it (2019, 18) – which is evident in the way Felice talks about it too. By not wanting her blood sugar to go up too much (managing), she takes what she deems the right amount of insulin. It would be easy to conclude that her blood sugar dropped because she was “too confident”, but we can also question whether it was simply a result of the “guesstimation”⁸⁰ approach to carbohydrates. As Brechtje discussed, and as I also experience it, the amount of insulin she took could have been the right amount the day before, but be too much this day (due to, for example, stress, exercise, or other hormones that were triggered). In other parts of this conversation, Felice talks about being fully aware that this is the case, and she talks about how she manages her diabetes by carefully listening to her body, watching the trends of her blood sugars, taking into account potential variables. Yet, she still chastises herself for ending up with a low blood sugar: perhaps because she feels that if she *did* count carbohydrates, this would not have happened (even though

⁷⁹ Felice, interviewed by Diana Willelmijn Helmich, Amsterdam, 1/10/2021. Translated from Dutch by the author.

⁸⁰ Slang used in the online diabetes platforms I discuss in the next chapter, which refers to guessing rather than calculating carbohydrates.

she has experiential expertise to know this is also not a successful method to prevent hypos). She does not want to “reward” herself to make her blood sugar go up by ingesting something she enjoys eating. She blames her abilities, questioning her own rationale (“I was too confident”). I would locate this as a result of the overemphasis on neoliberal “self-management” and personal responsibility (feeling as if she did not act rationally). She blames herself because the hypo means she cannot be productive. Indeed, ‘any digression from the exalted norms of bodily productivity in a postindustrial society will lead to charges of dysfunction’ (Bennett 2019, 19). As the last remark demonstrates, Felice is aware that the individual is not to fully blame, but at the same time recognises how she also has this tendency.

The notion of internalised blame and shame did not strongly emerge during my interview with Sille: Sille is also the only one of us four who is part of diabetes communities, such as a chat group in which women with diabetes give each other advice. This also gives Sille more connection and contextualisation about other people’s experiences with unstable blood sugars. In this way, shame is not strongly present for Sille because of her interconnectedness with others (as Ahmed argues, shame is a relational affect). Even though shame/blame were not strongly present in our conversation, Sille did offer an interesting counter-example on the flaws of the logic about how good results are exemplifiers of “good diabetes management”:

S: In the first few years I just pretended that everything went well. You had to keep a diary with your glucose levels and insulin intake. I never did this – I always filled in those diaries a day before I had to go to the hospital [...]. I never measured my blood sugar. I intuitively took insulin. I estimated carbohydrates. It was all a guessing game – but it went well, because the test results in the hospital were good. And well, as long as things go well that way, you keep going. [...] And they believed it, right? Especially the insulin intake. I always lied about forgetting my glucose monitor so they couldn’t get the data and see that I was lying.⁸¹

Sille discusses how the way she acted in the early years was carelessness, a carelessness that was perpetuated because she got away with it. She never checked her blood sugar (this was before glucose sensors were widely available), she did not work with carbohydrate-insulin ratios either. Yet, because the results were good and because she could lie about actually performing such practices (filling in the required forms, probably through “desired forms” of what should theoretically work to attain stable glucose levels), this level of carelessness was not detected. Sille discusses how this practice derived from the fact that diabetes management as it was presented to

⁸¹ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021. Translated from Dutch by the author.

her was not compatible with how she lived her life: she was a teenager, who – like a lot of other people in puberty – wanted to be “like everyone else”. By acting in such a way, she could minimise the grip diabetes had over her life, which was a form of mental health care that does not line up with medical ideals. The consequences were minimal at the time (she did not feel extremely disabled by her diabetes). Perhaps not admitting to her endocrinologists that she acted in this way – despite maintaining “good” levels – was also a form of internalised shame. She knew that, according to the books, she was not doing a good job. However, there was also a rationale behind why she was doing it. To read this simply as “carelessness” only perpetuates and validates a certain form of care – it overemphasises how medical ideals of control through tight management can lead to a better quality of life. Whereas Sille shows, quality of life is a matter of negotiation: “bad diabetes practice” without too many immediate consequences and good results allowed her to “be like everyone else”.

Sille is now impaired by her diabetes to such an extent⁸² that she has chosen to go under tight regulation, as in this moment in time, it does – at least promise to – improve her quality of life. As noted in the previous chapter, Sille is unemployed due to the disabling effects of diabetes in combination with other disabilities. Despite the tight regulation, she still suffers from a lot of hypo/ers. She notes that she does not feel her hypos and hyps physically, and thus relies on advanced medical technology rather than intuition of her body to identify when something is off. At this point, she feels that tight regulation might offer her possibilities (as opposed to B, F, and me).

What is the function or affective life that shame takes on in these ways? It makes a certain dimension of living with diabetes unintelligible, because these practices are outside of what is deemed “acceptable” or “desired” behaviour for diabetics. The metanarrative that diabetics do not take care of themselves (Heather and Frazer 2021) – especially if their blood sugars are not stable – persists. Ahmed argues that ‘shame as an emotion requires a witness: even if a subject feels shame when she or he is alone, it is imagined view of the other that is taken on by a subject in relation to herself or himself. I imagine how it will be seen as I commit the action, and the feeling of badness is transferred to me’ (2004, 105-106). I am convinced that if there was not a mutual

⁸² Sille is multiply disabled, and her diabetes and PTSD mutually influence one another. On top of that, she has epilepsy and developed “hypo unawareness” (though this remains undiagnosed because she has never been hospitalized as a result). (disclosed during our conversation).

understanding between us through our shared lived experiences of the unpredictability of our diabetes, these moments of internalised shame would not have been discussed. There is always intuitively a need to defend our actions and the rationale behind what we do, to postulate that we are “self-managing” but differently, to justify that we still care, but care differently, to justify that we take our health, bodies and life seriously, even if it is not done through the accepted routes (which do not work for us). Caring about diabetes and caring for ourselves runs through all conversations (we have no choice, because otherwise we would not be able to function and we are acutely aware of this). We are not passive subjects when it comes to our diabetes. Our form of caring for ourselves also relies on the acceptance that messiness and unstable blood sugars are part of our diabetic embodiment. Yet, we cannot fully disidentify from the persistent neoliberal agentic subjectivity of medical ideals that creates feelings of internal shame when such messiness occurs. The function of shame, and the shame that exists in these experiences, makes that these matters are less likely to be up for discussion because the immediate reaction is to locate blame, to locate how we should be taking “better care” of ourselves.

I cannot over-stress the influence this has on being able to create and forge solidarities, communities, and kinship. I was surprised and amazed at the parallels and level of recognition I found in hearing people talk about similar feelings of shame, and alternative forms of managing their diabetes than the common discourses. It made me realise that I also had internalised shame that made me turn inwards. The place of failure – in recognising failure to attain perfect blood sugars despite our best efforts, failure to live up to normative neoliberal expectations of how diabetes should be managed and forge certain results – proves to be a fruitful site for re-configuring being diabetic. To locate where this internalised shame comes from, and how it functions, uncovers the power and persistence of cultural, neoliberal myths of control.

The power of internalised shame goes much further and plays into the able-bodied portrayals and discourses of diabetes and successful normativity. If such shame, the shame of unstable blood sugars (due to whatever reason) is your own fault, it can make you turn inward, which makes it difficult to discuss or bring to light how diabetes can be impairing or disabling. It is precisely the stories of people with diabetes that attained normativity through successfully keeping their blood sugars⁸³ in check (which is a form of what Puar calls “disability

⁸³ Which is truly dependent on a variety of reasons such as socioeconomic position, gender, environment, genetics, and how your body responds to treatment, instead of through perseverance and “adequate self-care”.

exceptionalism” (2017)) that obscures those of us for whom this is not a lived reality. Speaking from my own experience, I outwardly portray a form of successful normativity – in that I am enrolled in higher education, I (basically fully) participate in society, my diabetes is hardly noticeable to the casual bystander. In this context, the perpetuating stories that diabetes is casually managed and controllable makes it difficult to make the day-to-day disabling effects of diabetes legible. The strong focus on management leaves no space for the lived experiences of when such control is unattainable. Shame causes us to turn inwards, to not publicly discuss whenever our diabetes disables us because a part of us always feels like it is our own fault.⁸⁴ Neoliberal agentic subjectivity that focuses on strict management postulates that we do not possess a certain amount of self-control, rather than frame unstable blood sugars as part of the lived diabetic experience (for some people). Acknowledging diabetes’s unpredictability aligns with the current interest of Feminist/Critical Disability Studies to show how, even within the category of a singular disability, human variations exist. It allows us to break out of the neoliberal narrative of personal responsibility, because it also acknowledges how aspects such as gender, class, race, and infrastructural access play into the way that diabetes (and success generally) is experienced, managed, and made (un)controllable.

Shifting diabetes and disability focus: from control and long life to everyday realities

A lot of diabetes research and literature is indeed either focused on attaining stable blood sugars, (the progress of) technological and medical development or the search for cure, and more recently, survivability⁸⁵. Bennett points to, when he first got diagnosed, he noticed that he got the conflicting message both that diabetes “is not so bad” and stories of fatality (or people that lost a foot). Indeed, this seems to echo cultural notions of how illness is experienced: you get diagnosed, your situation gets worse/better, you die/overcome.

In *The Logic of Care* (2008), Annemarie Mol discusses how

⁸⁴ An alternative interpretation could of course also be that not wanting to outwardly portray these disabling factors is a form of internalised ableism; yet, I cannot help but feel like this would be reductive. I argue instead that *because* diabetes is always positioned in its (close) approximation to the normative body, it feels like personal failure when such control is not reachable.

⁸⁵in the U.S. the soaring prices of insulin lead to inaccessibility and death for people who are insulin dependent—this is a serious issue that is of a different calibre than the discussion I am having hereThe edited volume *(Un)doing Diabetes: Representation, Disability, Culture* (Walker and Frazer 2021) has many contributions that focus on this and the activist movements that are trying to raise awareness about this, for example.

people with diabetes are encouraged to be moderate [...] the crux of modesty that care demands, is not that beer, cake and the likes are bad because they give you pleasure. The point is that they will raise your blood sugar levels now, and thus prevent you from enjoying life later on. If you indulge in them at present, before long you will get complications. You will no longer be able to see, to walk. You may even die. It would be best to avoid such complications, or at least postpone them. Thus, you may enjoy life a little longer. In the logic of care it makes sense to give up pleasures if other pleasures are likely to result from this (41)

Whilst Annemarie Mol tries to offer a well-meant, nuanced intervention in the logic of health care and patient choice, undergirding this statement is a wide range of assumptions and common moral beliefs: behaviour is disciplined through the promise of an able body (displacing diabetes outside of disability). This places disability as something undesirable that, if thought about rationally can be controlled and avoided through behavioural discipline. That indeed, holding off “now”, is a form of ‘rational, calculating, and self-motivating’ behaviour. What is more, we are scared into abiding certain rules of behaviour by the promise of the good life, which is equated to a long life. Indeed, ‘lurking just below the surface is an acknowledgement that control is achievable only after bracketing some of the most byzantine factors related to healthy living’ (Bennett 2019, 6). Bennett continues saying that ‘the almost compulsive urge to guide people’s behaviour reveals that the constructed nature of “health” can be just as diabolical as any disease’ (6).

Interestingly, long-term complications did not come up once during the interviews. The only times that Brechtje, Sille, or Felice talked about not indulging in certain behaviours was when their blood sugars were already on the high side, and indulging in these behaviours would make their already unstable present situation harder to regulate. Even though long-term complications are often the focus of public diabetes campaigns (either by preventing them through cure, or by pointing to how diabetes can lead to mobility disabilities – which reveals something about personal and public attitudes about the types of disability truly feared), it hardly seems to be the focus point of our experiences or the basis of the choices we make. We are trying to navigate everyday life alongside/with diabetes. In Bennett’s discussion about diabetes, the focus of management that centres “activating patients” through the prevention of long-term complications ‘overlook[s] the point that sometimes people with diabetes are simply drained emotionally by their disease. Sometimes the struggles of everyday life prevent those affected by the disease from focusing on serious medical issues occurring below the surface of the skin. And sometimes the emphasis on management is overbearing and simple-minded’ (2019, 165-166).

It is reductive to say that the fact that we do not think of long-term complications is a form of denial: what if we read more generatively, and interpret this as a form of acceptance? As is widely accepted and discussed in Feminist/Critical Disability Studies, everyone is temporarily able-bodied. Puar (2017) points to how the workings of neoliberalism and capitalism sooner or later debilitates us all. As Berlant (2011) and Wendell (1989) contend, health is both a sign and symptom of notions of successful normativity and a matter of luck. Like Sille said in the interview: ‘I am not going to not do things just because there is a risk that I might die. I’m not scared of dying. [...] I don’t necessarily want a long life, I’d rather die at age 60 having had a good time, than be alive until I’m 70 and be dependent on everything and everyone. In my current condition, that’s what’s in the future for me. When I look at things I already cannot do (physically/mentally), I don’t want to know what life would be like when I’m 70’⁸⁶.

Even though long-term complications are a much focused on aspect of living with diabetes, it did not come up strongly as a desire or wish to hold on to in the interviews. Indeed, it can be read that we reject the neoliberal narratives that long-term complications can be avoided if you try hard enough and perform certain forms of self-care. We accept that “out-of-control” diabetes is part of diabetes embodiment and navigating the world having diabetes (while we also feel shame about being the cause of these instabilities). However, diabetic experience is much more nuanced – diabetes is a fluid state of ability and disability, marked by the (in)effects of bouts of stable blood sugars and bouts of irregularity and unpredictability. I have good days where my diabetes is in range most of the time; I also have bad days, where – despite being a creature of habit – those same ways of regulation lead to bouts of hypo/hypers and graphs that look like mountain ranges. We expect that our diabetes experience is not focused on aiming for the long run of a healthy life – partly because we are drained and exhausted from day-to-day struggles, and partly because focusing on how you might (not) be affected in the long-term can be extremely depressing. For us, tight regulation also does not equal an increased quality of life, both because such standardised, normative regimes do not work for us for a variety of reasons (they do not garner better results, they have a negative influence on our emotional and mental state) and because strict protocols do not guarantee a long, healthy life. In this way, we reject the “pull yourself up by the bootstraps” narrative. We offer up a counternarrative through our failure to comply to what is expected and wanted of us, because we envision things done differently, and ‘while failure certainly comes

⁸⁶ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021.

accompanied by a host of negative affects, such as disappointment, disillusionment, and despair, it also provides the opportunity to use these negative affects to poke holes in the toxic positivity of contemporary life' (Halberstam 2011, 3). We are not mourning the potentiality of a shorter life span or complications (even though this feels expected of us); we are too busy being dis/abled in the moment.

The issue of diabetes management and dis/ability imagination

A popular phrase in Dutch diabetes patient activation is 'meten is weten' (measuring is knowing): Brechtje, Felice, Sille and myself all questioned this assertion as oversimplistic and reductive; we all have glucose sensors, which give us continuous overviews over the course of our blood sugars. It has enhanced the ability to play into the trends that we see portrayed in the graphs, but it has not given us a sense of complete control. We are still disabled by diabetes – temporarily, through fluctuating blood sugars, but also continuously, through effects of these fluctuating blood sugars. Brechtje and Sille specifically noted how their diabetes makes them tired all the time: my night's sleep is also interrupted by hypos/hypers more often than not. These disabling factors have very little to do with agency (diabetes, the body, and life can simply be unpredictable), but they are made invisible through notions of agency: even writing this, I am wondering where I have fallen short and how many of those interrupted nights I could have prevented through different interventions. However, at the end of the day, diabetes does not just *exist* in the medical sphere; there is a social, lived side to diabetes too. Existing with diabetes in this world goes beyond the attainment of control in the short and long-term; it is about navigating day-to-day life through and with diabetes.

The overemphasis on individualised management and personal responsibility in order to suspend long-term mobility disabilities or death reinstates diabetes in the medical model of disability which (Feminist/Critical) Disability Studies has worked so hard to overcome. The medical model poses disability as undesirable, that posits that 'the proper approach to disability is to "treat" the condition and the person with the condition rather than "treating" the social processes and policies' (Kafer 2013, 5). It also inhibits the configuration of diabetes within the social model, as the disabling factors of diabetes as a result of unpredictable blood sugars can only be interpreted as a personal failure, rather than a result of (abstract) factors and variables beyond personal control.

Thus, the aim of this chapter was to not only critique the neoliberalisation of diabetes discourse, but to also highlight how it plays a part in the fact that people with diabetes often do not consider themselves as disabled or part of the disability community (and are often also not considered “disabled enough” to be taken into account when writing about disability). As Bennett argues, ‘the tendency to ground diabetes management in a language stressing individualism has a strong gravitational pull, and contemplating productive strategies for centering the body politic remains a challenge’ (2019, 197). With diabetes, and chronic illness more generally, firmly placed within the medical realm rather than the social realm, there is a sense of individuation that makes it forgo the forming of communities and likeness. (Health) care is focused on individual behaviours and acting, rather than seeing it as a public, interdependent concern.

Troubles with diabetes are not seen as something that can work as a connecting factor amongst people who experience similar negative affects. I argue that questioning ‘neoliberal conceptions of agentic subjects’ (Bennett 2019, 15) and troubling the notions of management and control through experiential knowledges is a way to imagine living with diabetes *otherwise*, which allows to create recognition, communities, and kinship. Focus should not just be on management, and getting the right results, but on how diabetes is continuous fine tuning, intuitive feeling, direct decisions, navigations. The unpredictability is part of the course and should not be experienced as a shameful aspect; if anything, focusing on this aspect exposes normativity embedded in diabetes discourse. Troubling neoliberal ideals of management as control opens ways for potential spaces to forge communities committed to combating ableism. Secondly, it can (dis)place the (in)visible disabling aspects of diabetes as part of the course of life with diabetes, rather than a personal responsibility. Indeed, by resisting and questioning neutralised and de-politicised aspects of diabetes care, I argue that I queer diabetes and the diabetic body as a site of radical resistance. In the following chapter, I will explore how the concept of affective identification can offer space for potential communities and alternative ways of thinking and feeling diabetes and dis/ability.

Chapter 4: “Inter-relationality”

(dis)placing diabetes as dis/ability through affective identification and queer temporalities

Introduction: Diabetes - From Doing to Feeling

The last two chapters highlighted how we are *made* to feel about our diabetes through public and medical discourses. Both spheres disregard or obscure the disruptive, unpredictable character of diabetes. I showed how focusing on the lived experiences of those who are “queer” in relation to normative diabetes management/regulation is a fruitful place for critique of the neoliberal dimension of diabetes. We fail to live up to – and are critical of – control and the ideal that stable blood sugars can and should be achievable for everyone who has access to insulin and technological aids. Medical ideals are incongruent with lived experiences, and public diabetes discourses are imbued with moral and ideological ideals of health and “long life”. Despite the commonality of unstable diabetes, the experiences of me and my interviewees were not necessarily homogenous (from experiences at the clinic to social interactions). The affects it produced, however, were – which led to the realisation of the potentiality of highlighting the affective dimension of diabetes. The affective potential of these experiences could create a radical form of resisting and refusing, and critically interrupt, neoliberal and linear narratives around personal responsibility, shame, and “it will get better” if you “try hard enough”.

The framing question of this research, namely why diabetes is (not) considered a dis/ability, has partially been answered so far, through the exploration of the place of chronic illness in feminist/critical disability studies scholarship; the concept of a “disability identity” and the way that diabetes does (not) configure in this; and the problem of a neoliberal subjectivity in diabetes management and care, which forges individuation and positions diabetes in the medical model of disability (something that can be managed, the social, cultural and environmental factors not really considered). In this chapter, I expand on (different) ways of inter-relationality both within diabetes experience and dis/ability as a (social) category or state of being. For this, I turn to affect theory, which ‘ask[s] us to consider those elements that have been ignored in favour of more public, measurable and structural indicators’ (Goodley, Liddiard and Runswick-Cole 2018, 199). Goodley, Liddiard and Runswick-Cole make sure to also emphasise that ‘we are subject to various

affect economies in which bodies and emotions are shaped and stifled [...] nurture, affection and care are shaped through complex, political, cultural and social economies' (Goodley, Liddiard and Runswick-Cole 2018, 199). In this chapter, I hope to mobilise affect to find resistant discourses that allow for an acknowledgement of diabetes's dis/abling character, for it to be recognised in disability communities/discourses. I do this through a focus on queer temporalities and humour both as coping and making the affective disabling effects of diabetes legible.

In order to explore the affective life of diabetes and its significance in answering the question of "why is diabetes (not) considered a dis/ability?", I start with locating the affective dis/ability dimension of diabetes embodiment through an autoethnographic account. From here, I theorise what I call "affective identification" as a way to create radical inclusivity⁸⁷ (Keating 2013) and different forms of solidarity and kinship. Following this, I focus on the way that queer temporalities can offer possibilities for making the fluid disabling character of diabetes legible. I investigate a variety of ways in which affect allows for inter-relational experiences; from conversations I had with my interviewees, to acknowledgements in academic works, to diabetic meme accounts on Instagram. Following Halberstam (2011), 'the texts that I prefer here [...] might offer a strange and anticapitalist logics of being and acting and knowing, and they will harbor covert and overt queer worlds'⁸⁸ (20-21).

Re/pre/senting Diabetes: from *able* to un(st)able

I want to shift the rhetoric surrounding diabetes and the process of identification from the realm of what the body/mind does (administering insulin, checking blood sugars, calculating carbohydrates) or cannot do (namely, producing insulin), to what the body/mind feels (failure, exhaustion, disillusionment, empowerment, affective dimensions of dis/ability). I feel disabled when the fluctuations in my blood sugars cause brain fogs⁸⁹; I feel disabled when I experience a hypo or a hyper, when my cognitive and physical functions are temporarily disrupted; I feel disabled by the unpredictability of diabetes, and the many nights that are disrupted through this

⁸⁷ See Chapter 2: "Self"

⁸⁸ The 'texts [Halberstam] prefers here' are from what he terms the "silly archives" of comedies and children's movies and cartoons. Whilst we obviously do not prefer the *same* texts, as we use different examples, I would say that the examples I use are from still from what could be considered "low cultural archives" (or popular culture).

⁸⁹ I want to emphasise that these fluctuations do not have to signify a hypo to a hyper – even within the target of 'species-typical blood sugars' (Walker 2021, 283)

unpredictability; I feel disabled by having to anticipate – and be paranoid by – all types of situations. By how the precarity of life is constantly in the back of your head (did I accidentally under/overdose? What if I get in a situation where I will not have access to insulin?). Diabetes is an ‘in-my-face’ condition, as Anzaldúa described it (2009, 300) – not because of the injections you have to take daily, but because of the affects diabetic life produces.

I feel disabled by the contradictions in the public sphere that diabetes is “not that bad” combined with ableist comments I still have to navigate day in and day out. For example, I have noticed how people who are wary of the COVID-19 vaccination because they are “unsure” of what it would do to their body think it is natural and normal that I *did* get vaccinated, because “my body is different”. The pandemic has made it more than clear how people view those bodies that are compromised by impairments and disabilities – those that are deemed “high risk” – as expendable. In those same interactions, I am also reminded that you can simultaneously be positioned as having an able body and a disabled body, but depending on the moment in the interaction, it is either disability or ability that is foregrounded.

I recognise that what I outlined above are incredibly fluid, personal, temporary states of feeling disabled rather than questions of (physical) access and inclusion. I also recognise that these interactions are instances of ableist microaggressions rather than grand forms of oppression. However, I wonder, if these disabling dimensions of diabetes experience are not made legible, then how might we envision (if at all) different forms of care, kinship, and solidarities amongst the diabetes/disability/non-disabled communities? Whenever someone would ask me how they “could help” when I disclosed that I had diabetes, I never quite knew what to say, because for a long time I also believed that diabetes merely existed in the realm of administering insulin and treating hypos. Everything else I experienced as results of personal mismanagement, and were thus not parts I could or should receive “help”, “care”, or “consideration” for. Similarly, I do not think diabetes is often included in analyses of the effects and consequences of ableism, both because we are seen as having (mostly) able bodies and because diabetes is not known for its disruptive character that can limit functioning.

I never felt more connected to another diabetic than when I read the acknowledgements page of Jeffrey A. Bennett’s book *Managing Diabetes* (2019), where he says ‘I hate having diabetes. I recognize there are more polite ways to communicate that sentiment, but probably none that are as forthright or sincere. I hate the constant monitoring of my body. I hate the bouts of

severe hypoglycemia in the middle of the night. I hate how those sleepless nights make me feel the next day. I hate navigating airport security while wearing technologies that are meant to keep me alive' (203). It was the first time I saw someone foreground the negative a/effects diabetes has on day-to-day life *outside* of management. I had never acknowledged, or heard it acknowledged, that diabetes messed with my nights so much - because it always felt like something *I was doing* to *myself* rather than as simply an aspect of diabetes ("I should have managed it better"/ "Maybe I should not have eaten pizza/had a late-night snack"). This is also the first time that I saw someone so openly acknowledge their struggles with diabetes without being dismissed as careless, ignorant, or stubborn⁹⁰. Through something as small as a remark in the acknowledgements, Bennett opened up a space for different forms of recognition of diabetic experience by accentuating the (negative) affective relationship of having diabetes, both within embodiment (tiredness) as well as in public and cultural settings (airport security). Consequently, this enables a different form of making diabetes legible: Bennett conveys the struggles of diabetes outside of individual management, and places them in affective dimensions that shape how one moves through the world. There is also something humorous about finishing a very articulate and complex work about a topic by outright and bluntly stating that you "hate" the topic you just wrote about (and have a personal investment in).

The question I have often asked myself – specifically in this writing, but also in the conversations I have engaged with since embarking on the project of diabetes as dis/ability – is how to make these aspects of diabetes legible without making it heavy in trying to convey the difficulties of the (un)stable nature of diabetes and the a/effects it has. This was also an undercurrent in the conversations I had with my interviewees; on the one hand, we talked about the limits of our body, our abilities (both in doing and in control), how we feel and what we feel. On the other hand, we also acknowledged all our abilities – in relation to management, in what we could and did achieve. I would refer to this as a politics of ambivalence, which allows for a portrayal of living with diabetes and dis/ability that emphasises a multiplicity of affective states of being. "Ambivalence", read in this way, allows to evade the trap of disability as tragedy (Swain

⁹⁰ After all, Bennett managed to write and publish a book at NYU Press about the cultural politics of diabetes without conforming to the image of the "proud" or "happy diabetic".

Secondly, I mostly know women who were positioned as stubborn, ignorant, or careless. It would be worth investigating what role gender plays in such accusations.

and French 2000; Kafer 2012) and the image of the supercrip⁹¹ of disabled hero (Meekosh and Shuttleworth 2017, 186) and perhaps most importantly, the binary pride/shame and (un)acceptance logic. The focus on the (negative) affective dimension of diabetes is not a move to garner sympathy about how hard living with diabetes is, it is about configuring the way that those aspects of diabetes can be read *as* disability so that diabetes can be made legible in disability studies as well as in disability justice frameworks – a move to make people with diabetes realise how they can ‘claim [...] crip identity or disability’ (Kafer 2012, 14).

As I have stated throughout the thesis, there are many aspects of living with diabetes and chronic illness more generally that are very depressing and offer a sober outlook on the course of life. In the interviews, it came out that humour proves to be an important aspect of the signification of diabetes experiences without making it *too* heavy to the point that it becomes unbearable. Felice has a tattoo of a blue circle (the international symbol of diabetes), with the text “diabeetje jammer”. “Diabeet” is the Dutch word for diabetic. “Diabeetje” is a diminutive of “diabetic”. “Beetje jammer” is a cynical remark meaning “a little unfortunate”. Indeed, this tattoo is a marker of difference – it shows the international symbol for the diabetes community and visibly marks Felice as having diabetes. Simultaneously, this “coming out crip” also turns diabetes into a pun. The pun in combination with a visible diabetes marker, in turn, allows diabetes to be read in a space of ambivalence because its meaning resides in multiplicities of affect.



Sille also emphasised how her personal coping and relating to and with others in her diabetic embodiment relies on the “lightness”⁹² that humour can offer. She says that she is open and honest about her struggles with diabetes, but always adds a humorous quip:

⁹¹ Alison Kafer (2012) argues that supercrips are those disabled figures favored in the media, products of either extremely low expectations (disability by definition means incompetence, so anything a disabled person does, no matter how mundane or banal, merits exaggerated praise) or extremely high expectations (disabled people must accomplish incredibly difficult, and therefore inspiring, tasks to be worthy of nondisabled attention)’ (90) and points to how ‘Supercrip stories rely heavily on the individual/medical model of disability, portraying disability as something to be overcome through hard work and perseverance’ (141).

⁹² The term Sille uses is “luchtigheid”.

S: ‘With people who are close to me, I discuss the more serious aspects of diabetes – in two ways; I will talk about serious things, and can laugh about it. I will first laugh, and then say: “I could cry”.’⁹³

Sille often makes use of humour through hyperbolic statements in our conversation when she talks about how to relate with/through the disabling or frustrating aspects of diabetic embodiment, and uses humour as a way to make these struggles visible. For instance, when she talks about being moody after experiencing a bout of hypoglycaemic episodes in a row, she says that she feels like she ‘wants to throw all her equipment out of a window and jump out after it’⁹⁴ (implicating that she wants to end her life). However, it is through the use of language and hyperboles that it is clear that she is not serious about that intention; she uses this turn of phrase to express and convey the frustration and impact the unstable nature of her diabetes has on her.

Brechtje also uses a lot of hyperbolic phrasing to convey her frustrations when she talks about taking the prescribed amount of carbohydrates to treat a hypo, for example. She says that she can wait for hours and nothing happens, and then she decides to take more, and her blood sugar rises to, in her words, ‘300 mmol/l’⁹⁵. Her diabetes nurse interprets the spike in her blood sugars as overeating out of fear for her hypo, which, speaking as someone who experiences hypos, is a reductive observation.

B: I’ll tell them I waited for half an hour, I died for half an hour, and at some point I was just like, “I need to get it up no matter what”.⁹⁶

Even Brechtje’s metaphoric hyperbole of “dying for half an hour” rings true in recognition – I always metaphorised a hypo to myself as “dancing with death”. The humour and hyperboles allow to convey the frustrations of dealing with diabetes in its unpredictability and frame the rationality of treatment undergirding the notion of management as an element of absurdity in lived experience. It also offers a strong counternarrative to both the able-bodiedness surrounding diabetes, and the downplayed manner in how much time/energy/investment goes into managing diabetes, and how

⁹³ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021. Translated from Dutch by the author. The original (Dutch) statement is ‘kan wel janken’, which is a specific turn of phrase that, used in certain contexts, emphasises both misfortunate but also expresses a hyperbole.

⁹⁴ Sille [pseudonym], interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021. Translated from Dutch by the author.

⁹⁵ A hyper after a hypo would more likely more be situated anywhere between 15-30mmol/l, to emphasise the hyperbole.

⁹⁶ Brechtje, interviewed by Diana Willemijn Helmich, Rotterdam, 5/11/2021. Translated from Dutch by the author.

frustrating it is when the results of your investment are different from the expected outcome – which for us is not uncommon at all.

Before I went to interview Sille, I spent the weekend inserting 6 faulty sensors, until I reached the end of my supply. I warned Sille that I was moody because I was tired because I had not slept well because of this ordeal. She told me that she had plenty of supply; that I could borrow one of her sensors, and return one at a later time when I was restocked. Normally, I would have never considered opening up about these frustrations, because I was worried about judgement that I must have been doing something wrong when placing the sensors. It was in this moment, where I realised I felt comfortable and safe enough to disclose my struggles because Sille and I connected through our frustrated relationship to diabetes, that I fully understood how management is not and should not be an individuated task, I realised how, in the words of disability justice activist Alice Wong, ‘*Community is political [...] Community is magic [...] Community is Power [...] Community is resistance*’ (2020, xvii-xix).

Diabetes/disability: Towards Affective Identification

The connective factor between me and my interviewees was the – daily – struggle with the unpredictability of our diabetes and our feelings of alienation from able-bodied diabetes discourses. The medical dimension of our experiences with diabetes – from the way we manage it, the technological equipment we use, our hypo remedies, to experiences in the clinic – were as divergent as they were similar. It was not in the discussion of this aspect of diabetes where we felt sameness. Rather, we felt connected and willing to discuss our diabetes through the acknowledgement of the frustrations and challenges we experience with our failure to achieve ‘species-typical blood glucose levels’ (Walker 2021, 283); through our frustrations with how we are expected to be and feel about our diabetes; our frustrations of how and where diabetes lives in the public sphere; and our frustrations with feeling misunderstood both within and outside of the diabetes community. These are just examples of how affect can form ties in and between those who have felt like outcasts in the diabetes community. But what about, for example, feeling like an outcast with diabetes in the disability community? I deeply identify with Dana Leigh Combes (2021) describing her experience of living with sarcoidosis, it is ‘a life of straddling the threshold, of being stuck in liminal space between ill and well, disabled and non-disabled’ (209). I argue that

focusing on what the body/mind feels creates space to identify and relate to one another through recognitions of social/embodied dimensions of living with diabetes/disability, and can consequently be a way to shift public perception on diabetes/disability more broadly.

As I have already mentioned, I do not feel disabled by having to inject myself up to 10 times a day. I also do not feel disabled by having to check my blood sugar. These are also not aspects of diabetes that others can take *care* of you for, or where the importance of interdependency is needed⁹⁷. These are *independent* and *individuated* aspects of diabetes. Yet, these are the primary aspects of diabetes that are most commonly centred in outsider interpretations of diabetes, either through the interlinking to diabetes and management, or simply because they are visible, quantifiable, and thus legible aspects. The public focus on individuated management is also the aspects that do not allow for diabetes to be read as a disability as it makes the diabetic seem (in close proximity of) the able-body; Goodley, Liddiard and Runswick-Cole (2018) note that ‘ableism is associated with the broader cultural logics of autonomy, self-sufficiency, and independence’ (209). As I critiqued in the last chapter, the focus on this neoliberal subjectivity in diabetes management does both not recognise diabetes as a disability (management relies on those logics of autonomy, self-sufficiency, and independence) and forecloses the creation of community through its emphasis on individual responsibility.

What would it mean to shift focus from management, control, and personal responsibility to collective care and interdependency? Another facet that I have only recently started to consider, which my interviewees very strongly positioned, is how diabetes influences your mood. Hypos/hypers can make you irritated, shorten your fuses, make you say (mean) things you do not mean. Felice⁹⁸ talks about how during her teens, when her blood sugars were more unstable than they currently are, she was always moody. She just assumed she ‘was not a fun or nice person’ until she realised this moodiness was a result of her diabetes. Sille, Brechtje, and Felice all discuss how friends and family notice that their blood sugars are highly fluctuating by their uncharacteristic moods. The focus on affects rather than the actions within diabetes surveillance (have you taken your insulin, should you be eating that?) is subverted from policing the body

⁹⁷ Mitchell and Snyder define in(ter)dependent/in(ter)dependency to signify ‘the ways in which disabled people pursue the invention of alternative cultures of living as a foundational value of navigating life in an able-bodied world created for a narrow range of bodies, aesthetics and capacities’ (2019b); Akemi Nishida (2017) emphasises the importance in recognising that a politics of interdependence works against the logics of neoliberal, capitalist independence and can offer a reconfiguring of (affective) relationality.

⁹⁸ Felice, interviewed by Diana Willemin Helmich, Amsterdam, 1/10/2021.

(Walker and Frazer 2021) to communal care. Indeed, Hobart and Kneese (2020) argue that care ‘theorized as an affective connective tissue between an inner self and an outer world, [...] constitutes a feeling with, rather than a feeling for, others’ (2). By focusing on affect and affective identification in diabetic experiences, I hope to envision and imagine different forms of care, caring, and interdependency when it comes to diabetes and dis/ability more generally. For this to be able to happen, the disabling dimension of diabetes in the immediate present needs to be centred more than it currently is.

I call this form of identification and inter-relationality through shared feelings and emotions “affective identification”⁹⁹. I argue that “categorical” identification can create alienation across people who have diabetes, and it also excludes diabetes to be considered a disability both within and outside the disability community. Affective identification enables more open and accessible ways of identification rather than a focus on individual management, ideals of management, and the able(ist) discourse that “diabetes does not stop you!”¹⁰⁰ (for this creates inclusion and exclusion on who that is attainable for).

In ‘Affective Solidarity’ (2012), Clare Hemmings makes a similar move to mobilise affective dissonance and using affect as a way to create solidarities across both ontological and epistemological frameworks. Hemmings says that her ‘delineation of affective solidarity in this piece [is] concerned to keep ontology and epistemology together within feminist theory, and to integrate an account of experience that is dynamic rather than essentialising’ (158). She wants to ‘think through such an approach in order to move away from feminist politics based on identity or a naturalised femaleness, while nevertheless retaining the importance of politicised transformation of gendered social relations’ (158). The words “femaleness” and “gendered” could easily be replaced with disability. I see affective identification, in a similar way, as a generative space to relate within, across, and outside, to acknowledge social power differences without hierarchising them over ontological realities, in order to create community, kinship, and solidarity.

This form of identifying with and alongside each other is not merely tied to a specific social/embodied position (namely, having diabetes or being disabled), but focuses on feeling a

⁹⁹ Not the same as empathy, because it is not about placing yourself in someone else’s shoes, nor is it about interconnected bonds between two people – rather, it is about a way of forming connections, aligning amongst an identity through a feeling *with* that supersedes a(n imagined) power dynamic nor involve feelings of pity (Hemmings 2012)

¹⁰⁰ The risk of “positive disability identity”?

sense of belonging through shared affect. As many dialogues across Disability Studies, Critical Disability Studies, and Feminist disability studies have suggested, the creation of different models or separations between different categories always relies on meeting certain requirements. Affective identification allows to be radically inclusive, because the basis of inclusion is not grounded in whether your embodiment (does not) possess a list of qualities in order to fully qualify¹⁰¹. What is only experienced as an impairment for one can be a disability for someone else. The truth of the matter is that a label, word, or category with a fixed meaning is never going to account for the fluidity of embodiment and feelings. Affective identification allows for an understanding of the body as (un)stable, which enables diabetes to be configured into disability because it understands bodies as both stable and unstable at the same time; it facilitates a different and generative figuring of relating to others in community. Identification in the affective manner takes into account multiplicities of being, and allows for a queering of categories through the recognition of sameness in difference and difference in sameness. With this, I mean to say that the embodiment of different disabilities and chronic illnesses can find commonalities through the production of recognisable affects – from the frustration of encountering ableism, to the experience of brain fog, having limited energy, or the constant confrontation with the frailty of the body (none of these experiences are unique for a specific disability). The concept of affective identification in this way also aims to work against the – sometimes inevitable – hierarchising of disabilities.

Additionally, it positions itself against the idea that the category of “disability” can and should be gatekept, and consequently tries to undermine the question of whether you are “disabled enough” to be included in disability discourses. By focusing on affective inter-relationality, the question of how/where disability should be (in)visible is displaced. In proposing “affective identification”, I do not imply that social/embodied positions are not important or not influenced by intersectional axes such as race, sex, gender, ability (in disability), and class. Rather, I am hoping to, in the words of AnaLouise Keating (2013), find ways to move *beyond* intersectionality whilst still taking it into account. The focus on the produced affects rather than the origin of such affects allows to find community without obscuring or overriding or hierarchising these (interpersonal) differences. The incorporation of personal experience then becomes a project of radical inclusivity (Keating 2013, 30) that moves away from questioning ‘who is most oppressed’

¹⁰¹ For a more posthuman, critical race approach to this form of disability inclusion, see David T. Mitchell and Sharon L. Snyder’s ‘low-level agency: disability, oppression, and alternative genres of the human’ (2019b).

(Hill Collins 1990; 270) to inter-relational understandings that create forms of kinship and connection which can strategically be utilised to build strong coalitions in and outside of the disability community. Such coalitions can then join together to combat social oppression in the form of ableism and the culture of ‘compulsory able-bodiedness’ (McRuer 2006), but can also critique, for example, the way that big pharma makes money and stays powerful through our survival (and determines who can survive)¹⁰², or the way that people with disability and debility are forced to be customers of the medical-industrial complex.

Fluidity, queer temporalities, and diabetic experiences

I am also inspired by trans theorist Atalia Israeli-Nevo (2017) and her use of queer temporalities to analyse experience and being. Israeli-Nevo similarly talks about the intelligibility of experiences – albeit in relation to trans(itoning) identities – and offers a different way of being and (transgender) identity formation by looking at queering temporalities from switching to “one gender to another” to an eternal process of becoming¹⁰³. Rather than focusing on how to prevent the unpredictability of diabetes, or not acknowledge its unstable nature, I offer that the un(st)(predict)ability of diabetes experiences both operates by and actively queers temporalities. Queer temporality is applicable to the experience of chronic illness, which in and of itself already messes with the linear temporal logic of Western understandings of linear progressive/regressive forms of “illness”. The common narrative understands that you get diagnosed – your illness gets worse/better – you die/overcome. What happens when the position of illness in your life is not necessarily based in this linear progression or regression, but is rather just there, with good days, bad days, interrupted days, and uninterrupted days? It begs the question: does chronology as an interpretive framework make sense to make sense of living with a chronic illness?

Alison Kafer (2013) argues that queer time *is* crip time, not just because queer temporalities often use disability and illness as a reference in theorising queer time, but also in the way that

¹⁰² See, for example, Jeffrey A. Bennett’s contribution ‘Diabetes Twitter: A Communal Retort to Capitalism’ in *(Un)Doing Diabetes: Representation, Disability, Culture* (2021), which discusses how the soaring price of insulin in the United States has caused the death of those to whom it has become inaccessible to as a consequence. This has led to community organising to challenge lobbyists and politicians about the issues of capitalist healthcare. Bennett argues that ‘insulin has become a metonym for the necessities of universal healthcare programs’ (25).

¹⁰³ The intersection between trans and disability has been much highlighted in recent queer scholarship. See, for example, Jasbir Puar: ‘Bodies with New Organs: Becoming Trans, Becoming Disabled’ in *The Right to Maim: Debility, Capacity, and Disability* (2017).

‘shifts in timing and pacing can of necessity and by design lead to departures from “straight” time, whether straight time means a firm delineation between past/present/future or an expectation of a linear development from dependent childhood to independent reproductive adulthood’ (34). Whilst chronic illness is inherently implicated in time through the adjective “chronic”, an analysis through queer temporality might also offer more fluid articulations that could – conversely – make lived experiences of diabetes more susceptible to be included in/as disability. The focus on fluidity also allows for a disruption to the static idea that one is either abled or disabled (moving towards dis/ability). Thus, a focus of reading diabetes experiences in or *as* queer temporalities allows it to be moved away from the able-bodied narrative surrounding diabetes – and consequent ‘neoliberal inclusionism’ (Mitchell and Snyder 2015; 2020) – by focusing on its disruptiveness instead.

In an attempt to understand what having diabetes is like, the most common questions I get asked when I inform people (be it in professional, friendship, or dating settings) that I have diabetes are “does it interfere with your life often”? “Are you affected by it a lot?”, or, after a hypoglycemic or hyperglycemic episode, whether “everything is okay again”. All these questions share a few implicit temporal ideas undergirding them: that it is a matter of yes/no, instead of a more fluid states of an “always and never”; that there is a “normative” state of being that diabetes *sometimes* interferes with (as if diabetes is not always embedded in your life); it also shows that diabetes somehow always gets displaced from the here and now. I would argue that the use of temporalities, the focus on what I would call “normative points of departure and arrival” are a common method to interpret and understand complex and fluid experiences, such as disabling effects of diabetes.

It is not true that diabetes does not interfere with my life a lot; it is also simultaneously not true that my entire life is continuously interfered with or defined by diabetes. Outside of how *I* relate to my diabetes, it always felt difficult to articulate the abstract experiences of living with diabetes to outsiders, because it does not fit a linear progressive or regressive frame of experiencing something. Indeed, “chronic illness” is as tangible in what it signifies as it is abstract in how it operates in lived experiences. We see it in the activism surrounding diabetes, which always focuses on (the possible prevention of) long-term complications of diabetes and a tragic futurity for those living with the disease¹⁰⁴. Diabetes also gets (dis)placed in futurity with the public discourse surrounding the focus on potential cures. A common way people try to discuss diabetes with me is when there is something in the news about a “break-through” science experiment that *could* lead

¹⁰⁴ See Bennett (2019) ‘Chapter 3. Lethal Premonitions: Fatalism and Advocacy’

to curing diabetes. As I mentioned in the last chapter, none of my interviewees (nor myself) ever really express a strong investment in a potentially more “hopeful future” through cure.

In ‘Taking (my) Time’ (2017), Israeli-Nevo discusses how ‘narratives are the tool with which subjects incorporate time and chronology into the anecdotal pieces of their daily life’ (35). Israeli-Nevo especially identifies this in relation to trans narratives and mainstream understandings of transgender identities. For Israeli-Nevo, “taking time” in transitioning is a way to posit identity as something that is constantly in flux, in conversation with past, memories, interpretations that are formative, which then influence how one envisions the future. In this way, Israeli-Nevo accesses a ‘mindful embodied present’ (39), one that positions her trans identity not in future prospect of ‘turning from one gender into another’ (37). This positioning of a start- and endpoint of transgender identity, she argues, both offers a false safe future where they can “pass” (as if transphobia then disappears), and it follows ‘linear and progressive notion[s] of classic trans temporalities’ (37), which defies ‘the fluidity of gender itself’ (41). This inverted logic could be applied to diabetes; as the present is imagined “safe” through the absence of an acknowledgement of disability, the “disability” of diabetes is transposed onto an (imagined) future.

I want to draw a parallel between Israeli-Nevo’s strategy of taking time to mindfully embody the present instead of focusing on an imagined future and the defiance my interviewees and I feel against the imagined future where tight diabetes management promises no complications. For us, to not focus on the linear line of pro/re/gression into potential complications is a way to access a ‘mindful embodied present’. It also allows to open up the space to reconsider how “diabetes is not that bad” (unless you get long-term complications), and to trouble the able-bodied narrative and the dis/ability distinction. The mindful embodied present, or “affective identification”, allows us to provide insight and access to consider how diabetes in the present – and not in potential future complications which relies on a linear pro/re/gressive temporality of illness – can be configured in disability studies/justice/communities.

Simultaneously, “taking time” takes on a double meaning when thinking of disability accommodations. I cannot help but be reminded of the way that “taking time” functions in the institutional inclusion of diabetes and other disabilities. When looking at the disability services that my university offers, ‘extra time when sitting exams’ is one of the main listings for special

facilities¹⁰⁵. I also had a “time pass” in high school. I always had very mixed feelings towards “taking extra time”, because the way that hypo/hypers influence your cognitive function is not (re)solved by getting an extra half hour when you sit an exam. I remember using that pass primarily for when I could not finish a test simply because I was “taking my time” not because I needed to, but because I could. I felt like because I had to go through daily struggles with diabetes, as well as the superficial and reductive form of “inclusion” in education built for the able-bodied, I was entitled to do so. This strategy of “taking my time” felt like a subversive practice at the time, but it also made me hesitant to do ask for extra accommodations in higher education. If I am struggling with unstable blood sugars while writing a paper it feels redundant to ask for more time, because there is no guarantee that my diabetes will be “better” in a few days. This incongruity is what I refer to when I point to how the fluidity of diabetes experience is falsely incorporated in “normative points of departure and arrival” – unpredictability does not configure in linear, straight notions of time and static understandings of disability. Pointing to the unstable nature of diabetes and dis/ability shows how most accommodations are superficial when the issues of actual, fitting inclusion are systemic.

The focus of people in my surroundings on “interfering moments” invisibilises the contingent character of the way diabetes works, and it obscures the contingent labour in trying to “manage” diabetes. Diabetes also has a temporal contingency where each previous moment influences the next moment. Bennett (2019) points to the fact that ‘diabetes is [...] a *chronic* disease, structured around the gradations of the calendar and the gradualism of the clock’ (34). You delve into the expertise you have gained from past situations and apply them to similar situations in the present, with no guarantee that the outcome is going to be the same – in this sense, the future is always already uncertain. In unpredictability, you always have to be attentive to what your body and the functioning of your mind are telling you – in this way, diabetes forces you to *mindfully embody the present*.

The future, present, and past, are also always entrenched with anticipation; past, present, and future are all encapsulated in the decisions that you make in terms of carbohydrate intake/activity/insulin intake. Kafer (2014) refers to anticipatory time in relation to PTSD and

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<https://students.uu.nl/en/guidance-and-development/student-guidance/studying-with-a-disability>.

Interestingly, on the Dutch version of this page, diabetes is listed in their list of examples of what “counts” as a disability; it is omitted on the English page.

MCS, which involves ‘scanning their days for events or exposures that might trigger a response’ (38). She calls this ‘time of anticipation [...] itself a kind of queer liminality, always in anticipation of the moment that has not yet arrived’ (38). Indeed, when we look at the excerpt in chapter 2 about how Anzaldúa (2009) describes her relationship with diabetes, this is the anticipation of potential complications, but also the anticipation of potential unstable blood sugars when ‘eat[ing] & exercis[ing], when I stay up all night, when I socialize, & when I travel to do speaking engagements’ (300). More broadly, future temporalities are always *uncertain* and focused on anticipation with diabetes, as I pointed out in the previous chapter, in relation to the potential of long-term complications, and when or how your body/mind might start to decay (simultaneously, in the logic of temporary able-bodiedness, this is also simply a fact of life). The public focus on futurity with diabetes, however, forecloses a consideration of how diabetes is dis/abling in the here and now: anticipatory queer temporalities are a way to uncover such dimensions.

The emphasis within the questions outsiders pose is on action or climax, or so I assume: if your blood sugars would be mostly stable, diabetes does not “interfere” in the sense that it does not often (temporarily) disable you. Would that still mean that diabetes is not always there and always affecting you? Moreover, where is interference located? Is it within the self and the functioning of your body? Is it located in your capabilities and capacities to participate? A hypo is disabling, as it slowly stops your body from functioning and can lead to a coma if it is untreated. Felice talks about how half of her face sometimes – temporarily – becomes paralysed when she has a hypo. In the same conversation, she talks about how she sometimes changes a child’s diaper with a dangerously low blood sugar – feeling disabled – but because it is not outwardly noticeable to others, people do not pick up on it. In the disabling state of the hypo, Felice does not have the patience to take time or explain how she feels, she continues the task, because Felice is still “able” to do what is required of her. Sille says that she cannot function with low blood sugars in a work environment. Yet she also talks about how she went to pick me up at the station by bike while having a hypo. I can treat my own low blood sugars, but simultaneously feel the functioning of my body decreasing in the process.

The contradictory situations described above outline how there seems to be no stable distinction between capacity/debility or ability and disability within diabetes – in that we do not always know when we are (going to be) debilitated, impaired, disabled. Rather than trying to aim to create such clear delineations in order to make clear distinctions, it is precisely this fluid aspect

between being able and unable that captures the illegibility of diabetes as disability. According to Halberstam, cripistemologies should focus on ‘knowing, unknowing, and failing to know’; he argues that ‘a cripistemology will surely begin and end with a subject who knows merely that his or her ability is limited and that the body guarantees only the most fragile, temporary access to knowledge, to speech, to memory, and to connection’ (Halberstam in “Proliferating Cripistemologies: a Virtual Roundtable” 2014; 152). As I just mentioned, we do not always know, we rely on speculative anticipation. Additionally, sometimes we have hypers and hypos without knowing. But also, what about the brain fog I mentioned earlier? Is that also not a temporary state of unknowing? What about knowing if diabetes is a disability? Or an impairment? Or knowing how (often) diabetes affects your life? According to Halberstam, cripistemologies do not aim to give rigid answers to these questions; rather, they originate and end with the experiential knowledge that the (st)able body in itself is a myth.

The way that Felice, Silje, and Brechtje talk about how their diabetes is interfering in their lives is by the way that they have to constantly (re)negotiate what they are able to do and not able to do. Felice discusses how people are mindful that she has diabetes, but there is also an element that they cannot conceive: for example, why she chooses to eat a pizza at some times, but not at other times (she considers whether she wants to have irregular blood sugars all night or whether she does not have the energy to deal with this). According to her, this leads to ‘the expectation that you participate, but there is also the expectation that you do not feel bad. [...]. Recently, I was going to go out drinking with a friend. My blood sugars were extremely unstable so it was not a good idea, my friend got annoyed because my disease messed with our plans’.¹⁰⁶ Brechtje also talks about how she feels everyone around her ‘can get by’, and thus she should be able to as well, which often leaves her feeling tired, moody, and unable to properly function. However, Brechtje also points to how, for example, she is aware that the extra stress, organisational practices, and things to be mindful of when going on holiday – or the anticipatory temporality - make her feel tired to the point where she needs ‘a second vacation to recover from her vacation’¹⁰⁷.

¹⁰⁶ Felice, interviewed by Diana Willemijn Helmich, Amsterdam, 1/10/2021.

¹⁰⁷ Brechtje, interviewed by Diana Willemijn Helmich, Rotterdam 5/11/2021.

Memes and Counternarratives: Destabilising through the unstable

After connecting with my interviewees (I found two out of three participants through an Instagram call¹⁰⁸), diabetes meme pages started coming up in my algorithm. Up until this point, I only encountered diabetes representation venturing in what I would classify as ‘inspiration porn’ (Young 2012). Haller and Preston (2017) identify inspiration porn as ‘stories’ and ‘images’ that show people with disabilities who were ‘strong enough to ‘overcome’ their inadequacies and strive to be ‘normal’’ (41). When you search the hashtag #diabetes¹⁰⁹ on Instagram – which shows you popular entries posted with this hashtag – you see a lot of images of food, of skinny, smiling people, of management tools, or (motivational) tips on how to manage your diabetes better.

The meme pages that were suggested, however, framed diabetes outside of normative narratives and images. What makes these pages so appealing is that they usually start from a point of failure – picturing how you feel after taking too much insulin after a meal, the impatience when you have corrected your blood sugar with an insulin shot but nothing happens so you overcorrect – and therefore appeal to a “queer failure” (Halberstam 2011) dimension of diabetes. Thus, these meme pages provide a tangible case study to show how affective identification and the use of queer temporalities in diabetes experience come together. They also, in an almost surprising turn, show the potentiality of anti-capitalist and anti-neoliberalist communal organising. More on that later.

¹⁰⁸ See ‘Notes on Method/ology’ for a more elaborate discussion on this.

¹⁰⁹ See: <https://www.instagram.com/explore/tags/diabetes/>. Accessed on 30/01/2022.

The aim of these meme pages is not to offer a sense of “inspiration”, but rather create recognition and (un)intendedly shape communities specifically by steering clear from authoritative, dominant, or reductive norms of how one should live their life with diabetes. As I



Figure 2: https://www.instagram.com/insulin_and_tonic

discussed in chapter 2 and 3, such narratives can create a form of alienation for those whose diabetes is more unstable than it is stable. Just like my interviewees, using memes to convey the affective experience of living with diabetes allows to portray both the frustrations and difficulties by incorporating humour (either because of the combination with text and a humorous image, or because the situation described is “funny because it’s true”, to quote *The Simpsons*).

Figure 3: source https://www.instagram.com/insulin_and_tonic/



Figure 3: <https://www.instagram.com/dankdiabetesmemes>

Michelle Nario-Redmond describes this phenomenon as ‘disability humor’: instead of able-bodied people poking fun at people with disabilities, it is now ‘disabled people themselves poking fun at societal ignorance and their mistreatments’ (2019, 106). Figure 2 shows one such way in which this is applicable in relation to diabetes and ableism; the fact that 1,421 people have liked this post shows that a lot of people must recognise such a situation.

In ‘Laughing at Injustice’, Aimée Morrison (2019) analyses the way in which humorous hashtags on Twitter are being used to provide a response and create a counternarrative to structural oppression in institutional settings. In her analysis, she focuses on ‘women in science and race-based affirmative action in admissions’ (23) and examines the ways in which ‘the productive social justice work that can come from this sometimes uncomfortable context collapse between humour and seriousness, between pop culture and matters of law and politics’ (ibid.). Whilst her object of study is differently situated, I stand with her observation that the memes posted on the Instagram pages that I use as an example here also perform in this “uncomfortable context” of mixing humour with the seriousness of dis/abling aspects of diabetes, specifically in social contexts (see Figure 4), as well as the difficulties of management and tight regulation in conjunction with living your life (see Figure 5 and 6).



Figure 4: source: https://www.instagram.com/insulin_and_tonic/

Taking to public platforms and using meme templates to expose counternarratives that are generally unrecognized ‘change the script on these debates’ (Morrison 2019, 45). As is evident from the screenshots included here, these posts garner a lot of traffic in the form of likes and comments; judging from the fact that they came up through algorithms, these pages are fairly popular. Morrison, in her analysis, shows that the hashtags on twitter ‘aim at different outcomes [than merely simplified institutional inclusion]: visibility, diverse and inclusive representation, solidarity, and laughter’ (2019, 45). Indeed, the meme pages that offer diabetic counternarratives work to disentangle the image of the perfect, happy, healthy diabetic, the phantasmatic idea of tight management and attainability of stable blood sugars, and instead show how diabetes is mostly experienced in the affective dimension – they offer alternative logics of the lived realities of diabetes, outside of disciplining, control and management. This is not ‘to suggest that the online humourists are themselves unserious. It is [...] a viral means by which the unrepresented and misrepresented can write themselves back into the story’ (Morrison 2019, 43).



Figure 5: source: https://www.instagram.com/_betweentwolines



Figure 6: Source: https://www.instagram.com/insulin_and_tonic/

The focus on experience without a subject (in the sense that the situations described are conveyed through general meme templates instead of individual experiences) allows these Instagram posts to avoid both a paternal/authoritative tone as well as prescriptive ideas about what *you* should be doing. They are not looking to see how experiences of diabetes can and should be located in able-bodiedness, and by this, enter into a dimension of vulnerability; ‘vulnerability and dependency are not only widely shared, but they are what make us human [...] [and it] makes unstable the boundaries between any notion of health and un-health, and between ability and disability’ (Goldfarb and Armenta 2017, 164).

They focus on failure, and counter the idea of the neoliberal subject – if anything, they front the irrationality of navigating the world with diabetes. They move away from how diabetes functions within the individual, and rather focus on the situational, social, and cultural contexts that influence experiences and management of diabetes. According to Margrit Shildrick (2015), ‘In place of neo-liberal entreaties to optimism, hope, happiness and success, the willing embrace of falling short of normative expectations acts as a method of survival in which debility might no longer carry a negative charge’ (20). Shildrick acknowledges that this is the possibility opened by cripqueer theory and its celebration of Halberstamian failure. These Instagram accounts offer a form of visibility that does not rely on neoliberal logic – as nothing about their portrayal of diabetes makes diabetic experience seem particularly ‘willing, capable, or able’ (which Goodley defines as the ‘marked identity of a neoliberal citizen’ (2014, 52)). Indeed, in this way, these accounts can be read as cripistemological counternarratives of diabetes and dis/ability.

These platforms offer a form of community that is alluring to those who have felt *othered* within diabetic communities through their ambivalent, queer relationship with diabetes (example: me, who avoided everything diabetes on Instagram at all cost before this). While they post memes on their feed, they use the function of Instagram Stories¹¹⁰ primarily for community care: they share experiences and ask questions, generate community engagement by asking questions and then sharing the answers of their follower. What is more, these pages are also used as a platform to share and redistribute material resources¹¹¹. This redistribution is not limited to the US; I have

¹¹⁰ temporary posts that do not appear on a feed and stay online for 24 hours.

¹¹¹ People with a surplus of supplies contact the hosts of these pages through direct messages; the host of the page posts these messages, and so people can get in contact with each other.

seen resources redistributed within Europe too. In this way, these pages form the ultimate move away from normative, individuated management and personal responsibility to community forms of care and interdependence. It is also a way to minimise waste/ing, and circumvents the capitalist and consumerist dimensions of diabetic experience. I turn to Lisa Jonhson and Robert McRuer:

cripistemological inversions, or, in less binary terms, dysplasias of ableist logic, might pause over the endless deferral of comfort within this system of compulsory able-bodiedness [...] to reflect on the futility of this idea of future comfort as it propels us further into discomfort [...] the decision to be capable – like the decision to be thin [...] – is a winding road of self-deprivation presented as culturally good. The decision to be unstable, incapable, unwilling, disabled [...] opens up a world of possibility. (McRuer and Johnson 2014, 137)

Conclusion: open-ended we's

I hope to have shown how affective identification and queer temporalities offers a way to think of diabetes *otherwise*, using it to unveil question and resist normative expectations. Forging affective communities is important because it validates different forms of being, it creates connection and recognition and offers alternative forms of care rooted in interdependency. The redistribution of resources on Instagram through a community shaped around “failure” or “unwillingness” is one such instance. Another beautiful and tangible instance is a diabetes WhatsApp chatgroup Sille is a part of: they turn to one another whenever they have questions regarding the regulation of their diabetes. This is partly because responses from nurses can take up to three weeks, whereas issues with diabetes often need immediate action. Additionally, input from others with experiential knowledges often proves to be more effective in solving problems. A foregrounding of affective relationality (of failure, of inadequacy, of disappointment, but also humour) is important to break away from the (st)able-bodied neoliberal subjectivity surrounding diabetes. People who feel marginalised by (individuated) mainstream diabetes/disability representations can, through affective identification, forge a radically inclusive community. This community, I argue, is important in combatting ableism, redistributing resources, and a move from disability to dis/ability, as fluid, inclusive, and transformative. To (re)instate how care is a ‘relational set of discourses’ (Hobart and Kneese 2020, 2).

Of course, the case studies and examples given in this chapter are only some imaginative ways in which to think differently about diabetes, disability, and affect; there is a whole world of possibilities at the level of organised activism not mentioned. I return to ‘the open-ended we’ mentioned in the method/ology, which according to Jaarsma (2017) is vital to keep Critical Disability Studies moving. I see the open-ended ‘we’ across questions of diabetes and dis/ability and within diabetes as dis/ability. The cripistemological queering of diabetes in this chapter showed how the open-ended we is produced through queering temporalities, making them unstable instead of straight; the open-ended we is produced by creating fluidity in time and affective identifications, which break open instead of reproduce binaries of dis/ability. Indeed, I envision embracing the (un)stable aspects of diabetes and disability as part of the open-ended we we should be aiming for.

Conclusion, or, “What is at Stake?”

In this thesis, I explored the question of “why diabetes can(not) be considered a disability”. Through various angles, I investigated how certain paradigms are created and continue to be (re)produced. I hope to have shown that this question is not just about rethinking the boundaries of disability, but the question also reveals that diabetes is caught in an able-bodied, neoliberal subjectivity of personal responsibility and individual management that prevents it from fitting into disability discourse. In other words, it is not just the way that disability is theorised and viewed in culture and society, but also about how diabetes type 1 is perceived as merely a medical disease that can be managed and controlled. I argue that a criptemological queering of diabetes type 1 – through a focus on resistance, refusal, alternative forms of care/ing for the self and about the future, and its unstable character in general – allows to reassess how diabetes can be read not as ability or disability, but as a dis/ability. The queering of diabetes as dis/ability, in turn, also queers the limitations and boundaries of different approaches to disability as a (social) category.

This research question developed further into the question that if the unstable character of diabetes experience is not made legible, for example through existing frameworks, ideologies, and belief systems about ability, disability, and the able-body, then how might we envision (if at all) different forms of care, kinship, and solidarities amongst the disability community and beyond? I started this research project with the idea that diabetes was an individual problem to be (mis)managed by the “agential subject”, something that was unintelligible to the outside world because some feelings and experiences cannot be articulated. Even though the theme of care, and caring for, was something always present in the back of my mind – this is a feminist and queer project, after all – I did not realise how much was at stake in claiming diabetes as disability, and the importance of forging communities by shedding light on liminal, displaced diabetes experiences. Because indeed, what is at stake by (not) claiming diabetes as disability?

In order to reach a different kind of understanding of diabetes, a criptemological queering of diabetes, we need to call attention both to the inadequacies of the current existing frames through which diabetes is understood, and step out of binary thinking of the able body versus the disabled body – in this, I am not saying people with diabetes need to call constant attention to how their condition disables them. Rather, this thesis sought to open up space for these narratives and more. That is, through embedding lived experiences and theory, I aimed to open up the space for these

kinds of narratives that queer the binary understanding of being disabled or able-bodied, of being proud or ashamed of your disability, and of normative, neoliberal ideals that are embedded in (health) care. This reframing could create a kind of radical inclusivity that does not reproduce “status-quo” stories in order to fit in with western logic of sense making (Keating 2013), or to make diabetes and disability as susceptible to be included in neoliberal ideals of productivity and capability. The idea is that the willingness to outwardly show the unstableness, or to *claim crip* is a way to defy ableist logic. It is also a way for people with diabetes to think of themselves differently; what accommodations, help, and care can we ask for? How can we imagine interdependence as a move away from personal responsibility? And how can we form community not in a way to reproduce (st)able-bodied ideals, but rather in order to defy them?

In terms of transnational justice, there is no guarantee that the health care system in the Netherlands will always be as cushy; look at the United States, where diabetes is now a problem of survivability instead of liveability. We can see the beginnings of the acknowledgement of diabetes as disability scholarship taking shape there; I contend that these moves should be happening all over the globe to capture a better image of what living with diabetes is, means, and how it moves in a variety of contexts. The forming of an (inter)national community and raised consciousness over how diabetes is *not* a matter of personal responsibility needs to happen in order for diabetes to be taken seriously and into account. The *self* in self-regulation needs to be displaced from individuation to community. Questioning the (st)able-bodied, neoliberal normative approach to diabetes in society is more important than ever : with the decline of the welfare state in the Netherlands, increased neoliberal idealisms of self-sufficiency, capability, and personal responsibility in the West, the growing pressure on the health care system due to budget cuts and global pandemics, waiting lists, and restrictions about which hospitals you have access to depending on your insurance, the moral and normative judgements and values attached to the way diabetes *should be* managed and experienced (and any divergence thereof to be classified as unwillingness or stubbornness). This is not just a diabetes issue, or a disability issue, this is a queer issue, a feminist issue. As my favourite feminist/queer theorist Sara Ahmed once wrote, ‘any acts that are not in compliance with the order of things become an imposition of a feminist agenda and the order of things’ (2017; 56).

When we start thinking dis/ability differently, we can move away from the desire to attain to the able-body we will always fail to approximate. Let us use our bodies as a site of resistance,

not as a form of carelessness about our own well-being, but as a way to defy the ideology of both ability and disability, of (st)able-bodiedness. In the words of Robert McRuer – we need to claim crip, produce cripistemologies, and find our own way to be ‘Severely Disabled’ (2017, 402) both to feel acknowledged, understood, belonging, kinship, and to call out the normative, naturalised, compulsory (st)able-bodied scripts in society.

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Interviews

- Felice, Interviewed by Diana Willemijn Helmich, Amsterdam 1/10/2021.
- Sille [pseudonym], Interviewed by Diana Willemijn Helmich, Zwolle, 11/10/2021.
- Brechtje, Interviewed by Diana Willemijn Helmich, Rotterdam, 5/11/2021.

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Appendix

This appendix features the original Dutch transcript excerpts that were used in the thesis. They are sorted per interviewee.

Felice interview transcript excerpts

F: ‘Ik denk dat daar wel.. de vraag die bij mij opkwam toen we het net hadden over mensen op hun platform, ik vraag me af wat een onderzoek zoals wat jij doet gaat oproepen bij mensen. Ik denk misschien dat het controversieel is, ook dat mensen zich begrepen gaan voelen. Ik ben benieuwd welke kant het op gaat’.

F: ‘Of je laat aan iedereen zien dat je een proud person met diabetes, dat je alles wil vertellen en laten zien én ik hoef me niet te schamen voor .. versus je verbergt het dus je zal er wel niet zo comfortable mee zijn .. terwijl, dat is niet het geval. Ik heb al 23 jaar diabetes, je kan me alles vragen, dit is geen probleem, ik voel me top in m’n vel voor zover dat gaat met diabetes, ik heb nooit de behoefte gehad om het te verbergen, maar ik hoef het ook niet te displayen.’

F: dat precies. Ik heb heel erg dat ik bepaalde keuzes maak in m’n dieet, of ik doordeweeks wel of niet drink. Het is eigenlijk gewoon super naar, dat ik bepaalde keuzes moet maken die niet per se gebaseerd zijn op wat ik wil, maar meer wat ik noodzakelijk acht. En wat ik best wel merk, dat ik het soms moeilijk vind dat ik dat niet kan delen die dan wel .. of dat je dan als reactie krijgt, ‘oh maar, je kan toch wel gewoon een pizza eten vanavond?’. Nee dat kan dus niet. Als ik dat dus doe, heb ik een ontregelde bloedsuiker de hele nacht, en dan is dat weer een probleem. Ik merk dat ik dat best af en toe lastig kan vinden. Dat je dus niet echt terugkrijgt wat je input. **Er wordt verwacht dat je mee doet, maar er wordt ook verwacht dat je je niet rot voelt.** Dus zeg maar, bijvoorbeeld, ik had laatst met een vriendin van mij dat we zouden gaan stappen. Ik had ontregelde bloedsuikers dus dat ging hem gewoon echt niet worden, en toen was zij boos dat mijn ziekte de planning in de war schopte. Dus.. toen dacht ik van, eigenlijk wil je dat ik meedoe, en dat wil ik ook. Maar je wilt ook dat ik leuk meedoe, of uberhaupt aanwezig ben. En dat is wel soms iets waarvan ik denk; woaaaa, dat vind ik wel lastig.

F: ‘De reden dat veel van mijn vrienden nu zeggen van volgens mij zit je te hoog of te laag want je doet een beetje raar. Dat is omdat ik – zeker aan het begin – veel heb uitgelegd over dat ik apart kan reageren door best wel grondige zelfreflectie. Mind you, zeg het me als ik een beetje gek doe, zeg het me, dan is het waarschijnlijk m’n diabetes en zo niet, dan gaat het gewoon niet zo lekker met mezelf. Maar altijd in de context dat het buitenproportioneel is, is het mijn diabetes. Altijd.’

F: ‘ Ik wil iets lekkers, of, kijk ik hoef mezelf natuurlijk niet te “belonen” voor het feit dat ik laag zit want **vaak is het ook nog wel m’n eigen schuld** maar, dan denk ik van, ja [mompelt] ik weet niet ..’

F: ‘ja maar dat is dus wel echt zo. Elke keuze die jij maakt heeft gevolgen voor hoe je je voelt, en wat jij uitdraagt. Ik heb heel erg dat als ik te laag zit en ik weet, stel je voor ik heb iets gegeten en daar een beetje te agressief voor gebolust [insuline toegediend via insuline pomp], vervolgens denk ik dus van ja .. zie je wel. Ik heb weer te blij gedaan, waardoor ik me dus nu rot voel en niet m’n studie nu kan doen zoals ik die wil doen. Dus ja.. omdat jij de verantwoordelijke ben kan ik me voorstellen dat er automatisch ook een soort schuldgevoel is.’

F: ‘ik heb heel lang gedacht dat ik geen leuk persoon was, eindstand; ik zat vaak te hoog en dan bleek ik gewoon een hoge bloedsuiker te hebben en daar werd ik dan niet leuk van.’

F: ‘daarnaast, ik weet niet of jij dit ervaart, maar mijn hypo’s zien er elke keer weer heel anders uit. Ik heb wel eens hypo’s dat ik compleet dubbel ga zien, dat ik niet op woorden kom, dat m’n gezicht aan het verlammen is, dat is echt heel eng’

F: ‘Ook op werk bijvoorbeeld, dan sta ik met een bloedsuiker van 2 een kindje te verschonen. En dan denk ik echt, ‘hoe ben ik dit aan het doen?’. Maar je doet het. En niemand vraagt er ook naar.’

Sille interview transcript excerpts

S: ‘Ik werk dus niet – ik kan niet werken.

D: is dat diabetes gerelateerd of zijn er andere redenen?

S: ja psychische klachten, in combinatie met m’n diabetes. Mijn diabetes houdt me heel erg tegen in mijn psychische herstel. Diabetes gecombineerd met ptss zorgt ervoor dat ik continu in een neerwaartse spiraal terecht kom: depressies worden telkens weer uitgelokt.

D: vanwege ook de diabetes, telt ook echt aan [?]

S: omdat ik zó moe ben steeds, en zó slecht slaap. Uiteindelijk kom je in die cirkel weer terecht, weer onderaan, en dan zit je in een depressie.’

[...]

S: ‘Maar de mensen die ik nu om me heen verzameld heb, dat zijn wel echt mensen waarmee ik het kan delen. Die heb ik ook wel echt daarop uitgezocht. Als je me ontmoet, dan begin ik altijd met mijn levensverhaal delen. Als je me dan niet moet, dan is het ook gewoon klaar. Dan kan ik ook niks met je. Anders is het zo dat mensen meteen open tegen mij zijn, en dan zitten we ook gelijk op één lijn.’

S: ‘. In de eerste jaren was het altijd zo dat ik deed alsof het heel goed ging. Ik moest altijd in een schriftje bij houden wat je had geprikt en had gespoten: ik deed dat ten eerste niet, ik deed dat altijd een dag van tevoren, want ik ging bijna naar de middelbare school ongeveer toen ik net diabetes had. Ik meette nooit. Ik spoot op gevoel. Ik rekende koolhydraten uit op gevoel. Het was allemaal nattevingerwerk – het ging heel goed want mijn hba1c was goed. En nou ja, zo lang het goed blijft gaan blijf je zo doorgaan, maar de dag voor ik wegging, of soms nog een uur van tevoren, ging ik al die cijfers gewoon invoeren, soms had ik wel wat metingen, en dan ging ik het nog doorpassen. En dan geloofden ze het ook hè? En overal die spuihoeveelheden. Je moest ook altijd je meter meenemen: “ja sorry, die ben ik vergeten, die ligt in m’n kluisje”. Ik kwam er altijd mee weg – ze konden hem uitlezen met zo’n draad in de computer’

S: ik ga niet dingen laten doordat ik zal komen te overlijden. Ik ben niet bang om te overlijden, ik ga gewoon door. [...] ik hoef het niet, ik ga liever op m’n 60ste de pijp uit en dan is het wel leuk geweest, dan dat ik op mijn 70ste afhankelijk ben van iedereen en alles. Dat is natuurlijk wat mij te wachten staat. Als ik nu al kijk naar wat ik soms niet kan, weet ik niet hoe ik op m’n 70ste erbij zit.’

S: ‘bij de mensen die dichtbij me staan heb ik het wel over de serieuze dingen – aan twee kanten: ik heb het over serieuze dingen, maar ik lach er ook wel om. Dan lach ik er eerst heel hard om, en zeg ik daarna: “ik kan wel janken.’

S: “ik gooi alles uit het raam en spring er zelf erachteraan”.

S: ‘Ik doe er altijd heel luchtig over’

S: ‘maar meer omdat ik niet kan werken, daar ben ik gewoon te moe voor. Mijn hoofd gaat ook niet mee, zeg maar, ik heb in die zin overdag regelmatig afspraken en ik stap bijvoorbeeld wel op de fiets met een lage bloedsuiker [om mij op het station op te halen]. Maar ik functioneer niet goed met een hypo, dus als ik thuis ben en ik heb een hypo vergeet ik weer dat ik een hypo heb – en dan krijg ik wel elke 5 min een alarm op mijn telefoon. Dan zet ik de volgende stap, bijvoorbeeld dan pak ik een pakje appelsap, en dan zie ik weer iets anders wat ik moet doen en dan vergeet ik dat pakje appelsap weer. Want mijn hoofd functioneert gewoon niet mee. en dan krijg ik weer een alarm, en denk ik, oh ja laat ik dat pakje appelsap eens gaan drinken. Maar soms heb ik gewoon echt géén zin, dan denk ik, laat me gewoon zitten.’

Brechtje Interview transcript excerpts

B: ‘mmm, dat ligt eraan. Vorige week had ik **een paar goede dagen**, en toen merkte ik dat toen ik op 14 zat, ik hoofdpijn kreeg ... alleen nu, vannacht naar 21 gegaan en dan naar 18, en dan merk ik er eigenlijk niks meer van.

B: ‘toen ik net begon had ik een dietist en verpleegkundige en ging best wel vaak naar de internist, en daar lag best wel vaak die nadruk op “meten is weten” en “tel alles” en dan komt het goed.

Maar ook al deed ik dat, weken achter elkaar elk dingetje opschrijven, die koolhydraat-ratio's, daar kwam gewoon niks uit. De ene keer steeg ik met vier punten na een maaltijd en de volgende dag precies dezelfde maaltijd op hetzelfde tijdstip met dezelfde beweging ging ik gewoon naar beneden. Na een tijdje was ik daar echt moedeloos van geworden en was ik ook wel in afkeer van het hele tellen en het hele beheersbaar krijgen.. na een tijdje dacht ik, ik tel nog steeds bijna geen koolhydraten, omdat het eigenlijk heb ik zo lang daar eigenlijk geïrriteerd op geweest omdat het dus was van “meten is weten en dan krijg je het daarna wel onder controle” en dat gewoon niet ging en daar kreeg ik toch wel een beetje “misschien is het m'n eigen schuld want ik doe wat ze zeggen en krijg het echt niet goed”, en daar is dit wel een groeipuntje voor uit het ziekenhuis, ik kreeg wel echt het gevoel van jij bent student en jij doet dit niet goed, bij sommige mensen is het ook gewoon echt van ook al doe je alles, dan is het nog steeds niet goed, dan ligt het niet aan die persoon maar dan ligt het gewoon aan hoe jouw lichaam reageert.'

B: 'nee, en een andere keer, de ene keer als je een hypo hebt eet je drie snoepjes of drie dextro en dan is het wel weer prima, en de andere keer moet ik 47 boterhammen eten en een banaan en dan gaat hij daarna meteen door naar 300'.

B: 'ja, heel erg. Dan blijft die laag, laag laag, en dan denk ik, “kut, we zijn nu een half uur verder en ik zit nog steeds in mijn hypo”. En ik trek het niet meer.. en dan eet ik eet ik eet ik – en dan ga ik weer naar 20. En dan is het van “dan had je niet zoveel moeten doen”. Dan zegt de verpleegkundige van “ik denk dat je overeet, is dat je angst voor die hypo?” en dan zeg ik, “ik heb een half uur gewoon gewacht en een half uur gestorven, en daarna dacht ik gewoon, ik moet het omhoog krijgen. Ik heb het ook een keer gedaan dat ik dan een half uur wacht, en niet te veel neem, nou dan was ik 2 uur later gewoon nog steeds in m'n hypo.'

B: 'terwijl ik het gevoel heb van “de rest kan doorgaan dus dat moet ik ook”,'

B: Mijn vrienden die pakken hun tas in en zijn klaar, terwijl voor mij is het altijd super veel gedoe; dextro moet mee, koeken moeten mee, daarom, er komt altijd wel wat extra's. Er blijft altijd zo'n deel in je hersens die actief en alert is. En dat vind ik soms wel lastig, [...] Ook met die vakanties, ik kom dan vaak, dan heb ik super veel leuke dingen gedaan maar dan moet ik wel daarna een tweede vakantie om bij te komen van de vakantie. Dat is wel heel anders.