

**Title Page**

Title: Representing diabetes: 'brightside' and 'chaos' in autobiography

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**Abstract**

This paper examines six autobiographical sources written by people with type 1 diabetes. In seeking to improve the understanding of diabetic lifeworlds; some of the autobiographies present heroic stories of ‘overcoming’ diabetes while others present a more ‘chaotic’ narrative. Regardless of their form, all the autobiographies highlight how the everyday problems and concerns associated with diabetes can be hidden and silenced. Therefore, I ask the question of how to use autobiographies as sources of evidence, being aware of the power constructs that may have directed their form. Despite this question, I argue that autobiographies remain crucial sources for exploring the experience of everyday life and much of the silencing in the texts reflects spatial and emotional challenges faced by the authors. I also consider the limitations of representation in the autobiographies calling for an understanding that the experience of diabetes carries with it feelings, emotions and affects that are non-representable and so never entirely knowable. Thus, this paper builds on recent geographical research on emotion and ‘contested’ illnesses, especially those that are not obviously visible or are easily hidden.

**Key words:** diabetes; health; emotion; autobiography; narrative; representation

## Introduction

Type 1 diabetes is caused by an inability of the pancreas to produce insulin; the hormone required to metabolise carbohydrates and provide the body with energy. Prior to the 1920s, a diagnosis of diabetes would be akin to a death sentence, with life expectancy of about a year at most. In the early 1920s, insulin was manufactured for the first time and today, most people with diabetes are able to self-manage their condition. Modern technologies available for self-managing diabetes mean that, for the most part, living with diabetes no longer entails such hardship and can even lead to an “experiential disappearance” (Scheldman, 2010: 154) of the condition in everyday life<sup>1</sup>. While this may be true for many people with diabetes, I argue that for others such a disappearance may be more of a façade, disguising the intensive and sometimes troublesome management of diabetic bodies. To demonstrate this I explore six autobiographies written by people with type 1 diabetes. While all the texts aim to communicate diabetic experience in order to carve out a more recognised place for diabetic bodies in society; some of the authors do this through heroic stories of overcoming diabetes, and others detail their more messy experiences with the condition. Both types highlight the hiddenness of diabetes in everyday life: heroic narratives can overwrite everyday struggles, while messy narratives reflect on the lack

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<sup>1</sup> Of course, the availability of these technologies are far from worldwide. I acknowledge that this paper is written from a ‘Western’ perspective and the experience of living with diabetes may be very different in other places.

of space to discuss these struggles in everyday life. I contend that, through attention to autobiographies, the silenced, hidden and emotional aspects of life with diabetes can be brought to light through a critical *re*-presentation. I also temper this re-presentation by acknowledging that life with diabetes can be so pervasive that there are aspects of living with the condition that remain non-representational. My aim is not to consider how to represent these ineffable aspects but merely to seek acknowledgment that diabetic lifeworlds, like any other, are never fully knowable but perhaps through reflective methods, like autobiography, they may be further brought into view.

### *Illness Narratives*

In this paper I draw from three categorisations of illness narrative: brightsiding, chaos and quest. Brightsiding (Diedrich, 2007)<sup>2</sup>, expands on a social directing of illness narratives, to positive outcomes, that many authors have identified. For instance, Frank, (1997: 143) writes of a moral imperative for people to be ‘successfully ill’ - indeed brightsiding narratives are akin to Frank’s (2013) ‘restitution’ typology – while Bury (2001: 277) writes that ‘failing’ illness may be “unwittingly reinforced ... by those stressing the value of success in all areas of life”. Robinson (1990: 1177) notes the possible effect of such an imperative:

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<sup>2</sup> Diedrich borrows the term ‘brightsiding’ from Barbara Ehrenreich’s book: *Bright-Sided* (2010).

The nature of the narrative accounts of individuals can be seen to be framed and conditioned – by the audience to whom they are directed, and by whom they are seen and assessed. Although the stories are to a degree ‘self-stories’ ... in that they are in part addressed to the self and constitute a representation of the individual self, together they also constitute an accumulated and collective experience ... The social moulding of ‘allowable’ narratives appears to be a key factor in influencing their form and style.

Diedrich (2007: 54 *italics original*) writes that such, “socially sanctioned illness narratives dwell not on loss and failure but on the *overcoming of loss and failure*”. Diedrich continues to argue that such authors: “seem almost desperate to screen the real with a story of heroism – a story for the self – even as the self that this story is for disappears from the scene they have constructed” (p. 67). Both Diedrich and Robinson refer to a receding ‘self’; individual experiences which are overlaid by representations that are more dominant. Diedrich (2007) presents her argument in the sense that this brightsiding leads to a demise of more politically informed activism about the treatments of and for breast cancer. She (*ibid*: 53) writes that, “according to this rhetoric, the dead and dying have failed: failed to survive and so failed to have cancer improve their lives”. Thus, brightsiding leads to a particular configuration of a ‘public patient’ (Roney, 2009), who has not only survived but thrived through illness.

Frank (2013) explains the seeming dominance of brightsiding narratives by contrasting them to the chaos narrative, which, he argues, is often rejected by society. Chaos narratives describe despairing bodies; those without futures and hope; problems that cannot be fixed. They are the stories of those who do not do illness properly. While brightsiding subjects have mastery of their bodies and environments, chaotic subjects do not. Frank (2013: 102) contends this is why society is quick to valorise brightsiding and shun chaos: “all of us on the outside of some chaos want assurances that if we fell in, we could get out. But the chaos narrative is beyond such bargaining; there is no way out”.

However, brightsiding and chaos are not mutually exclusive. For the most part, both types are attempting to achieve the same goal: to communicate the experience of illness and create relatable stories for others to draw support. Frank (2013) calls this a ‘quest’ narrative. As Frank describes it, all illness narratives could be quest narratives, although some may lean towards brightsiding; and others towards chaos; most likely contain some form of balance.

### *Autobiography in Geography*

For some research, autobiographies can be more insightful than ‘conventional’ methods. For example, Davidson (2007:663) notes that for people with autism, autobiographies can provide insightful accounts, due to the authors having time to

reflect and not be under pressure to give immediate answers to questions<sup>3</sup>. Using such sources in research, Davidson and Henderson (2010: 462) argue, allows the reader to “travel in parallel” with the author of the autobiography, promoting a greater understanding. Although Chouinard (2012: 146) notes that autobiographies may result in a “more ‘distanced’ analysis” than an interactive research method leading to them: “draw[ing] primarily on authoritative discourses of ‘madness’ (e.g. as aberrant)”, she also notes that, “they [autobiographies and their authors] sometimes rescript the manic-self-in-place in socially valued ways (e.g. being productive in work-places)” (ibid: 150). Autobiographies therefore enable their authors to grasp an element of control over their representation to others and to, as Davidson (2008: 791) extols: challenge “expert outsider” perceptions. Nonetheless, Moss (2001) cautions us against ‘truth claims’ in autobiography that serve to legitimise and marginalise certain experiences.

Paterson (2014: 97) and Smith (2012) both note the advantages of “rich descriptions”, available with autobiography in challenging entrenched biomedical and/or social views of, respectively, blindness and epilepsy. Paterson argues that autobiographical accounts of visually impaired people instil a greater understanding in the sighted reader, working towards dispelling misconceptions about the blind lifeworld as somehow ‘lacking’. Smith (2013) also draws on Diedrich to discuss how brightsiding epilepsy narratives

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<sup>3</sup> I do acknowledge that there may be a difference between solicited autobiographies, such as requests to participants to complete ‘diaries’ for a research project, and published autobiography, which is not necessarily intended by the author to be used as a source for research and analysis.



can create a fractured epilepsy community with overly positive stories becoming dominant through charities. However, Smith (2012) employs autobiography to expose the overlooked strategies that people with epilepsy use to negotiate space and the threat of seizure. Autobiography is therefore important for *re*-presenting misunderstood lifeworlds and similarly I contend that autobiographical accounts may provide a level of understanding of life with diabetes otherwise inaccessible through ‘traditional’ methods, precisely because autobiography allows reflection rather than being a ‘reactionary’ method, like interviews.

While re-presenting lifeworlds through autobiographies is a crucial aim of this paper; more recent work in human geography has turned our attention to the limits of representation. Non-representational theory (NRT) provides new ways to search for subjectivity. But Thrift (2008) argues that this subjectivity may be non-biographical: that our experiences do not build up this subjectivity but that it exists before experience. However, others such as Wylie (2016) point to the creative processes that help us come to understand our roles and subjectivities. Wylie’s approach warns against the dangers of a non-biographical approach removing the search for subjectivity from social context. Following Wylie’s lead, autobiographies present an ideal opportunity to explore this non-representational subjectivity, as creative texts, saturated in social context.

Dewsbury (2003: 1911 *italics original*) reflects Wylie in considering the limits of representation arguing that:

The point being that representation left critically unattended only allows for conceptual difference and not for a concept of difference *as such* ... the representational system is not wrong: rather it is the belief that it offers complete understanding – and that *only it* offers any sensible understanding at all – that is critically flawed.

An autobiography cannot stand as a finished testament to experience; it only represents one way of conveying experience; one that offers some opportunities: such as space to detail hidden everyday experiences. However, it is also important to note the limits to autobiography. For instance, Harrison (2007: 604), discusses an autobiographical account which, while providing a full, detailed account of experiences of torture also has a ‘tear’: “a suspension of correspondence, an inscription or an incision of incommunicability”. The experience of torture is so incommunicable that we cannot hope to understand it through merely representational methods. It is important to question autobiographies and the narratives they deploy but it is also important to attempt to ‘relate the non-relational’ (Harrison 2007). These tears can have a profound affect on understanding and intimacy with others, and so the study of tears in autobiography can provide a step towards acknowledging, at least the presence of a deeper experience and its emotional aspects.

*Representations of Diabetes*

Frank (2009: 185) refers to cancer as a “deep illness” as “it casts a shadow over the rest of a person’s life and that shadow never really goes away”. Likewise, Atkinson and Rubinelli (2012: 13) refer to cancer as “biographically continuous”, challenging a potentially periodical conception of cancer as a ‘biographical disruption’. Diabetes is probably a condition considered not so ‘deep’. Popular conceptions of the disease often counting it as minor and unproblematic in everyday life. For instance, Mol (2008) notes a Dutch advertisement for a blood sugar meter in which people with diabetes are depicted hiking in the hills, apparently not constricted by their diabetes while their meter displays an ideal reading, representing complete control. Such technological advances have led diabetes to be considered as easily overcome by responsible citizens (Feudtner, 2003). For this reason many people with diabetes find their relationships with clinicians problematic as they do not always take seriously ‘minor’ worries (Rasmussen et al., 2007) and some people with diabetes feel that it is not a “‘real’ illness with an appropriate social response” (Sarkadi and Rosenqvist 2002: 605).

Popular reporting of diabetes does little to help and often serves to stigmatise type 2 diabetes by implying individual responsibility for contracting the condition (Gollust and Lantz, 2009; Hellyer and Haddock-Fraser, 2011). Although this research concerns type 2 diabetes, the moral values and expectations of personal responsibility are still placed on *all* people with diabetes (Anderson-Lister and Treharne, 2014). The moral imperative to overcome diabetes creates a social opprobrium where space to talk about

diabetes is restricted. It is these views that can lead to diabetes being hidden and silenced as people wish not to be seen 'failing', admitting that they may have difficulty managing the condition (Lucherini, 2016). Diabetes is therefore a 'contested' illness (Moss and Teghtsoonian, 2008) but perhaps one that is less readily considered in this way.

### **Reading Autobiographies**

The autobiographies under scrutiny in this paper were selected from internet searches and represent a convenience sample of available texts. Each of these texts was read in a leisurely pace and in leisurely places (buses, beds, chairs), as complementary sources to help inform my knowledge for a larger project which examined the everyday geographies of living with diabetes through questionnaires and in-depth interviews. The results of this project found that the condition is subject to a medical and normalising gaze that can obscure the everyday realities of the condition (Lucherini, 2016). This paper engages more fully with the autobiographies through examining their role in constructing 'realities' of life with diabetes. I read each text with an attunement to their mentions of space and place and how the authors communicated their diabetes to others. Much of the reading has been absorbed over time with each text being revisited on multiple occasions over a four-year period (2011-2015). I used annotations and notes in the texts themselves along with memos to link my thoughts to wider concepts in the narrative literature. Such an approach might be considered a methodological form of

‘slow scholarship’ (Mountz et al., 2015), enabling a more reflexive reading of each text which is inevitably mixed with my own understandings of diabetes (Lucherini, 2017).

## **Autobiographies of People with Diabetes**

### **Brightside**

Nicola Johnson. *Living With Diabetes* (2001). Johnson is from Florida was diagnosed in 1993 at the age of 19. Johnson won the Miss America competition in 1999 with diabetes awareness as her discussion platform. She continues to be an advocate for diabetes awareness, publishing a number of diabetes cookbooks and writing frequent columns in a number of magazines.

John Keeler. *Living Life with Diabetes* (2004). John was diagnosed in 1975 at the age of five years old. John recounts key incidents from his life where his diabetes has affected him. He is a keen sportsman. John is from Dublin and he is involved in promoting activity amongst people with type 1 diabetes.

### **Chaos**

Nic Lee. *Sugar Beat: Diabetes From the Inside Out* (2010). Lee tells of his struggle to maintain control of his diabetes. Lee is from England but has lived throughout the world. He is a qualified nurse and continues to promote diabetes awareness.

Norman Savage. *Junk Sick: Confessions of an Uncontrolled Diabetic* (2010). Savage recalls his life of struggling with diabetes, along with drug and alcohol abuse. He was diagnosed age eleven in 1958. Savage is from Brooklyn, New York. Savage maintains a poetry blog JUNK SICK (<http://normansavage.blogspot.com/>) in which he continues to write about his life with diabetes.

Andie Dominick. *Needles* (1998). Dominick tells her tale of how diagnosis with diabetes, aged nine, affected her life. Dominick is from Des Moines, Iowa. Dominick continues to write about life with diabetes, having recently won a Pulitzer Prize for editorial writing in the Des Moines Register about access to medical insurance in the US (<https://www.pulitzer.org/winners/andie-dominick-des-moines-register>)

### **Limits to representation**

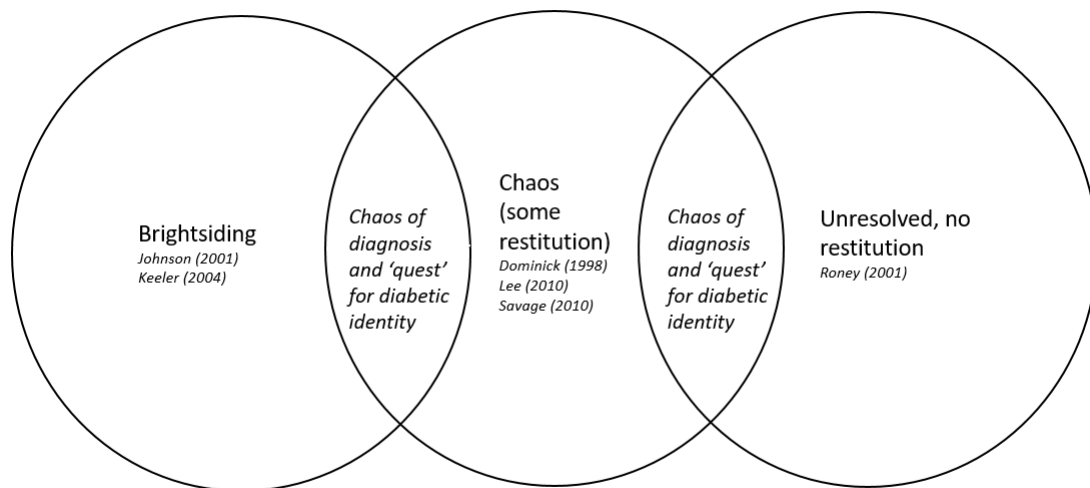
Lisa Roney. *Sweet Invisible Body; Reflections on a Life with Diabetes* (1999). Roney was diagnosed in 1972 at 11 years old. Roney is from Tennessee and writes about her struggles with life, relationships and diabetes. She is currently an Associate Professor of English and Creative Writing at the University of Central Florida.

**Box 1. Summary of autobiographies and their authors. All autobiographies are published and available for purchase as hard copies except Savage (2010) which is only available in electronic form.**

Although the autobiographies were a convenience sample of available published texts, as I read, I began to identify two distinct approaches to writing about diabetes. One, the heroic, ‘brighsiding’ narrative; and two, the ‘chaotic’ narrative. However, one autobiography stood apart, being notably chaotic even as the story ended, serving to highlight the ineffability of life with diabetes. However, elements of each narrative certainly exist in each text, reflecting Frank’s (2013) overarching ‘quest’ typology, and so this system of categorisation is intended to create an operational analysis rather than represent a definitive classification. For instance, all authors experienced a period of chaos after diagnosis in childhood or young adulthood and their subjectivity as a person with diabetes is established throughout their texts. Similarly, the three chaos authors all retribute to an extent, finding fulfilling jobs related to diabetes (Lee); a partner that is accepting diabetic bodies (Dominick), or simply coming to terms with diabetes’ role in their life (Savage). The classification therefore represents the overall form of the narratives. The categorisation of the narrative styles of the autobiographies is represented in Figure 1.

With a reading of these six narratives and their congruence with identified autobiographic styles, I felt that saturation was complete. A common theme among all the texts was that diabetes, despite being the subject of the author’s story, is often quiet in the telling. The condition occupies the authors’ minds and words but the experience is often not explicitly expressed to readers. I want to challenge the hiddenness of everyday life with diabetes. I also want to illuminate some of the ‘tears’ that exist throughout the authors’ experiences, moments in their life when they were unable to

express their experience of diabetes. By taking brightsiding and chaos narrative in turn; my aim is to establish a more intimate understanding of what it is like to live with diabetes. However, it must be noted that although the texts represent extended periods of the authors' lives; their lives have not been static since publication (ranging from 1998-2010, Box 1) and so the paper is not a definitive testament to the experience of diabetes in their lives.



**Figure 1: Representation of three overlapping outcomes of the quest narratives. This diagram has been constructed to indicate the distance between the brightsiding outcome and unresolved outcome.**

### **Brightsiding**



A look at the ‘praise for’ pages of two autobiographies immediately reflects the brightsiding narrative:

Nicole Johnson shares her struggles and pain with transparency and vulnerability. Her passion to live life to the fullest is contagious. Her story is an inspiration to all of us (back cover praise for Johnson, 2001).

In this honest and heart-warming book he describes his journey from childhood to adulthood; from that initial diagnosis, through dealing with pain fear and ignorance, to his situation today, where he feels in control of his diabetes – **it no longer controls him!** (back page synopsis for Keeler 2004, emphasis original).

I accept that in the discussion that follows I am only extracting the brightsiding points of Johnson’s and Keeler’s texts and that they both do experience chaotic episodes in their autobiographies (see Figure 1). However, the point is that in both their narratives ultimately overcome diabetes through control of their own bodies and attitudes. Often this is expressed through mastery of temporal and spatial aspects of everyday life.

*Limitless horizons*

Johnson writes that diabetes should not hold people back from anything, in her case becoming Miss America in 1999:

Some people like to be negative. They sometimes excuse it in the name of ‘realism’. But diabetics – who have this one extra hurdle – can’t afford to be negative or to listen to negative people. If you accept being told ‘no’, if you give up, then you will never achieve anything. But if you refuse to give up, then it’s impossible to fail (Johnson 2001: 138).

Johnson continually and explicitly regards herself as a role model for people with diabetes, especially young people. While her role as a successful woman with diabetes can certainly be inspiring, she presents an extreme example as Miss America, a role based on an ideal female body image, possibly an unrealistic example to set. Johnson also skirts over the impact that diabetes can have on many important life experiences: for instance, that of relationships, sex (an issue she regards very much as private and not suitable to discuss), depression (although Johnson does discuss being depressed at times due to diabetes, it is never a lingering thought throughout her book and is resolved ultimately by her own positive attitude), and the day-to-day challenges of having diabetes<sup>4</sup>. Johnson’s narrative does invite us to ‘travel in parallel’ with her diabetic

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<sup>4</sup> In a recent diabetes ‘self-help’ book Johnson (2014) has addressed issues of intimacy, sexual intercourse, drugs, alcohol and depression among many other life experiences with diabetes. However,

experience and it could be interpreted in a similar vein to Paterson's (2014) work that challenges perceptions of different lifeworlds being somehow less than or incomplete. However, another interpretation is that her narrative brightsides everyday life with diabetes, representing a different form of this travelling than Davidson and Henderson (2010) describe. Instead of understanding the minutiae of a diabetic lifeworld and its tensions with the non-diabetic 'normal' experience, diabetes is sidelined: a hurdle to jump over and leave behind rather a condition that constitutes an evolving identity.

### *Spatial Mastery*

John Keeler (2004) presents a similar type of brightsiding story, although not so initially obvious, since he does discuss more difficult and chaotic elements of his life with diabetes such as discrimination. He nonetheless 'overcomes' his diabetes through living a physically active, outgoing lifestyle, which allows him to complete rigorous physical challenges. After completing a mountaineering challenge, with a group of other people with diabetes, he recalls his sense of achievement: "the conditions were awful, but we overcame them all to show that life with diabetes, though often a struggle, can still be a fantastic adventure" (Keeler 2004: 69-70). With this passage, Keeler reflects Mol's (2008) concern about representations of people with diabetes overcoming the challenge

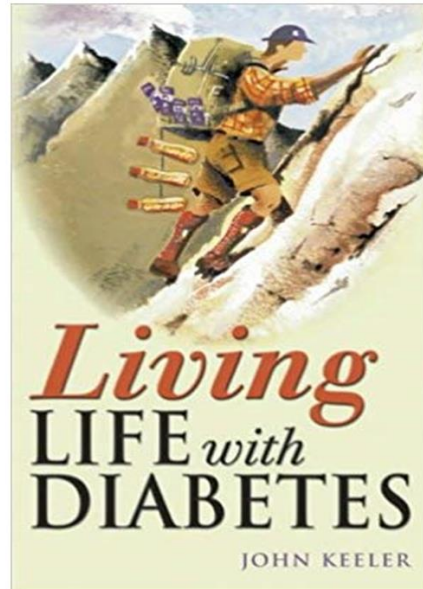
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while she does acknowledge these aspects more directly than she does in her autobiography, her advice does not go far beyond acknowledging that diabetes can exacerbate problems with such issues.

of landscape. While autobiography can be used to extrapolate the spatial strategies of managing illness: as Smith (2012) does; Keeler's autobiography views space, specifically the physical landscape, as space to be conquered, rather than space with which to adopt a different relationship. Again, I am cautious of being overly critical of Keeler's views on diabetes and physical space, as he does acknowledge how during his adventures he must still bring his diabetes with him. For instance, the front cover of his autobiography shows an illustrated version of Keeler overcoming the landscape while being literally and figuratively weighed down by diabetes in the form of chocolate bars and Lucozade bottle attached to his backpack (Figure 2). However, despite this image, Keeler (2004: 83 emphasis original) is frustrated when a friend, upon seeing him inject insulin:

Asked a question I have never forgotten. 'Are you sure you will be OK?' I was not sure whether to laugh or scream with frustration! This was someone who knew me and who was aware of my myriad physical activities, such as swimming, hill walking and judo, and who openly admired my fitness. He **knew** that I could look after myself – yet here he was asking me whether I would be OK.

The pride he has in his physical abilities highlights the prominence of the brightsiding narrative as Keeler is insulted by the insinuation that diabetes could hold him back or could be a source of disruption in his active lifestyle.



**Figure 2: Front cover of Keeler’s (2004) autobiography. The figure climbing the mountain is weighed down by the extra baggage of diabetes: chocolate bars and Lucozade to counter low blood sugar events. Source: <https://www.amazon.co.uk>**

Despite my critique of Johnson and Keeler they may be reflecting Chouinard’s claim and using their autobiographies to represent their desired ‘ill’ self. However, as Moss (2001) warns we must be cautious; Frank (1998: 331) feeds feed this vigilance by considering narratives as inextricably bound up with broader power relations, noting that “Foucault’s middle-period work [referring to *Discipline and Punish*] leads us to ask whether any evocation to tell the truth of one’s self – including first person illness stories – is panopticism in a benign disguise”. On the one hand, Frank believes that such stories should be taken at face value, a trust that the story is a ‘true’ story, not influenced by social and cultural expectations. On the other hand, and following Foucault’s interpretations, such stories are influenced by a social and cultural power

which “operates by convincing us of the selves we want and need to become, in order to be ‘true’ to ourselves” (ibid: 333). Frank (ibid: 333) asks: “can the telling of the story resist ‘relations of subjection’, or is the story necessarily part of what is produced in the manufacture of subjects?” Much like Smith (2013) found with the overly positive stories from epilepsy charities, I believe Johnson and Keeler are creating a particular diabetic subject, or ‘public patient’ (Roney, 2009), that reflects Moss’ (2001) caution that some stories serve to legitimise and marginalise others. The diabetic public patient is characterised by a refusal to succumb to and an ultimate triumph over, illness, which is the only socially acceptable outcome. I turn now to the autobiographies that do succumb to illness at times and therefore highlight some of the messier aspects of living with diabetes.

### **Chaos Narratives**

While illness narratives can be moulded to conform to social and cultural expectations, they can also be resistant. Frank (2013) believes chaos narratives are important to demonstrate the failure of survival and reflect some of the less salubrious experiences of living with illness and impairment. Savage, in heavy contrast to Johnson, writes as a self-confessed ‘uncontrolled diabetic’ and presents a somewhat morbid overall picture of his life, in part due to his drug addictions but also because of his diabetes. Lee also presents a chaotic narrative, as someone who struggles to maintain a balance between low and high blood sugars despite exasperating attempts. Dominick struggles to manage her diabetic self in time and space: her autobiography also a witnessing of her

older sister's death due to complications with diabetes. While the brightsiding narratives present a heroic and confident diabetic subject, the chaotic narratives present a diabetic subject struggling to reconcile diabetes and others aspects of life into a stable identity. The chaos narratives are silenced and anxious in both space and time.

*Silencing and hiding diabetes*

While diabetes is hidden in the brightsiding narratives through a possible obscuring of the everyday difficulties, the chaos narratives reflect on the possible effect of brightsiding dominance and the authors describe the limited space to discuss the condition. Contrasting Keeler's feeling of offence when asked about his diabetes, Savage (2010: Ch VIII) was frustrated that his diabetic experience was difficult to share with his family:

I'd never had anyone in my family offer words or actions that showed empathy or understanding in regard to my diabetes while cancer, brain tumors, leukemia and the like were fawned over, loved, understood and respected. I've no idea if that fact alone shaped some of what I'd become [possibly referring here to being both an 'uncontrolled diabetic' and a 'junkie'], but certainly I am sure that diabetes was, at that time, too slow a death for me and not nearly romantic enough for me to appreciate.

Savage here reinforces the “socially sanctioned” (Diedrich 2007: 54) sense that diabetes should not be difficult: any problems that you have are your own making or exaggerated. For Savage, there is little expectation of sympathy or empathy for diabetes-related problems and so it is better to let it go unacknowledged, silent.

At points in his autobiography, Lee is also frustrated at not being able to express what it is like to live with diabetes. When attending an interview for entry onto a nursing programme, Lee is asked what he learned at his previous job and how this can be applied to nursing:

I wanted to tell Julie [one of the interviewers] that I learned to fight for my right to test my blood sugar at my desk and not in the toilet, and that I never had a conversation with a customer while having a hypo, but instead I tell her, ‘ ... I learned to adapt to the demands of shift work in a customer service environment’.(2010: 67)

Lee is referring to a spatial expectation for people with diabetes to conduct their daily management needs of injecting insulin and testing blood sugar levels in toilets (Lucherini, 2016). Lee’s ‘true’ self, a proud person with diabetes who has previously fought for his rights in the workplace, recedes in favour of a more socially accepted person with diabetes, one who adapts rather than resists.



*The anxious spaces of diabetes*

In addition to Savage's and Lee's autobiographies, Dominick conveys aspects of the chaos narrative discussing her foreboding sense of dependency when on a camping trip in Alaska with a friend and suffering diabetic problems with her eye:

I look around the tent, wishing I could enjoy the solitude I had sought so eagerly only two months ago. Instead, I long for a doctor or hospital. I'm scared. As much as I dream about finding peace out here in isolation, the reality is that I will always need civilization. I will always need medical supplies (1998: 133).

Her dependency is on that part of infrastructure that contains networks of doctors, clinics, referrals, prescriptions and pharmacies. Dominick's account contrasts with Keeler's mastery of space; suggesting that diabetes limits a sense of adventure, freedom and enjoyment.

Lee (2010: 11) also reflects this limiting of spatial imagination, foretelling that "if there's a nuclear war or something and I end up on a bunker or on an island somewhere like New Zealand far away from the fall-out, what chance have I got if they run out of insulin? I'll be like an astronaut without oxygen". The chaos authors approach space differently from the intrepid Keeler: they are cautious of its everyday dangers, dependency and possible isolation.

Upon returning from her Alaska trip, Dominick (1998: 145) continues to reflect on her changed relationship to space:

I will learn to ask. I will tell Ann [her friend] that I can't drive at night. She will maneuver her car across the busy streets of Des Moines and come ten miles out of her way to pick me up. I will learn to swallow my pride, pick up the telephone, and dial the telephone numbers of my friends.

Savage (2010) also adapted his relationship to space. Describing a series of one-night stands with female companions, Savage would always try to convince them to come back to his place so that he would not have to rush home in the morning to get his insulin shot. Savage also frequently falls back on the care of his parents and the parental home and relays a sense that he feels unable to deal with diabetes on his own. In this way he is also rooted in space, never wanting to leave the familiar spaces and emotional ties of the family. Unlike Keeler, who masters space despite diabetes, Savage's and Dominick's accounts, reflect the epileptic experience of Smith (20102) and tell of a specifically 'diabetic' approach to navigating space that, while being difficult for both, is not necessarily a giving in to the condition, but a way to incorporate diabetes into everyday life.

*Temporally diminished worlds*

Along with creating anxious spaces for people, diabetes can also contribute to reducing temporal horizons. Diedrich (2007: 134) discusses the act of witnessing in the case of HIV/AIDS, discussing how, “prior to becoming sick, the person who is HIV+ often experiences – as friend, lover, and/or caretaker – the illness and death that awaits him or her; the PWA [person with AIDS] dies before dying, in between two deaths”. Dominick (1998: 117) witnesses the death of her sister, who also had type 1 diabetes, and who she describes as “self-destructive”: ignoring her diabetes and engaging in excessive smoking and drinking. In her concluding chapter, Dominick contemplates her own sense of fatalism. Talking to her sister at her gravesite, she says:

Sometimes it feels like I still don't really fit in anywhere though. It's like I'm waiting for something that other people aren't waiting for. Waiting for something to go wrong. To go blind or die or for my kidneys to fail (p. 215).

Roney also reflects on being in ‘between two deaths’. As she explores some abandoned apartments with colleagues, above the diner where she worked, Roney’s awareness of her mortality is heightened. She discovers some long abandoned needles and, reasoning that they belonged to illicit drug users, recalls the brief exchange with her boss Mary upon returning downstairs to the diner:

‘What did you find?’ Mary asked, back downstairs.

‘Dust’ [said one colleague]

‘Junk’ [said another]

‘Death,’ I whispered, awakening to my own condition, feeling more alive in this trembling awareness than I ever had before (Roney 1999: 110).

Roney feels death in the abandoned apartment and feels somewhat cast loose, fearing potential future destitution and longing to return home. She hints at the despairing feeling that this space dislodged in her: “I felt suffocated, paralysed, frozen, punctured, stabbed and afraid. What was I doing here, so far from home? Would I ever live in a room like this?” Space is relational; we experience it through our own subjectivities: Roney’s colleagues have no particular strong reaction to the abandoned apartment seeing only detritus but Roney see her own future; heavily featuring her death in this otherwise innocuous space. This extract provides an insight into how space and time is constantly interpreted through the lens of life with diabetes.

### *Limits to Representation*

Both the brightsiding and chaos narratives include elements of ‘quest’, in which authors work towards a sense-making of their lives as people with diabetes. However, I have argued that Johnson’s and Keeler’s attempts can perhaps go too far, obscuring the everyday realities. While chaotic narratives might provide a relatable account, they may also be characterised by too much negativity. Of course, Johnson and Keeler do touch on the difficult realities and the ‘chaotic’ writers do reconstitute to an extent; coming to understand how diabetes fits into their lives. While Frank considers the quest narrative to be something of a moral imperative to relate one’s story for the benefit of others;

perhaps this blurring of narrative hints at the difficulty of being able to satisfactorily represent one's life with diabetes.

For instance, Diedrich discusses an “ethics of failure” (2007: 148); a failure of language and medicine to convey the experience of illness. Diedrich writes: “to some extent, this is what all communication is: we can't hear – and know – the thing (the ‘experience,’ the real) itself in the moment, we can only listen for its echo, its effects in time” (ibid: 146-147). She advocates a continuing attempt to go further, deeper, to “open up the possibility of new routes, new treatments: in and between art, medicine, philosophy, and politics” (ibid: 166).

Following Dewsbury's (2003) arguments, while diabetes may be known as a difference to many people, the everyday form of this difference is unknown. To question the sufficiency of representation for understanding the lived experience of diabetes, I visit Roney's (1999: 254-255) autobiography, as she recounts a recurring dream of hers:

I meet a diabetic stained-glass artist named Jacob, someone I have never known in real life, and his work dazzles me with its vivid blues and yellows and its incredible precision and fragility. He says that working with glass reminds him of insulin syringes, of taking injections, which in the dream makes complete sense to me. His work, though completely nonrepresentational, is all about diabetes, and we both understand this, though it is never stated.

Roney and Jacob do not have to speak to understand Jacob's art, their shared affective qualities of diabetes mean they just do, even though the art does not obviously represent diabetes. In the context of Roney's book, this is a particularly telling quote. She frequently relates her fall-outs and disagreements with friends and lovers, most being attributed to misunderstandings of what it is like to live with diabetes. In this world of signs and language, she is unable to explain her body to others, and hence the title of her autobiography: *Sweet Invisible Body*. When she slips into a dream, however, she discovers, with the imaginary character of Jacob, that she can obtain some sense of peace and tranquility in not having to explain herself any more.

Discussing a novella written by Olga Tokarczuk, *The Hotel Capital*, Dewsbury (2003: 1921) writes:

Thus ... we have an example of this more modest engagement with representation, we have a literary-ethical style of expression because it becomes a space to witness those intangibles that are about being unbound from notions of identity and the support of representational systems.

Reflecting the novella, Roney becomes 'unbound' from the "regular world" as she calls it (1999: 252), but, like Doel (2004: 150-151), who warns against the excesses of NRT, she does not "wish to elude the gravitational pull of the world in order to float freely amongst signs and images". Rather, Roney (1999: 252) writes that:

Acceptance seems such an inadequate, even flaccid word for what I mean. What I mean is so profound as to be almost indescribable, and it has to do with experiences of reality. All these years, my diabetes has presented to me, in moments, in glimpses, a reality that is seldom acknowledged by the normal world. It's not that I want to give up being a part of the regular world, but I do want to be happy with what in me is beyond that. I want to have faith in my own experience of reality, which often finds huge lacks in ordinary attitudes and beliefs.

Roney wants to be re-presented and explained to the rest of the world, but has found that her diabetes disrupts these attempts, making her something that cannot be represented by conventional means. Throughout her final chapter, Roney struggles with exactly how to represent herself and unpacks why she experiences difficulty in establishing meaningful relationships. She ruminates on her isolation:

I assumed that someone, whether friend or paramour, would meet my criteria soon enough. Now nearly eight years have passed [of living alone], as though magical invisible bricks have flown in from nowhere to fill up the doorways and windows, more and more solidly closing me in here ... (ibid: 225)

... My own secretiveness, avoidance of rejection by hiding away the reality of my life, I know, keeps me from being really known, really loved ... (ibid: 296)

... Writing about this is an attempt to change it, an interim way through this lonely time, a way to make myself visible without taking the bullets directly. Here on the page I can be both myself and my disease, without ignoring the latter or being subsumed by it, without subjecting myself to the fear I evoke in others. But I also want this off the page: to live as fully, to be as completely known ... I abide with that hope (ibid: 297).

The second two extracts are taken from the final two pages of Roney's autobiography and indicate that, at the end of her story, she is very much alone and isolated. She has difficulty representing herself, both in text and in real life, feeling that her true self is stuck, in some liminal space, off and on the pages.

The incomplete subjectivity of Roney contrasts to the complete diabetic subjects presented by Johnson and Keeler. Keeler is confident in his physical abilities and his ability to tackle the challenges of the physical landscape: he is not 'floating freely' in a process of becoming due to the disruption of diabetes but can confidently represent himself in his autobiography: a quest narrative with a decisive end. Johnson (2001: 94) likewise comes to a similar realisation and reflects the confidence in herself that Keeler demonstrates along with Keeler's sense of being a subject of others' admiration:



But now – now with the crown on my head – with the fulfilment of everything I had worked and hoped for, I felt not only wonderfully excited and happy, I felt content and confident. I was confident in my imperfection. And in that instant, I suddenly became a role model not only for millions of people with diabetes, but also for anyone with a chronic illness.

Following ideas of NRT (Wylie, 2016), we can conceive of subjectivity as emergent and incomplete: something that can never be fully knowable to others or ourselves. Therefore, a published autobiography, although a ‘completed’ text, can never present a completed subject. Brightsiding narratives however, attempt to do this, by creating a finished representation of the ill person as having overcome illness. Chaos meanwhile emphasises the impossibility of achieving this end. Perhaps, the best we can hope for is to abandon our assumptions on an experience and attempt to ‘travel in parallel for a while’ with another’s experience.

## **Conclusion**

While advancing technology may allow something of an “experiential disappearance” (Scheldeman 2010: 154), diabetes can still be a pervasive presence in people’s lives. People with diabetes often lament their limited time for discussing everyday problems

with health care professionals (Rasmussen et al., 2007) and so perhaps autobiographies can provide a source for clinicians to appreciate the small issues in diabetic life. However, a moral imperative to ‘brightside’ pervades the experience of living with diabetes, which can have the unintended effects of pushing diabetes towards the margin of acceptable conditions. The impact of this is seen in the chaos narrative where diabetes has become a liminal disease that does not fit with social understanding of illness, and so is rendered silent and invisible. Through this re-presentation and discussion of its limits I have worked towards Frank’s (2013: 111) call for “an enhanced tolerance for chaos as a part of a life story”, which may bring some diabetic experiences back from the margin.

The brightsiding authors (Johnson and Keeler) are the ‘public patients’ (Roney 2009) of diabetes, the ones held as the ideal standard of what a person with diabetes can achieve so long as they are responsible and motivated. However, perhaps my interpretations of Johnson and Keeler are unfair; if I were to interpret their stories more as a quest narrative, I could be more understanding of their story as self-story: a journey through their own experience of getting to know, and be comfortable in, their diabetic bodies. However as Diedrich and Frank argue we cannot escape the entanglements of power in which our stories are inevitably caught. The chaos autobiographies are caught in this entanglement; unable to express their feelings in everyday encounters but able to do so in writing. Publically available testimony, such as the autobiographies discussed here, needs to be considered critically to understand what it is they do for people. Do they assist in providing relatable accounts of living

with illness, or do they create idealistic public patients that embody a narrow model of what it is like to live with illness and disability? Even so, writing is still limited, as Roney's reflections reveal: stable diabetic subjectivity remains out of reach.

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