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RESEARCH

Diabetes Year One. Drawing my Pathography: Comics, Poetry and the Medical Self

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In this article I reflect on the creation of my graphic pathography *Diabetes: Year One* (2018). I discuss and evaluate the ways in which, trying to articulate a patient perspective that is both personal and universal, my work moved into comics, and how the process involved the discovery of an aesthetic, that required the negotiation of the elements of comics, including: the visual interpretation and development of my 'self' and avatar, and the construction of a narrative viewpoint; the understanding and use of a spatial 'rhythm and metre' within the panel sequence; the layering of the page through colour and medium; the 'designing' of the narrative, and the interrelation of words and image. I then consider my project in the context of the field of graphic medicine (Squier & Williams, 2015) and the work of Nick Sousanis (Sousanis, 2015); from the position of imaging and articulating a complex, or immersive account of patient experience and argue that this approach can provide a nuanced account of medical identity that can enable a richer understanding of patient experience, which, in turn, can be a valuable contribution to the imaging and design of the patient-practitioner interface.

Keywords: Diabetes; Graphic Medicine; Identity; Patient Experience; Poetry

Pathography and Type 1

Diabetes: Year One is a graphic pathography – or a graphic 'narrative of illness' (Squier, 2015 citing Anne Hunsaker Hawkins: 45), a comic form that exists where memoir and ethnographic research meet the developing field of graphic medicine. It covers my first year (and a bit more now) after being diagnosed with Type 1 diabetes – the process, and research involved in my experience of becoming and being a patient. The graphic poems deal with the patient perspective to explore the doctor-patient interface; and are aimed at developing awareness and understanding of the patient experience for

new diabetics, parents and family, medical practitioners – as well as other people who just want to get a sense of what diabetes, and being a patient, can mean.

Type 1 diabetes is an autoimmune disease, where the body's T-cells (the security cells), attack the insulin producing Beta cells in the pancreas, and lead to the body being unable to produce insulin. Insulin is responsible for getting glucose from carbohydrates and sugars from the bloodstream into storage, so that the body can use this energy when it needs to. Without insulin the immediate effects are tiredness, extreme thirst, and frequent urination, and, longer term, diabetes can lead to heart and kidney disease, as well as nerve and eye damage – including amputation and blindness. Type 1s need to inject insulin through a pen or pump (I've got a pen), need to do frequent blood tests, and work out the amount of insulin to carbohydrate before meals. Getting the amount of insulin wrong can lead to going too low (hypoglycaemia), or too high (hyperglycaemia) – both of which can result in comas (Diabetes UK, 2018).

From someone whose relationship with the NHS was theoretical, I became very much bound up in the healthcare system; so much so, I took up the offer to participate in a drugs trial¹ – having been convinced that, placebo or not, this would give me access to knowledge and supervision that would help me get to know and understand what I was going through. I focused on knowledge as a way to regain some control.

Finding a Pathway

I was diagnosed two years ago, just before I took up my place on my MFA. An event that caused me to consider my own practice – and led me to consider how being a patient might affect my sense of who I am.

I found the leaflets I was given at the time both problematic and unsatisfactory. They communicate effectively, but also impersonally, and diabetes is personal. Although the definitions of Type 1 and Type 2 are known, the impact of the disease is different from patient to patient; for example, insulin ratios and proclivity to hypoglycaemia can vary based on diet, exercise, metabolism and circumstances; all of which means that my diabetes is not the same as someone else's diabetes.

¹ Supervised by Professor James Shaw at the Clinical Research Centre at Newcastle RVI/Newcastle University.

Instead my understanding of Type 1 diabetes has come through living with it, through reflecting on the impact on my day-to-day life, and through researching and experimenting to understand that impact. The notion of myself as a 'diabetic' – or person with diabetes,² has meant negotiating and re-negotiating my life: moment to moment, experience to experience – sometimes sequentially, often my understanding has been more ad-hoc.

Having been diagnosed I tried to find ways to express and think through my experience. By participating in the drugs trial, I was able to discuss the disease in detail with healthcare professionals – everything from diet plans, to insulin ratios, and the mechanics of an auto-immune disease. Prompted by these conversations I looked into medical research, learning more about the working of the pancreatic cells, the islets of Langerhans, and the history of diabetes treatment. But also tapping into online forums, seeking patient approaches, and beginning to get a feel for the differences between patients, and treatments across the country, and the world.

At present we can't explain what causes Type 1 – so there's not a lot of work on prevention; and I decided that, as a new patient, I didn't want to lecture or explain; I wasn't looking to create a didactic work about the symptoms and effects. Being new to living with diabetes, I wanted to voice the immediacy of what I felt, I wanted to create a work that was specifically based in my experience.

Why Comics? Drawing the 'Medical Self'

It became clear my experience didn't fit into a continuous narrative – how could it? After all experience is fragmented, arguably even momentary. I decided I wanted to contrast the information I was discovering in both my drawings and my writings to convey the complexity of patient experience; and once I decided on exploring juxtaposition it was a short step to McCloud's: 'Juxtaposed pictorial and other images in deliberate sequence', (McCloud, 1993: 8).

² The choice of terminology is a matter of debate within the diabetes community – during the period of writing I used the term diabetic, which I find fits for the time being, though it is problematic, and points to my understanding of the development of my medical identity.

My rationale was to provide a canvas that others can impose themselves on, or react against, so that individual experiences can be processed. I developed my comic as a sequence of graphic poems, to unpick meaning, and increase access to the complexity of the experience – something I felt was overlooked at my diagnosis. Whilst I appreciated the information I was given, I didn't feel I was given time or ways to consider the meaning of what I had. Feelings of guilt, questions of blame, changes to life-style and the development of new rituals; alongside implications for diet and the ways to approach the organisation of the day – and even the language around diabetes, were things I had to stumble through (Cooper & Swindell, 2018).

These thoughts would coalesce into a loose theoretical framework through David B's *Epileptic*, (B, 2005), Scott McCloud's *Understanding Comics* (McCloud, 1993) and Nick Sousanis' *Unflattering*, to bring together: the capacity to imagine disease and the idiosyncrasy of individual lives; alongside the technical and narrative potential of the comics medium; and the: 'simultaneous engagement of multiple vantage points... to engender new ways of seeing' (Sousanis, 2015: 32).

In my case poetry refers to my style, based in the musicality and playfulness of Beat and post-modern L=A=N=G=U=A=G=E poetry, moving between free-verse and rhyme as desired. Comics provided the medium to shape the textual drift towards poetry, and to let the images say something 'other' than the text or even to contradict it. My intention was to find a way to visualise Type 1 diabetes, and in doing so, to explore the notion of medical identity.

With images provoking the text and vice-versa they could negotiate the space – not to describe, but to articulate the **experiences** of being a patient. My thinking moved through recollection of events, to the need to unpick the moments of everyday life and consider *The Disease* away from *The Institution*. I intended the interaction of images and text would deepen the immersion within the experience; I wanted to produce a work that dealt with all that, and made it clear that confusion, uncertainty and doubt were okay – were to be expected. I feel that this permission to access complexity is often missing in communication with patient, with the intent to direct patient behaviour, rather than encouraging the patient to take ownership of their experience (Kar, P in Cooper & Swindell, 2018: 2).

Comics: Designing the Text

Framing the narrative as a collection of poems, allowed visual experimentation with style and design in collaboration with the written forms, as the whole is held together by the central point of view, and the personalised nature of the drawing – warts and all.

Experiments with rubbing out, colour, panels and metaphor lead to a first, ultimately unsuccessful, page that developed key elements. Using rubbing out I could *excavate* the drawings – adding a sense of the layering I wanted to convey; colour prompted a psycho-realism in my approach – something that fed into my design of the text, where poetry and image were developed in tandem.

Initially I used a quote I found by a diabetes patient cited by Tattersall (Tattersall, 2009) to develop animal metaphors as a reflection of the unseen diabetes, but as the comic has developed this has mutated into a focus on the debris of the disease, and the idea of the body as grotesque or *Other* (see below). A nine-panel format provided the rhythm to hang my first ideas around, like iambs in blank verse (**Figure 1**).

Through the design process of the comic I interrogated what I thought I knew, and how I thought I knew it. The poems and images pointed to a dialogue between the minutiae of daily life, and the psychology of being a patient. From a personal perspective the act of drawing allowed me to access my experience more completely. This ability of comics, as graphic pathography, to access both synchronic and diachronic time (Squier, 2015: 46) is a framework that can enable the patient and reader to 'slow-down' (Myers, 2015: 102), and become immersed within their experience.

Initially I considered the diagnosis, my first snippets of education and the sense of dislocation this engendered. I found my research taking me in new directions – considering the science of diabetes and the day-to-day of existence. Utilising and disrupting the orthodoxy of guttering to allow and deny the reader space between panels created a weight of time that gave coherence to the text – and the sub-text. In examining different elements of my experience, I found different emphases on time, which in turn led me to consider the use and arrangement of panels in narrating my interactions with the world. This license to experiment in terms of format and style broadened the design of the pages to use the juxtaposition

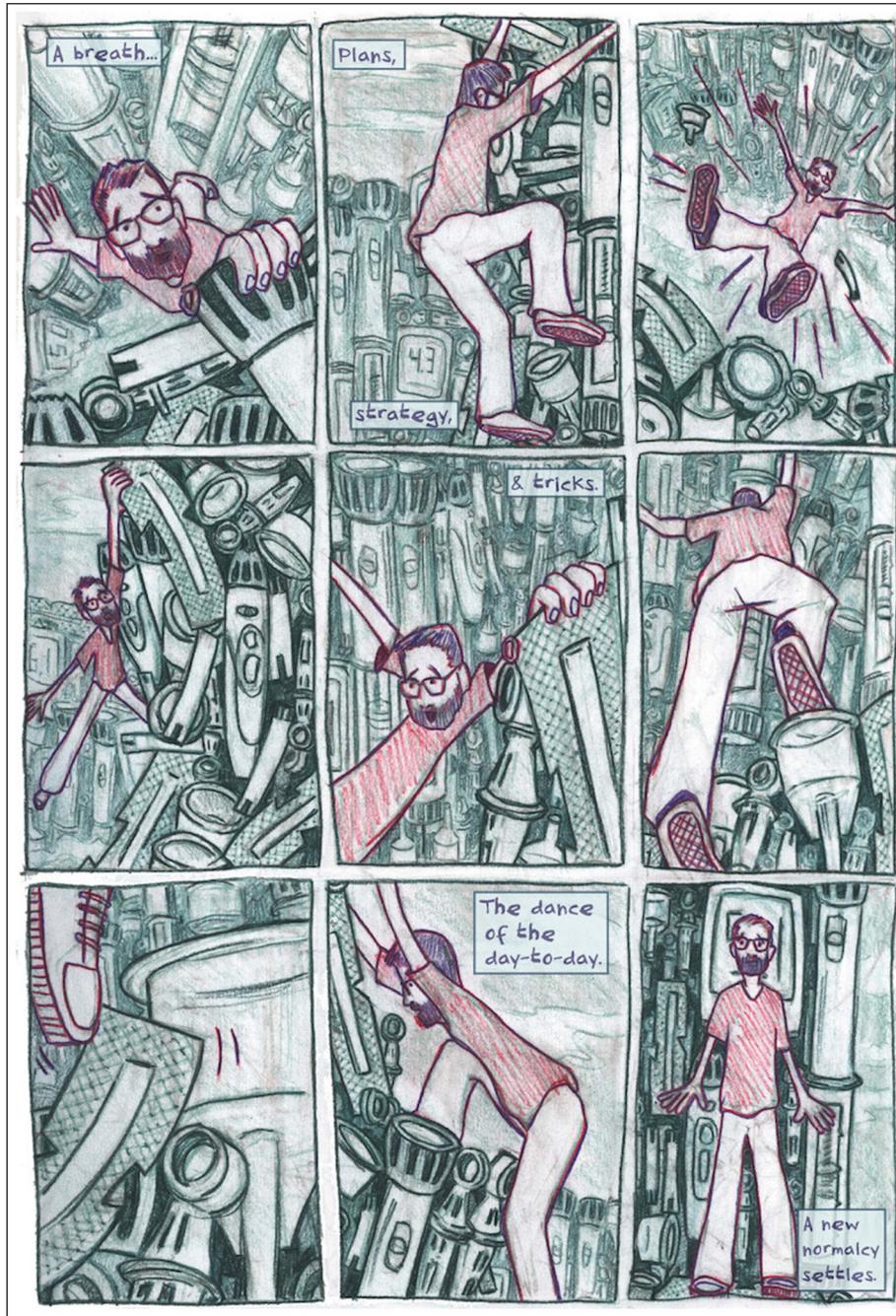


Figure 1: 'A breath'; (Pickering, 2018: 22).

of panels and one-page layouts, alongside flow and reveal, to impact my pacing, and explore alienation and anxiety in patient experience.

This can be seen further in two pages that explore differing treatments of the experience of a *Hypo* (Hypoglycemia) (**Figure 2**) – when blood sugar drops too low – causing disorientation, confusion, headaches, dizziness, and potentially a life-threatening coma, if not counter-acted with sugar. The page on the left emphasises the weight and fear of such an event, the three-panel close-up works with the page reveal abruptly confronting the reader with daily experience, whilst using the bathos of the last line 'I fumble to the buffet car' to place this within the realm of 'normal-life'.

The gentler aspect of the second page works with the increase of the panels to 'slow' time and emphasise the subtle differences from moment to moment, pointing to the time taken out of your routine by a hypo – not only it's oncoming, but it's aftermath. The panels and colours allude to a more pedestrian or suburban

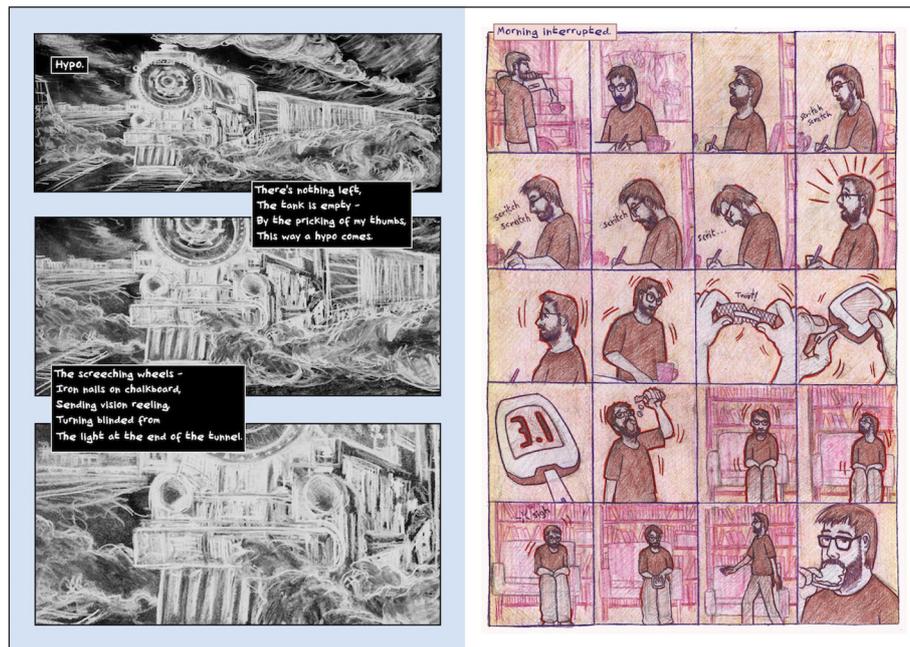


Figure 2: 'Hypo' & 'Morning Interrupted'; (Pickering, 2018: 401–41).

experience, but in focusing on the monotony of the experience, the pacing hints at the unrelenting and oppressive nature of diabetes.

The personal nature of the work required me to consider the nature and expression of the narrator – and the question of my avatar (**Figure 3**). Prompted by McCloud the reflection of myself is – in the main, a recognisable, but stylised figure. I switch between naturalism and caricature in the depiction of me – allowing the reader to alternate between the inner and outer viewpoints – to both empathise and critique my actions and conclusions (McCloud, 1993: 44).

The comic doesn't set out to tell the reader about diabetes specifically, but at points I have to deal with elements such as diet and carb-counting, insulin ratios, and even what is Type 1 diabetes – but from the perspective of me coming to terms with illness – not explaining it to others. Using footnotes and asides I wanted to suggest that any information was how I experienced diabetes, the maths and food that works or doesn't work for me; alluding to the individual nature of the illness, but also that it is received uniquely by the patient.

Erasing layers and overlapping lines are used to build up detail in the backgrounds – referencing my sketch-lines to depict a personal understanding of geography and imagination. This creates a textured style that supplements the rhythm of the panelling, working to draw focus and keep it for a moment too long, so that the reader/looker is immersed with the experience for a second, and so part of the



Figure 3: Avatars: 'Diaborg', '#Firstworld Problems' & 'My Eyes'; (Pickering, 2018: cover, 16, 38).

experience. There is also a dissonance created between the figure and the background, alluding to the air of strangeness created by the re-negotiation of identity.

The backgrounds also provide scope to extend metaphor to pathetic fallacy as the detritus of diabetes equipment comes to stand for both the physical and psychological presence of diabetes; seen here as the unpredictable psychological landscape of Type 1 diabetes (**Figure 1**). Elsewhere the equipment is ubiquitous – a symbol of hope and survival, and yet a constant reminder of the presence of a disease that does not take a break. In looking to explore the physicality of an invisible disease I have stumbled around the issue of the loss of trust, and the re-negotiation of the *Medical Self* with the body, through the formalization of a manager/managed relationship; attempting to imagine this new relationship through my avatar, through naturalistic interlude, and through gothic and design metaphors (**Figure 3**). This stumbling, with all its missteps and re-treads has formed my 'narrative of illness' – my pathography.

Embracing Complexity

The flexibility, and power of the strands of communication available through comics has enabled me to articulate, at least some of the complexity of patient experience. A project centred in the field of Graphic Medicine, where the place and impact of comics within the education and engagement of practitioners and patients in health-care has begun to be raised and articulated. Whilst Graphic Medicine has scope for many approaches, mine is anchored in my own experience, and in NHS findings that state patient involvement is, 'a key determinant in informing commissioning decisions and in shaping healthcare delivery', (National Clinical Guideline Centre, February 2012: 11). In this way, though patient experience is bound up in the relationship with clinical practitioners, it also exists in the space around, outside and other from treatment, and comics are a powerful strategy to mediate that space.

Traditionally the patient-practitioner interface has been practitioner orientated – centred on treatment goals or practitioner education, reducing patient experience (and the lived experience of the practitioner) to information. Green and Myers identify comics as a tool for use at the patient practitioner interface, emphasising the practical outcomes – the: 'connections between new information and existing knowledge [which increase] recall of health information' (Green & Myers,

2010). A device that can provide a 'soft foundation' [for] harder medical literature' (Revolve Comics, 2016). In this sense, the comic is designed as an entry point, but doesn't seek to provide a wider intersectional and immersive understanding of the experience for the patient (Squier, 2015: 48). The graphic pathography takes a different perspective – bringing in the wider impact of experience and identity that Ian Williams points out: 'create[s] valuable new knowledge, which informs the iconography of illness' (2015: 132); knowledge that ultimately can be dispersed within a patient community to re-negotiate and challenge our relationships to the patient-practitioner interface and thus impact on medical practice, and patient lives.

In this sense – though the content of *Diabetes: Year One* focuses on the beginnings of dealing with chronic illness, its purpose is designed as a mediation of the ongoing experience – as a provocation and articulation of the complexity of the experience.

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Competing Interests

The author has no competing interests to declare.

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