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Citation: Lennox, Solomon and Pettit, Fiona (2016) DOC: The Narrative Performance of Expertise. In: Performance and the Medical Body. Bloomsbury, London, pp. 115-128. ISBN 978-1-4725-7078-9

Published by: Bloomsbury

URL:

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DOC: The narrative performance of expertise

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The DOC: An overview

The term diabetes online community (DOC) refers to a multifarious network of social media outlets, primarily concerned with providing connection and community for people with diabetes (PWD). The DOC incorporates, but is not limited to, blogs and micro-blogging platforms and makes use of still and moving images, audio and text to engage with, portray and perform the narrative identities of individuals associated with diabetes. Whilst the community is primarily run by and for PWD, the community also represents and connects with medical professionals, representatives from pharmaceutical companies, local and national governments, and individuals who do not have diabetes but live with someone who does.

The community provides a space where the medical, commercial, popular and public narratives of diabetes, illness, and management interact with the personal auto-ethnographic accounts of PWD. This interaction is important, particularly when exploring notions of objecthood and subjecthood within the performance of science. This chapter explores how PWD engage with performative practices in order to navigate and perform narratives of diabetes. These narratives incorporate terms such as *care*, *compliance* and *management* and, in doing so, navigate the complex relationship between diverse knowledge systems. The DOC offers a degree of diversity in terms of the types of narratives performed and, as such, the type of expertise exhibited, owned and performed online.

By adopting Arthur Frank's (1995) typology of bodies, this chapter demonstrates that the DOC provides a space where PWD can perform and interact with notions of the *disciplined body* through *self-regimentation* and narratives and actions concerned with control (Frank 1995: 41). However, unlike previous coverage of the DOC (see Silverman 2012), this chapter is not concerned with how social media platforms facilitate better control of diabetes, the extent to which they promote compliance with medical procedures and expertise, or the manner in which PWD are able to demonstrate improved management of their chronic illness. Rather, this chapter explores how the performative practices exhibited in the DOC enable PWD to explore and expand upon narratives of the disciplined body, to offer new stories of subjecthood from the perspective of the expert patient.

From PWD as Objects to PWD as Subjects

Foucault asserts that human beings began to be considered as scientific objects in the nineteenth century (Foucault 1970: 376). Languages developed to articulate the knowledge of man (ibid). With the birth of clinical medicine and morbid pathology, surgeons gained access to the insides and once invisible portions of man. With this newfound, internal, gaze a discourse emerged that enabled medical professionals to 'see and to say' 'what had previously been beyond and below their domain' (Foucault 1973: xiii). Over the course of the century, subjective patient narratives were reduced and gradually replaced by analytics within clinicians' reports. Thus began the tradition of the objective medical gaze, resulting in treatments, care practices, and consultations that focus heavily on the management of internal factors

(such as blood sugar levels), measured through strict numerical indicators..

This chapter explores the performance of narrative within the DOC to examine the impact of the clinical gaze for PWD.

Through the clinical gaze, the body of a PWD becomes an object of study, explained and measured through a medical discourse that values an individual's management and control of internal factors. As Frank states, 'Every day society sends us messages that the body can and ought to be controlled. [...] Control is good manners as well as a moral duty; to lose control is to fail socially and morally' (Frank 1991: 58). PWD negotiate narratives of control and failure when engaging with medical discourses born out of the clinical gaze. Through an examination of performative practices within the DOC, we suggest that PWD are able to perform alternative narratives that provide greater authorial agency for the teller.

As authors of this chapter, we are not criticizing medical professionals for the adoption and implementation of a set of discourses that reduces the body of a patient to an object. Rather, we take inspiration from Frank's assertion that 'the body I experience cannot be reduced to the body someone else measures' (Frank 1991: 12) to argue that the DOC provides places and platforms where the experience of living with diabetes is performed and alternative narrative practices are adopted. We argue that these narratives provide PWD greater flexibility in how they make sense of their experience of living with diabetes; in turn providing them with greater subjecthood over their bodies and their chronic illness. The multifarious ways in which the DOC presents and represents the bodies and experiences of PWD means that

bodies are not merely described: experiences are performed and new discourses emerge.

Undoubtedly, within the DOC, the most common form of engagement and representation of PWD is through patient narratives. Narratives about living with diabetes are narratives of illness, a growing area of study within the medical humanities (see Waddington and Willis 2013). However, it is not without its critics, who point to the pitfalls of adopting a methodology that is limited and 'unnecessarily restricts what illness narrative might be allowed to mean, and even what it might look like' (Waddington and Willis 2013: iv). Adopting a performance studies approach enables a deep reading of the illness narratives presented via the DOC.

DOC illness narratives are often non-linear. As our case studies will show, they do not follow traditional story-telling forms based on a linear and progressive structure. They are fragmented, in-situ and ever-evolving documents of experience. They take various forms, ranging from 140 character tweets to lengthy prose; single still images and artwork to vlogs (video blogs) and more traditional performance pieces (dramas and films). The DOC does not simply present stories about how an individual is diagnosed with diabetes, seeks treatment, gains control of the disease, and lives a happy and enriching life thereafter. Rather, the DOC provides a space where individuals are able to present and perform their experiences and worlds, chronicling the ever-fluctuating relationship one has with a chronic illness.

The types of illness narratives performed by PWD via the DOC are different to that which are performed by the clinician during the medical

consultation. Similarly, they differ from the public and popular narratives about diabetes, primarily because the patient is able to assert agency over the narration of their experiences, something which is rarely permitted in other contexts. Hazel Morrison references British-American neurologist Oliver Sacks to describe two potential ways of describing the clinical experience: the 'purely nomothetic, "medical" or "classical" [...] objective description' of the illness; and an 'idiographic [...] "existential," "personal empathic entering into patient's experiences and worlds"' (Sacks in Morrison 2013: 18). The DOC mitigates this dichotomy by drawing together and performing both types of description.

Whether the description is the purely medical, numeric measuring of illness, or the more empathic auto-pathological accounts of experiences and worlds, both are stories of illness. One of the ways in which they are distinguished from one another is the extent to which the patient experiences authorial agency over their illness narrative. This is important, as medical humanities scholar Angela Woods argues, because the 'messy and complex subjective experience of illness as something distinct from the biological functioning of disease' requires greater recognition and understanding (Woods 2013, p. 38).

Further, recent studies on the UK's 'Expert Patient' programme, aimed at empowering people with the knowledge and skills to effectively manage their chronic conditions, indicate a tension between informed, empowered patients and their healthcare providers (Snow, Humphrey & Sandall 2013). Combining experiential subjective knowledge with objective bio-medical knowledge, these programmes encourage PWD to emerge as 'empowered ...

expert patient[s], no longer dependent on doctors for decisions, but able to talk about their treatment requirements with healthcare professionals as an equal' (Snow, Humphrey, & Sandall 2013: 4). The study points to the importance of respecting the expertise gained by patients through this programme and their lived experience. The potential benefits of individual empowerment and 'shared expertise' can 'change people's lives for the better in a way that is perhaps not fully captured by standard clinical and quality of life outcome assessments' (ibid 7 & 6). In a sense, the DOC exemplifies another form of patient education, brought out through the shared narratives of lived, experiential, subjective expertise.

Patient narratives are 'neither irrational nor passive but instead [are] actively and subjectively valuable stories of illness that give both meaning and context to the conditions of illness from the patient's perspective' (Willis et al. 2013: 55). The DOC does not necessarily present and perform illness narratives that contest the hegemony of the clinical gaze and associated discourses. Instead, they wrestle with the languages and practices of the clinical gaze and make use of idiosyncratic performance practices to make better sense of their lives as disciplined bodies. We have chosen to provide a detailed, qualitative, examination of the content presented and performed by one of the DOCs most avid contributors, Kerri Sparling.

Case Study: Kerri Sparling

Kerri Sparling identifies as a writer, speaker and diabetes advocate. Sparling has run the blog *Six Until Me* since May 2005, after growing tired of 'Googling "diabetes" and coming up with little more than a list of complications and frightening stories' (Sparling). When Sparling started blogging, she was

one of 'four or five diabetes bloggers' but now, as one of the most prominent voices within the DOC, Sparling's blog is one of many that demonstrate that PWD are not alone in living with their disease (ibid). Sparling's blog is a mixture of written narratives, images and vlog posts and the themes of connection, acceptance, control, management and an ever fluctuating and evolving relationship with type 1 diabetes stand out as core components.

Sparling makes use of her blog to present and perform her illness narrative. In doing so, she performs the role of expert patient, engaging with medical discourse and the clinical gaze. As such, Sparling's blog grapples with issues of the obedient body and the associated feelings of failure, as well as an uneasy, yet necessary, relationship with being a 'compliant' patient. Through a close reading of the blog, we argue that participation in the DOC has enabled Sparling to transition from what Frank refers to as a position of 'narrative wreckage' to that of an individual with a 'self-story' (Frank 1995: 55). We focus on five vlog posts that have been produced by, or feature, Sparling, to demonstrate how valuable and important the DOC is in providing PWD the opportunity to create self-stories. Simultaneously, we argue that the type of self-stories performed by Sparling never fully escape the medical discourse, the clinical gaze or the problematic relationship with understanding the body of someone with a chronic disease as a thing to be measured, managed and controlled.

In alignment with narrative theorists, we argue that human beings are storytellers. We live our lives through the stories we perform and the performance of stories informs the type of lives we live. Whenever we perform a story, we do so with a real or imagined audience in mind. Our bodies are

essential to our stories. We tell stories about and through our bodies, no more so than when performing illness narratives. Illness narratives have the potential to alter our sense of self as they derail or wreck our narrative trajectories.

For Frank, narrative wreckage occurs when a storyteller loses a sense of temporality, asserting that the 'expectation of any narrative, held alike by listeners and storytellers, is for a past that leads into a present that sets in place a foreseeable future. The illness story is wrecked because its present is not what that past was supposed to lead up to, and the future is scarcely thinkable' (Frank 1995: 55). Sparling dedicates a section of her blog to sharing the diagnosis stories of her readers and fellow DOC participants. For example, Simon narrates his life, at the point of diagnosis, as feeling like he had built his dream home only for a highway to be built through the middle of it, 'knocking the place down' (Simon in Sparling May 20, 2007). For Les it is one of confusion, 'What? I don't understand. What does it mean? That doesn't make any sense. I am literally confused at this point because what he [physician] has said makes no sense' (Les In Sparling June 8, 2007). For Les and Simon, the memory of diagnosis is presented as a narrative wreck.

In describing why she decided to start blogging about her experiences of living with diabetes, Sparling describes a feeling of isolation and a desire to know if she was the only diabetic 'out there who felt alone' (Sparling). Whilst we are not suggesting that Sparling's blog posts mark the beginning of the DOC, the lack of voices from PWD resulted in a dearth of information about the lived experience of diabetes and a void that was filled with the medical list

of complications related to diabetes and horror stories about living with said complications.

In trying to gain understanding about their chronic illness, Sparling, Simon and Les, describe their experiences as bewildering and chaotic. Frank identifies the chaos narrative as a story that 'cannot literally be told but can only be lived' (Frank 1995: 98). We argue that the experience of living a chaos narrative occurs at numerous points throughout a person's life with diabetes. Most notably, we suggest three main areas where the chaos narrative is experienced: 1) initial diagnosis, 2) the development of diabetes-related complications, and 3) the day-to-day fluctuation and turbulence of one's relationship towards the management and control of blood sugar levels. In part, a chaos narrative is propagated by the structure of medical discourse pertaining to diabetes and extenuated through the objectification of the patient and the submission of their voice due to the clinical gaze.

We argue that the voice of the patient is brought in to submission by the way the medical discourse and the clinical gaze work together as a performative structure. The clinician, as expert, adopts a position of authority and power during a consultation. Writing from our lived experience of type 1 diabetes (Pettit) and as the partner of a PWD (Lennox), the authority of the clinician, combined with consultations focused on the observation of internal measurements (blood sugar levels, HBA1C), results in the submission of the patient's voice. The totalizing relationship of the clinical gaze is dominant because the performative structure of the clinical consultation controls and curtails the types of narratives patients can perform. Consultations focus on the current levels of control the PWD has over the management of their illness

(determined by blood test results) and the measures they can take to exert greater control. On account of the domineering performative structure of the clinical gaze, the clinical consultation provides little room for the PWD to present narratives that are not focused on control.

However, we do not believe that expert patients provide a counter-narrative to that provided by medical professionals. Through the examples found on Sparling's blog, we demonstrate that PWD are unable to escape the medical discourse, the expertise of their endocrinologists and the clinical gaze. Instead, they engage with performative practices to make sense of their own lived experiences and to add more narrative layers to diabetes discourse.

Narrative Performances are Dependent Upon Authorial Agency.

Through a close analysis of five videos from Sparling's blog, it is clear that different types of videos solicit different types of illness narrative performances. Whilst all of the selected videos are aimed at PWD, two are shot by and for a manufacturer of diabetes medical equipment. These two videos are of interest not because of their high production value, or because they are commercials, but because they solicit from Sparling a performance of her illness narrative that is markedly different from those of her other videos. The other three videos are vlogs. They have low production value, shot by Sparling in her home. As the two commercial videos are shot for a pharmaceutical company as adverts, they understandably focus more heavily on the numerical indicators associated with the control and management of type 1 diabetes.

[Mid-shot of Kerri, in jeans and T-shirt, [speaking](#) over an upbeat instrumental bed.] Hi. I'm Kerri. I've been pumping for eight years, and here's why I love OneTouch Ping. I'm for escaping [Video cuts to close-up of hands pushing pins into a pin cushion. Over the cushion the text ESCAPING appears.] one thousand, four hundred and sixty insulin shots. Before I started pumping I was up to nine insulin injections a day.[...]That's actually three thousand, two hundred and eighty five shots a year. I would take them in my arm, my thigh, my stomach, my hips, my butt. It makes you feel like, when you take a sip of water it is going to come out of all the different holes in your body. The main reason I decided to start pumping was because I knew I wanted to have a baby, and that was the best way for me to gain better control of my diabetes. When I started on the pump, that helped alleviate those lows and my A1C dropped without those hypos. My endocrinologist knew how hard I was working to lower my A1C, so when we saw the numbers dropping after going on the pump we were both relieved (Sparling 2012b).

_____ This narrative performance has a limited focus on the personal experiences and reflections of living with diabetes. Understandably, the narrative performance focuses on the medical benefits derived from the use of the advertised device. Similarly, a second video for the same company features Sparling stressing how important it is to be provided with regular reminders about patterns in her blood sugar levels, 'The easier it is for me to

know how I am doing with my numbers, the more confidence I can have throughout the day' (Sparling & Edelman 2013). We include the excerpts of the commercial videos, not as a critique of Sparling's endorsement of these products, but as an example of how elements of the medical discourse are performed by medical professionals, pharmaceutical companies and patients when they engage with them.

We compare the performance in these videos to that in Sparling's blogs. From a post in September 2011 titled *You Are More Than Diabetes*, Sparling responds to the question, "What do you wish someone had told you about type 1 diabetes?": In contrast to the professionally produced commercial, this video is clearly self-filmed by Sparling. Throughout the vlog, Sparling speaks with incredible pace, which at times resembles spoken poetry. There are numerous cuts and edits to the footage, indicating that the narrative Sparling performs has been refashioned, reformed, and carefully considered.

I think one of the things I wish I knew when I was diagnosed - and one of the things I wished I remembered every single day is that these numbers don't define me. There is more to me than just the trail of test strips I leave everywhere. And there is more to me than just the A1C result posted in my logbook. And there is more than just the beeping, and the technology and the focus, focus, focus on what my body doesn't do right. I need to remember that I'm still me underneath all this diabetes stuff. And I'm still me even when my blood sugar is 300. And I'm still me when it's 30. I'm still me. [...]

None of it defines you! None of it is who you are. That these numbers are just measures of my blood sugar, not measures of who I am as a person (Sparling 2011).

Numbers still play an important part of Sparling's narrative performance, however, a desire to remember to establish a sense of self outside of the numerical indicators is of greater significance. As the tag line to the blog states, diabetes does not define Sparling, but it does explain her. Within this narrative performance, Sparling seeks to remind herself and her audience that the numbers measure the condition, not the person. Sparling's identity is formed not only in the instances when measurements are being taken, but also in those moments between. Further, the numbers and thus the management of the illness, whilst important, are not to be understood as a measure of the person living with diabetes.

[Medium close-up of Kerri, wearing a blue top, sat in front of an eggshell background. Kerri delivers her text at an incredibly fast pace (averaging around 4 words per second). The video is self-filmed and contains numerous cuts and edits.] I don't know what it is like to live with other diseases, but I do know what it is like to live with type 1 diabetes. And diabetes is a disease that comes with a lot of guilt. *[Kerri's delivery is slower when making the statements regarding numbers and medical complications, but speeds up when posing the questions.]* "Oh you're 216? Well what did you, what did you eat to make you get that high?" Or, "Oh! You have diabetic retinopathy in your eye? Well what did

you do to get that?" [...] Complications are a result of diabetes, not me! And I [text appears on the centre, lower third, of screen: 'I barely know what "absolve" means.] don't say that to absolve myself of any responsibility. Understanding that diabetes complications are caused by diabetes doesn't enable me. It empowers me. [...] Diabetes is a disease that is more than just the average on your meter or your last A1C result. Understanding those numbers empowers us. But feeling guilty about them and feeling so ashamed of certain results that you don't even react to them. That's not empowerment. That's...that's awful. Those numbers are important, but the psychosocial aspects of life with diabetes are just as critical (Sparling 2012a).

The management of diabetes brings with it a sense of guilt for Sparling. The medical discourse does not adequately account for the psychosocial aspects of life with diabetes. The discourse of control is born out of the medical narratives and the clinical gaze, where social norms suggest that one should manage to assert control over one's own body. Within this context, complications preventing the patient exerting acceptable levels of control mean that the patient has failed to be a 'good' diabetic.

Complications might come, they might not. But if you get them it doesn't mean that you screwed everything up. It doesn't mean that it is your fault, that you are a bad person. I feel like when

people are diagnosed with complications all of a sudden they feel like they have to hide somewhere and you know, they are not allowed to talk about it. ...if you are diagnosed with something difficult or a complication or something that people are thinking you're suppose to be able to avoid, you are suppose to keep your voice quiet. You're supposed to keep your story to yourself (Sparling 2014).

By engaging with the medical discourse and her personal illness narrative, Sparling performs a self-story about her lived experience of chronic illness. Her narrative differs slightly, dependent upon whether the video is self-filmed or shot in collaboration with medical experts. There is a subtle subversion of the gaze when Kerri authors her vlogs, over those videos where the message, script and material is shot and edited by someone else. However, at no point does Sparling's narrative reject the expertise of her medical team and the problematics inherent to adopting their narrative practices and a discourse that objectifies the patient's body through the clinical gaze.

Conclusion

'The body is not to be managed, even by myself. My body is a means and medium of my life; I live not only in my body but also through it. No one should be asked to detach his mind from his body and then talk about this body as a thing, out there.' (Frank 1991: 10)

Within the medical narratives about diabetes is a degree of universality, wherein normative numeric ranges (for things such as A1C counts and glucose levels) govern what constitutes a 'good' diabetic patient. Through the clinical narratives offered by physicians and medical professionals, PWD are constantly reminded to aim for a specific and limited set of numeric indicators. These numbers can be difficult to achieve and do not necessarily best reflect the complexities and diversities of the lives of PWD. As a result, PWD can routinely feel a sense of failure, guilt and shame when engaging with medical professionals.

The DOC offers a site where PWD are able to engage with the universal precept of diabetes management. Through the narrative accounts of their lived experience with diabetes, contributors to the DOC are able to challenge, refuse and contest the universal, by offering the personal and the individual as counter narratives. The lived experience of PWD is performed, consumed and adopted by the DOC. An expertise different to that offered by medical professions lies at the heart of the DOC. It is central to the success of the community and is the site where the true value of the DOC can really be measured. Failure to witness, accept and respond to the diversity of performed expertise by PWD is a violent rejection of subjecthood. The value of the DOC can best be measured when diverse perspectives and voices are engaged in discourse about living with, treating and managing responses to the day to day experiences of a chronic illness.

When performing an illness narrative about living with diabetes, patients are likely to perform different types of stories to different audiences. The illness narrative that one tells to the clinician is likely to differ in content

and structure to that told to a close friend, relative or fellow members of the DOC. The difference in the content and structure outlined in the examples above demonstrate how different audiences solicit different narrative performances. However, what the case study demonstrates is that when telling an illness narrative about diabetes it is impossible to escape the medical discourse. Medical terminology and language structures are embedded within the stories. As such, the clinical gaze, wherein the patient's body is objectified through the expertise of the physician's analysis, remains a dominant feature of diabetes illness narratives in the DOC. The narratives performed by the DOC are unable to reject the expertise of the medical professions, nor do they aspire to do so.

That said, the DOC provides a space where individuals can engage with illness narratives and the medical discourse in a way that allows PWD to reclaim authorial agency over their own stories and lived experience of diabetes. The narratives that PWD perform through the DOC are not counter narratives to those provided by medical professionals. Instead, they make personal and accessible experiences of living with diabetes for fellow members of the online community. The DOC provides platforms and spaces where the narrative wreckage associated with initial diagnosis, the development of diabetes-related complications, or the day-to-day fluctuation and turbulence of one's relationship towards the management and control of blood sugar levels, can be mitigated through narration. Thus, the DOC provides individuals with the opportunity to develop beyond a chaos narrative to a self-story with greater flexibility in terms of the types of lives it enables one to perform.

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