

Mediated self-care and the question of agency

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Abstract

This article analyses the discursive construction of agency in narratives of ‘mediated self-care’, stories of disease management and/or recovery in which particular material or discursive technologies play a central part. Specifically, it analyses two stories of self-care, one told in the context of an Alcoholics Anonymous meeting, and the other told in the context of a Quantified Self ‘meetup’. The analytical apparatus I will bring to bear on these data is *mediated discourse analysis* (Norris and Jones 2005; Scollon 2001), an approach to discourse whose primary focus is on the actions and identities made possible when people appropriate ‘technologies’ into particular situations (or ‘sites of engagement’). The analysis focuses on how narrators construct their relationship with the technologies they use, how they describe the process of mastering these technologies, and how these technologies are represented as emblems of group membership. The analysis reveals how different kinds of technologies of self-care are associated with different constructions of the self and individual agency and different constructions of ‘wellness’.

Keywords: *agency, mediated discourse analysis, narrative, self-care, technologies, Quantified Self*

Mediated self-care and the question of agency

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Introduction

This article examines the way people construct agency in narratives of ‘mediated self-care’.

What I mean by ‘self-care’ is those practices that individuals perform independent of medical experts, often in the context of lay communities, through which they seek to optimize their health or manage or recover from a particular disease (Ziguras 2013). By the term ‘mediated’ self-care, I mean to signal in particular those practices of self-care that are mediated through ‘technologies’ — such as iPhone apps, activity trackers, bathroom scales, as well as older technologies such as diaries, checklists, and even the ‘technology’ of narrative itself (Bury 1992; Pennebaker and Seagal 1999; Reisman 1990). As can be seen from this list, I am using the term ‘technology’ in a rather wide sense to mean any ‘cultural tool’ (Vygotsky 1962; Wertsch 1993) that facilitates self-care.

Some of these technologies are normally thought of as ‘material technologies’ (computers, smart phones, bathroom scales), and others as ‘discursive technologies’ (systems of recording and calculation, texts and text types such as confessions and narratives). This distinction, however, is largely artificial, since all discursive technologies depend on material technologies such as notebooks, video screens, or the human voice for their expression, and all material technologies depend upon a web of discourse which governs how they are used, who can use them when and where, and what kinds of ‘communities’ of users they are associated with (Jones 2016a, b). Put

simply, this article is concerned with how we talk about the tools we use to keep ourselves well, how these tools come to define what kinds of people we are, what kinds of communities we align ourselves to, and what meanings ‘health’ has in our lives.

The analytical apparatus with which I will approach these narratives is *mediated discourse analysis* (Norris and Jones 2005; Scollon 2001), an approach to discourse whose primary focus is on the actions and identities made possible when people appropriate different material and discursive technologies into particular situations (or ‘sites of engagement’). Mediated discourse analysis has the potential to take us beyond just considering how people talk about their health to understanding how this talk is inevitably embedded in complex entanglements of bodies, technologies, communities and selves (Lupton 2014; Scollon 2001).

The analysis focuses on two examples of stories of self-care associated with two distinct communities: the community of recovering alcoholics in Alcoholics Anonymous, and the other, the community of ‘self-trackers’ aligned with a movement that has come to be known as The Quantified Self (Wolf 2010). Although participants in these communities engage in very different kinds of projects of self-care for very different reasons and with very different goals, they display striking similarities in their reliance on technologies as meditational means to engage in these projects, in the way they structure stories around their uses of these technologies, and in how these stories themselves come to mediate their engagement with these technologies. .

There has, of course, been considerable work on narratives as a resource through which people faced with health issues make sense of their conditions (see for example Frank 1995; Kleinman

1988; Reissman 1990, 1993), as well as on therapeutic narratives told in the context of self-help groups like Alcoholics Anonymous (see for example Cain 1991; Humphreys 2000). Where my approach differs is in my focus on technologies as ‘characters’ in these stories, and how these narratives serve to imbue these technologies with meaning.

In what follows I will first expand on the relationship of ‘self-care’ to the cultural tools people use to perform it, using Foucault’s [ref?] concept of ‘technologies of the self’. Then I will describe my data and methodology, especially the framework of mediated discourse analysis that I use to analyse the data, before going on to compare and contrast two emblematic narratives of self-care. I will end with a discussion of how people portray their agentic relationships with the technologies they use to maintain their health or manage their recoveries and the implications of this for health behaviour more generally.

Self-care and technologies of the self

The World Health Organization (1983: 2) defines self-care as ‘the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health...derived from knowledge and skills from the pool of both professional and lay experience...(and) undertaken by lay people on their own behalf...’. Self-care includes all sorts of practices from diet and exercise regimens, to home remedies, from cosmetic surgery to religious rituals. They are not just individual practices aimed at solving health problems, but *social practices* which come to perform particular social functions and to take on particular social significance within communities (Ziguras 2013).

Self-care practices, of course, are not new. In fact, they long predate the development of professional healthcare practices. With the rise of personal digital technologies such as smart phones and wearable computers, however, there has been renewed interest in the ways self-care is *mediated* through technologies (Topol 2012). Such technologies include motion sensors that track users' physical activity and calorie consumption, sleep monitors and wifi scales, and a host of apps that help people to keep track of things like how much water they drink and how much sex they have (see Jones 2015). But the mediation of self-care through technologies is also not new. The philosopher Peter-Paul Verbeek (2011), drawing on the work of Foucault, insists that the *essence* of self-care has always been the interaction between humans and technologies, and the study of self-care is basically the study of how 'technologically mediated subjects come into being' (Verbeek 2011: 83).

Foucault (1988, 2003), in his famous examination of practices of self-care in ancient Greece and early Christian societies, calls the technologies through which practices of self-care are mediated 'technologies of the self', which he defines as those technologies

'which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality' (2003: 225).

Among the most important technologies people in the ancient world used in the practice of self-care, he notes, was the technology of writing. In the ancient world, he writes (1988: 28), 'a relation developed ... between writing and vigilance. Attention was paid to nuances of life, mood, and reading, and the experience of oneself was intensified and widened by virtue of this

act of writing.’

In his analysis, Foucault focuses on two kinds of practices of self-care, the kind which was *inwardly directed*, which involved keeping diaries and notebooks — recording and reviewing what one has done or should have done, and reading and reflecting on the writings of others — and the kind that was *directed outward*, consisting of writing treatises and letters in order to share one’s experiences, actions and reflections with others. These two modes of self-care popular among the Stoics persisted in early Christian practices of meditation and confession, and continue to be seen in the activities of ‘self-help’ groups, like Alcoholics Anonymous, which encourage members to engage in taking self-inventories and narrativizing their experiences, and the more recent practices of ‘self-tracking’ and ‘sharing one’s data’ that are associated with the Quantified Self movement.

The most important point Foucault makes about ‘technologies of the self’ (and why they are such effective tools for self-care) is that the act of *entextualising* (Jones 2009) – i.e. transforming one’s thoughts, actions, feelings or experiences into texts – inevitably brings about a new way of experiencing the self, and, eventually brings about a ‘new self’. ‘Technologies of the self’ operate chiefly by creating opportunities for ‘reflexivity’ (Archer 2007), the capacity for thought or action to ‘bend back upon itself’ and create a kind of awareness on the part of the social actor that can alter subsequent thought or action.

In both of the contexts I am interested in this paper — Alcoholics Anonymous meetings and Quantified Self meetups — individuals regularly discuss their use of ‘technologies of the self’ in

the context of stories they tell to other users. While my main interest is in how narrators of these stories describe the way they use ‘technologies of the self’ — such as texts, self-inventories, wearable sensors, iPhone apps and online social networks — to mediate practices of self-care, I am also interested in how these narratives themselves operate as ‘technologies of the self’, enabling participants to entextualise their experiences in ways that facilitate introspection, self-regulation, sharing and the elicitation of feedback.

Studies of narratives of illness and health have mostly focused on how storytellers represent their experiences, how they temporally construct their illness ‘journeys’, how they portray their relationships with healthcare workers and other caregivers, and how they construct their identities (see for example Bury 2001; Frank 1995). Some scholars have also examined the way tellers of illness narratives express agency in relation to their disease, healthcare professionals (see for example Arduser 2014), and even the technologies used to cure them or keep them well. In most cases these technologies are portrayed as part of the system of biomedical expertise that ‘colonises’ the body of the ill person and transforms him or her from an autonomous individual into a ‘patient’ (Frank 1995), rather than as a means through which individuals might exercise agency and become more independent. Lapum and her colleagues (2010: 754), for example, describe how, in the stories of patients who were recovering from open heart surgery, technology came to assume a controlling influence on how participants’ narratives were shaped and unfolded, resulting in patients themselves ‘becoming background characters and surrendering agency.’ In contrast, as we will see below, in narratives of mediated self-care, people more often talk about technologies as means through which they are able to reclaim agency.

At the same time, there has also been a tradition of narrative analysis in health communication that has seen narratives themselves as technologies through which people manage disease, deal with the ‘biographical disruption’ that comes with health problems, reconstruct their identities, and achieve a renewed sense of independence (see for example Bury 1982, 2001; Frank 1995; Kleinman 1988; Reissman 1990). Frank (1995) argues that telling stories is a means by which the ill seek to regain agency by showing that they can be ‘successfully ill’ (Frank 1995: 62). Others, such as Bury (2001), have noted that illness narratives give their tellers the opportunity to legitimate their ‘expertise’ — borne of the lived experience of managing a disease or medical condition — and to contest the dominance of biomedical frameworks of expertise around health and illness.

Data and methodology

In what follows I will illustrate some of the concepts I discussed above through the close analysis of two narratives of self-care: one told in the context of an Alcoholics Anonymous (AA) meeting, and the other told in the context of a Quantified Self (QS) meetup. Both are publicly available online.¹ The narratives are part of a larger study on narratives of self-care involving a corpus of stories collected from YouTube and other internet platforms (see also Jones 2013, 2016). These two case studies were selected because they both involve practices of self-care in which the use of particular ‘technologies of the self’ is emblematic of membership in a particular community, each with its own ideological stance towards health and individual agency. The AA narrative is told by Lizz H. as part of a ‘speaker’s meeting’. While the sharing of narratives is part of all AA meetings, ‘speaker’s meetings’ are a special kind of meeting at which a veteran member is invited to deliver a more formal and sustained narrative. The QS narrative is told by

Kevin Krejci, a tech worker in the San Francisco Bay area who, about a year before this talk, had been diagnosed with Parkinson's disease. His narrative relates how he came to use various self-tracking tools to help him manage his condition.

My aim is to use these narratives as a means of uncovering some of the ways people use discourse to 1) represent their relationships with 'technologies of the self' — whether they be material technologies like wearable sensors or semiotic technologies like written inventories or data visualisations; 2) represent processes by which they have come to *master* these technologies and make them part of their social practices; and 3) promote these technologies and the practices associated with them as aspects of group identity and emblems of group membership. In understanding the way narrators organize their stories around these technologies, my key focus will be on how *agency* is discursively constructed.

Analytical Approach

Mediated discourse analysis, the analytical framework through which I am analysing these stories, conceives of agency as a matter of *mediation*, locating it in the 'irreducible tension between the technologies people use and the unique, contextualized use of these technologies in carrying out particular concrete actions (Wertsch 1994). For mediated discourse analysts, agency is always distributed among human actors, technologies and the various discourses that circulate through them (see also Latour 1991). The task of the analyst is to explore how social actors discursively construct their relationships with these technologies and discourses. Such constructions may involve the ascription of agency to themselves, to the mediational means they are using, to the social situation (or 'scene'), to some kind of external goal or purpose, or to the

action itself (Burke 1969; Scollon and Scollon 2005). These discursive constructions of agency, however, are not seen so much as ‘windows into the souls’ of actors, revealing the degree to which they ‘feel in control’. Rather, they are seen as means through which individuals strategically perform social actions, enact social identities, and position themselves within communities of practice (Lave and Wenger 1991).

Lizz H. and the textual tools of Alcoholics Anonymous

Alcoholics Anonymous is a group that helps people to recover from alcoholism by engaging them in a variety of discursive practices mediated through ‘technologies of the self’. Through these practices members re-enact the conceptual framework for alcoholism promoted by the group and come to ‘understand their own conditions through the discursive constructions of the group’ (Ziguras 2013:169). These tools include: 1) lists (the most important being the list of the ‘12 Steps’ to recovery); 2) narratives (printed in the ‘Big Book’ [Alcoholics Anonymous, 1939] and told orally at meetings); 3) personal inventories written as part of ‘Step Four’; 4) confessions and verbal encounters designed to make ‘amends’ to those who have been harmed by the past behaviour of participants; 5) prayers, slogans, and other formulaic texts; and 6) material technologies such as coloured plastic chips that members receive after they have remained sober for a certain amount of time. Narratives, like the one told by Lizz H., typically recount how members have recovered through engaging with these tools. These narratives, as mentioned above, are themselves among the ‘technologies of the self’ members use to facilitate their recovery.

Alcoholics anonymous stories generally follow a three part structure in which tellers relate 1)

what their lives were like while they were drinking; 2) how they came to be socialised into the practices of Alcoholics Anonymous ('what happened'); and 3) what their lives are like now. This three-part structure is outlined in a passage from the 'Big Book' called 'How it works', which is often read aloud at meetings:

Our stories disclose in a general way what we used to be like, what happened, and what we are like now (Alcoholics Anonymous 1939:10).

And when storytellers in Alcoholics Anonymous meetings tell their stories, they often begin with a metadiscursive reference to this three part structure as a kind of 'abstract' (Labov and Waletzky 1966). This is the case with Lizz H., who starts her story:

Hi everyone, my name is Lizz, and I'm an alcoholic. (audience: Hi Lizz). My sobriety date is July 21, 1995 (audience: applause). Um, I would like to thank the committee for asking me to come and join you. This is actually a roundup that I've always wanted to attend but never had the opportunity, so I'm super excited to be here, thank you so much (audience: applause). And thank you to Mary and Christine who have taken such good care of me since I've been here. Two a.m. they picked me up from the airport, can you believe it? That's very nice. Um, alright, so I guess I'll tell you a little bit about what it was like what happened and what it's like now. I grew up in California in the bay area...

In this case, this explication of the tripartite structure of the recovery story at the beginning of this narrative functions not just as a rhetorical device to frame the story that is about to be told,

but also as an intertextual reference to the passage from the 'Big Book' cited above, and to other stories by other members the teller and her audience have heard. In other words, it is an explicit reference to the set of rules associated with this particular 'technology of the self' which is shared by the community, and, as such, a means by which Lizz H. portrays herself as a competent member. It is also a representation of a certain relationship of agency between the teller and the narrative, an acknowledgement, first of all, that she will be talking about 'what happened' to her as opposed to 'what she did', and, second of all, that the way she will be talking about this is also not determined by her -- in a sense, it is not she who is telling her story, but the story that is 'telling her'.

Another example of the instantiation of a community practice in the structure Lizz's narrative is the traditional way in which she begins ('Hi everybody, my name is Lizz, and I'm an alcoholic'), which is an enactment of the first of the 12 Steps to recovery ('We admitted we were powerless over alcohol - that our lives had become unmanageable'). Again, this statement and the intertextual reference it performs, positions the teller in a particular agentive relationship with alcohol, with alcoholism, with 'her life', and with the story she is about to tell. And just as the 'First Step' structures the beginning of the story, the rest of the story is structured around the subsequent eleven steps of the program as the narrator recounts her road to recovery. This journey is essentially the story of her mastery of various material and discursive technologies and her use of these technologies to negotiate her agentive relationship with the world and with her 'alcoholic self'. In other words, the act of telling the story itself is mediated through a constellation of technologies which create the scaffolding for Lizz to organise her individual experiences.

As with most AA stories, the first part of Lizz's story recounts her life before her engagement with the AA program, portraying it as 'unmanageable', and like most AA stories, this involves accounts of incidents with drinking and their consequences. What is particularly interesting about Lizz's story, however, is her characterization of her pre-recovery self as *discursively deficient*, lacking in the kinds of *literacy skills* so central to most of the technologies of the self the group makes available to members as means to recovery: she talks about her inability to read, and her inability to talk to others:

I was doing so poorly in school that they put me in the books on tape English class so it was me and the other kids that couldn't read basically you know were either English as a second language or were just as delinquent as I was.

I wouldn't talk to you if you spoke to me. I would swear at you and I couldn't tell the truth if you ask me a direct question I wouldn't answer and ... I didn't want to hear anything you had to say to me.

Her first step towards recovery, then, is essentially a 'literacy' event in which she begins to understand agency as a matter of being able to master the *discursive tools* of the program, which, in her case, involved learning how to read:

I looked at this woman Deb and I asked her for help, and Debbie became my first sponsor. Um, now, we opened the big book of Alcoholics Anonymous and none of it

made any sense to me at all. I you know hadn't read for quite some time, I was bad at it, comprehension was not, it just wasn't there for me, you know, it was all just super cloudy and foggy and and so we put the Big Book back down and we practiced reading first, and eventually we picked it back up and she's like all right we're gonna go word by word. If you don't understand something ask and I'll explain it to you. she got out a dictionary and we started reading and we got to the First Step.

Interestingly, Lizz's engagement with the linguistic aspects of the tools of recovery is replicated in her portrayal of her 'Twelfth Step' ('Having had a spiritual awakening as the result of these steps, we tried to carry this message to alcoholics, and to practice these principles in all our affairs') in which she recounts using the Big Book as a means to communicate with fellow alcoholics when she was living in Russia:

We went to Moscow, we got on the train went to Moscow and visited Constantine at the GSO in Moscow and bought a bunch of Big Books and Twelve and Twelves and sat down with my English Big Book on one side and a Russian Big Book on the other and I took these two guys through the twelve steps of Alcoholics Anonymous (applause) and, you know, they saved my life again you guys saved my life.

Consistently in her story, Lizz portrays her mastery of the textual tools of Alcoholics Anonymous as a means by which she redefines agency through coming to understand herself in terms of her relationships with people and objects in the world. To some extent, this process also involves a *surrender* of agency to the tools she is engaged with, and the ways these tools enable and

constrain certain ways of negotiating these relationships. As with many AA stories, Lizz's story is full of examples of her negotiating this tension between her using the tools, and the tools 'using her'. In her account of her 'Fourth Step' ('We made a searching and fearless moral inventory of ourselves'), for example, she talks about how she used the process of making an inventory as a means of *avoiding* getting to the 'Fifth Step' ('We admitted to God, to ourselves, and to another human being the exact nature of our wrongs'):

My first Fourth Step was over three-hundred typed pages. I really was terrified of doing a Fifth Step you know like I had never experienced unconditional love of my life, and I thought for sure if I told another human being all of these things, all of these resentments, all these things that I've done, all these situations I've been in, that and she would walk away, you know, and then what do I do, and so I just kept writing you know I wrote and wrote and wrote...

The thing that characterizes all of the steps that Lizz recounts in her narrative – labelling herself an alcoholic, learning to see herself in the descriptions of alcoholism in the Big Book, making a 'fearless' self-inventory, and confessing her defects to herself, to God, and to another human being—is the act of engaging with a 'textual double', a discursive representation of herself which conforms to the identity of an alcoholic promoted by the group, and of surrendering her old self to this new identity. The point of this exercise is not to replace a 'natural' or 'real' self with a discursively constructed one, but to come to the realization that the self one always believed oneself to be was also discursively constructed, that one of the essential problems of alcoholism is that it leads people to construct unhealthy textual doubles which are at odds with

what they are actually doing and how they are actually behaving. The Big Book (Alcoholics Anonymous 1939: 73) puts it this way:

More than most people, the alcoholic leads a double life. He is very much the actor. To the outer world he presents his stage character. This is the one he likes his fellows to see. He wants to enjoy a certain reputation, but knows in his heart he doesn't deserve it. The inconsistency is made worse by the things he does on his sprees. Coming to his senses, he is revolted at certain episodes he vaguely remembers. These memories are a nightmare. He trembles to think someone might have observed him. As fast as he can, he pushes these memories far inside himself. He hopes they will never see the light of day. He is under constant fear and tension - that makes for more drinking.

The effects of this process of trading in this 'contradictory self' for a more 'honest' and 'fearless' discursive construction are described by Lizz H. as follows:

I no longer had to walk down the street with my head down I no longer had to keep my hair in my face I could ask you how you were doing and I could care about what you said back to me and you know that wasn't holding on to all of that anymore like I wasn't afraid that you would figure out who I really was.

In this statement can be seen both of the dimensions of 'technologies of the self' that Foucault (1988, 2003) describes: the reflective dimension and the communicative dimension, as well as how these dimensions interact with each other. The construction of this 'more accurate' 'textual

double' is facilitated by being able to share it with others, and it is also what makes the act of sharing with others possible. In this sense, Lizz's authoring of herself is not an individual act, but an act of 'collaborative writing' that is performed together with the other members of the group and with the tools the group provides. Throughout her story, in fact, she credits the group as a whole with her success:

Your love changed my life and what happened for me was I was able to look at myself in the mirror for the first time in my life, you know, I was able to build on the foundation to have relationships with other human beings.

I finally felt like I was home you know like you loved me you made me feel safe and now I was finally home.

It is not just, as Cain (1991) and others have pointed out, that the discursive tools (such as narrative) provided by AA equip members with the means to become socialized into the group through 'legitimate peripheral participation' (Lave and Wenger 1991), but also that the group itself becomes a tool as members discursively reconstruct it and carry those reconstructions to other alcoholics through service. Lizz says:

Like I got to carry your voice and it was such a privilege and yeah the love that our trusted servants have the dedication that is there to carry your voice ...there's nothing like it.

Bateson (1972), in his famous analysis of Alcoholics Anonymous, attributes the success of the program to the way it helps members orient towards a more cybernetic view of the world (see Wiener 1948) in which agency is shared between the human actor and his environment. Rather than simply a surrender of agency, he says, the First Step is ‘a change in epistemology, a change in how to know about the personality-in-the-world’ (Bateson 1972: 313). In this new epistemology, members see themselves not as independent agents who think, act and decide, but as parts of ‘a larger field of interlocking processes’ which ‘does the thinking, acting and deciding’. As Lizz says:

I learned really early on that I just do what I'm told here and everything seems to work out alright.

Although such a sentiment might run contrary to our contemporary Western notions of freedom, agency and self-efficacy, the point that Bateson would make is that such a surrender does not constitute giving up agency so much as learning to share it productively with the people and the tools in one's environment. In the case of Alcoholics Anonymous, then, recovery is a process through which agency is gradually reconceptualised as a matter of the reciprocal relationships between the social actor and the tools with which members mediate their experience of the world. The program operates through a kind of paradox, the promise that surrendering control is the only way to regain it.

Kevin Krejci: Outsmarting Parkinson's with data

The second example of a narrative of mediated self-care I would like to present is the story of Kevin Krejci, a Silicon Valley tech worker with Parkinson's disease who talked about his efforts to 'outsmart' his condition through self-quantification in a Quantified Self Meetup in San Francisco in January of 2014. The Quantified Self is a community which, at the time this story was told, consisted of a network of over 170 groups with over 35,000 members in 121 cities and 38 countries around the world (<http://quantified-self.meetup.com>). These groups hold regular 'meetups' at which members take turns giving short, narrative presentations (usually supported by PowerPoint slides) of their experiences with self-quantification. Interestingly, like the stories told at Alcoholics Anonymous Meetings which describe recovery in terms of 'what we used to be like, what happened, and what we are like now', the narratives told at Quantified Self Meetups also have a tripartite structure. The website of the Quantified Self community, in fact, explicitly instructs members that the stories they tell at meetups should answer 'three prime questions':

- 1) What did you do?
- 2) How did you do it?
- 3) What did you learn?

And just as Lizz H. explicitly references the community sanctioned story structure of AA in her talk, Kevin Krejci alludes to the 'prime questions' of the Quantified Self community both in what he says and in the PowerPoint slides he projects as he is talking, which have titles like:

my challenges

my actions

my goals

lesson learned (so far)

At the same time, there are important differences in the ways stories are told in this community, and the way narrators use these stories to discursively construct agency. One difference is apparent in the ways the two communities *talk* about storytelling. As mentioned above, in AA, the agency of the narrator is downplayed in the formulation ‘what we used to be like, what happened, and what we are like now.’ In the QS formulation, on the other hand, the agency of the teller is highlighted, with the narrator focusing on what s/he *did*, and what s/he learned. Another key difference is that AA stories are framed as stories of transformation (‘what we used to be like’ being contrasted with ‘what we are like now’), whereas QS stories are stories of ‘learning’. That is not to say that QS stories do not involve transformation; most of them do. But this transformation is regarded as the product of creating ‘new’ knowledge rather than understanding the self in terms of a body of knowledge already provided by the community.

Related to the points above are the different ways AA and QS narratives provide for narrators to present themselves and position themselves as characters in their own stories. AA recovery stories, such as Lizz H’s story, typically begin with narrators identifying themselves as ‘alcoholics’, a ritual of identification which enacts the surrender of what, in AA, is viewed as an illusion of agency. Kevin Krejci also begins his story with an introduction, but his introduction provides a more multi-dimensional portrayal of his identity:

Okay I'm Kevin Krejci business development manager Fujitsu labs and a dad of two boys and also a dude with PD.

While in many ways, this introduction seems more individualistic and agentive, it also achieves for Kevin the function of ritually aligning himself with recognisable identities in this community: his mention of his occupation helps him to claim expertise in the kinds of technical skills needed for self-quantification, his identification of himself as a father helps to humanize him, and his identification as 'a dude with PD' identifies the problem he is trying to solve. All of these identities resurface later in his talk. He later invokes his family, explaining that his main goal in quantifying himself is so that he can 'be there for them', and he talks about his job as providing resources for him to develop new ways to understand his disease. It is his treatment of his disease, however, that is the most interesting aspect of his identity construction, and the aspect that contrasts most dramatically with Lizz H. The most obvious difference is that this aspect of his identity is construed as an attribute he possesses (something he 'has') rather than as an intrinsic quality (something that he 'is', such as a 'dad' or a 'business development manager'). In fact, while one of the central purposes of an AA story is to demonstrate that the narrator has fully taken on the identity of 'an alcoholic', the story of Kevin Krejci – and many other self-quantifiers – is an effort to distance himself from identification with his disease or problem. This is accomplished through the construction of an alternate identity, a 'data double' composed of the aggregate of all the carefully collected statistics about his bodily 'performance' of the disease over time, resemiotized by the various 'technologies of the self' he has available to him into charts, graphs, spreadsheets and other forms of information visualisation.

This process of distancing begins at the start of his talk with his first two slides, the first (Fig. 1) declaring ‘I’m a dude with PD, accompanied by a screenshot of his Twitter profile, complete with a picture of him smiling in a tuxedo, and the second (Fig. 2), with the title ‘What is PD?’, showing a drawing of a stooped, elderly looking PD ‘sufferer’, about which he says:

That’s me...maybe. No! I’m trying to avoid that. PD is a neurodegenerative disease that makes it hard to pronounce words like neurodegenerative. And it’s basically a motor disorder, so guys like me might end of looking like that a little before we should.

This contrast between his ‘real self’ (represented by his Twitter profile), and what he might become, were he to give in to conventional definitions of what it means to be ‘a dude with PD’, serves as an abstract for the remainder of the story, which is essentially a story of fighting against this conventional ‘patient identity’ by constructing a new identity for himself through the process of analysing and understanding his disease. This story is summed up in the quote from Michael J. Fox which he projects on a later slide: ‘Quote from Michael J Fox, he got diagnosed twenty-three years ago and he says, our challenges don’t define us, our actions do.’

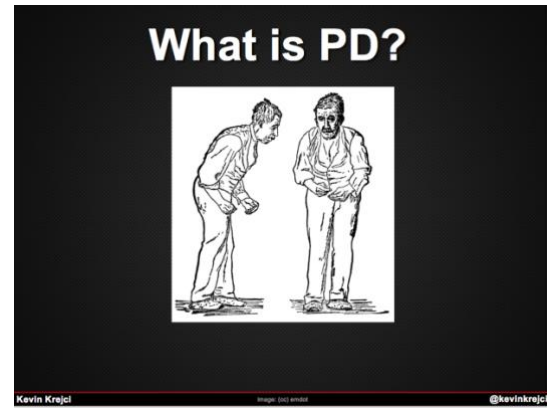


Figure 1

Figure 2

As I noted above, AA narratives are organized around how narrators master and use the tools the program makes available to them, such as the ‘12 Steps’, and the making of lists and taking of ‘personal inventories’. Talks at Quantified Self meetups are also organized around processes of tool mastery and use. In fact, in QS narratives, the tools are even more explicitly thematized. According to the group’s website, sharing in QS meetups is organized around ‘asking big questions about our self-tracking tools and what we do with them’ (Boesel 2013). For AA members, their stories are about ‘what happened to us and how the tools we used made that possible,’ whereas for QS members, their stories are more about ‘what tools we used and how they helped us to learn something about ourselves or change our behavior.’ In fact, there is considerable attention in talks by quantified selfers like Kevin Krejci to the technological aspects of the tools they use, and how these technological aspects serve to ‘energise’ them and push them to rethink their relationships with their bodies (Ruckenstein and Pantzar 2015). This relationship with technology is evidenced in Kevin Krejci’s talk, in which he describes his devices (‘his friends’) in terms of what they can do, and how their technological affordances serve to motivate him:

So these are my friends, they’re helping me to collect the data. Um, I’ve got Fitbit, iHealth taking my blood pressure, Bodymedia on this shoulder. My Withings scale, got this little Zeypher ...whatchamacallit. I don’t even know what they call it, it tracks quite a few things...Fitbit’s helping keep me motivated. I use Map my Fitness to to do family hikes and then do runs around the track and measure with Runkeeper. And loosing

weight's good for all of us too, including PD patients like me, and my Withing scale's inspiring me everyday to jump on there and see how I'm doing with that...And the folks at APDM Movement monitoring solutions were kind enough to loan me one of their cool kits over here you can look at later. Put some sensors around different parts of the body to measure movement monitoring like sway, how, you know gait, how well my arms are swinging and so on and they have a little panel here you can look at that, you know, different tests you can run, based on where you put the sensors, and what kind of exercises you do. Generate some graphs, which we all love to look at, but sometimes are hard to decipher.

Implicit in this account is not just a faith in technology, but a faith in data, a belief that the more data one collects the better. In other words, alongside the apparent 'goal directed' orientation of the Quantified Self movement, there is also a commitment to self-tracking even in the absence of clear goals. 'For many self-trackers,' writes Gary Wolf (2010: n.p.), the founder of the movement, 'the goal is unknown. Although they may take up tracking with a specific question in mind, they continue because they believe their numbers hold secrets that they can't afford to ignore, including answers to questions they have not yet thought to ask.'

For Kevin, his 'life goals', to 'maximize productivity, make my boss happy, make my wife happy and my kids happy ... reduce stress' are seen as intrinsically tied up with, and even dependent upon, his 'QS goals', to 'find efficient ways to measure and track my condition, establish some solid baselines, try some experiments and learn from them.' Similarly, what Kevin learns from his tools has just as much to do with the tools and processes of self-tracking as

it does with his condition. In fact, one might say that he has to some degree replaced the problem of having Parkinson's disease with the problem of figuring out how to best *entextualize* Parkinson's disease.

Lessons learned so far? Tracking is no easy task. Um, it requires a lot of discipline and commitment as we all know. But it's fun, and data's too scattered and hard to cross correlate, but that's where the real fun's gonna be...Challenges to quantify me, It's routines, routines, routines. Just trying to, you know, remember to charge the devices, don't lose my cables, and just make time for everything. Including family and work...it's turning that data, big data into good data, finding that good data... and turning it into actionable wisdom.

Among the most powerful ideological positions of the Quantified Self movement is a faith in the power of 'feedback', an explicit promotion of what Bateson (1972) would characterize as a 'cybernetic epistemology'. This focus on feedback is evident in much of the Quantified Self literature, including an often shared article from *Wired* magazine entitled 'Harnessing the power of feedback loops' in which the author Thomas Goetz (2011) writes:

...feedback taps into something core to the human experience, even to our biological origins. Like any organism, humans are self-regulating creatures, with a multitude of systems working to achieve homeostasis. Evolution itself, after all, is a feedback loop, albeit one so elongated as to be imperceptible by an individual. Feedback loops are how we learn, whether we call it trial and error or course correction. In so many areas of life,

we succeed when we have some sense of where we stand and some evaluation of our progress. (n.p.)

There are, however, important differences in the way the Quantified Self movement talks about feedback and the way it is discussed by Bateson, especially in his analysis of the epistemology of Alcoholics Anonymous. First, there is the belief that technology makes feedback ‘better’ or ‘more efficient’, and that more data results in more useful feedback, a premise most cyberneticians would dispute. Despite his characterization of feedback as ‘something core to the human experience,’ for example, Goetz depicts it as something that was relatively under-utilized until the advent of digital technology:

Despite the volume of research and a proven capacity to affect human behavior, we don’t often use feedback loops in everyday life. Blame this on two factors: Until now, the necessary catalyst—personalized data—has been an expensive commodity... Second, collecting data on the cheap is cumbersome. Although the basic idea of self-tracking has been available to anyone willing to put in the effort, few people stick with the routine of toting around a notebook, writing down every Hostess cupcake they consume or every flight of stairs they climb. (n.p.)

Bateson’s view, however, in his explanation of the therapeutic utility of AA, is not so much that ‘technologies of the self’ set up new ‘more efficient’ feedback loops, but that they help members become aware of the way their lives are *already* governed by feedback loops. Feedback loops do not have to be created. Rather, they have to be recognised and experienced for what they are.

The second difference is that, for quantified-selfers, engaging with feedback is seen as a way of ‘gaining control’ over one’s life. ‘The true power of feedback loops’, writes Goetz, ‘is not to control people but to give them control.’ Bateson, of course, would make the opposite point, that ‘control’ is always shared among multiple entities in the system and to believe that any one entity is in ‘control’ is to fall into the distortion of Cartesian dualism.

Finally, there is a distinct difference between Kevin Krejci’s story and Lizz H.’s story in how the community itself is constructed around ‘technologies of the self’. This is perhaps not surprising, since members of AA have a common goal (‘to stay sober and to help others recover from alcoholism’), and a common set of tools that they use, often in pairs (with a ‘sponsor’) or in groups (in the context of meetings). Quantified selfers, however, come to the community with disparate goals, ranging from managing chronic diseases to improving their personal relationships, and use disparate tools to meet these goals, tools they typically use alone. A common way quantified selfers refer to themselves is as ‘an n of 1’, a designation which highlights their commitment to self-experimentation and their suspicion of knowledge based on large clinical trials. In other words, the Quantified Self community is very much a community of individuals whose strength is seen to come from the individual efforts — the ‘self-care entrepreneurship’ — of individual members. While Lizz H. frequently addresses her audience as ‘you’ (constructing them as representative of the whole community), Kevin Krejci does not refer to his audience at all. Nor does he construct himself as a member of a community beyond referring to himself as ‘a big quantified self fan’. His orientation towards the community is instead an orientation towards particular individuals in the community that have helped or

inspired him:

E-patient Dave was here a few years ago and really inspired me, got me to start tracking my sleep and a few other things back then, even though I didn't know why I was doing it. Very inspirational to see, hear his story.

There is, however, one type of orientation towards collective experience that is central to the Quantified Self movement, involving sharing one's data with others engaged in similar experiments and trying to gain insights through the *aggregation* of 'quantified selves' — an 'n of many' — and Krejci does allude to this orientation, talking about his involvement in patient social networks like 'Patients Like Me':

I am part of the n of many, the us contributing my data to services like 23andMe and Patients Like Me, Care Together, and trying to connect with people and all those social networks, share good stories and data.

The kind of the collective experience that comes from being part of an aggregation, however, is very different from the experience of being part of a community. For quantified-selfers, then, the QS community is seen as a *source* of resources (data, tools and advice on techniques of using them) rather than, as in AA, as *a resource itself*, part of a system of distributed agency which supports members in their recovery.

In the Quantified Self movement, then, self-care is discursively constructed as a process of

entextualizing the self with the purpose of setting up ‘feedback loops’ which may (or may not) result in ‘learning’. In many cases, just being in possession of data is seen as a form of ‘learning’. These processes are centrally focused on technologies, which are seen as the means to ‘self-knowledge’, with the search for self-knowledge frequently associated with the search for ‘better technologies’. Agency is construed as a matter of controlling the world (including the self) through knowledge.

Conclusion

In both of these stories, self-care is construed as a practice of using ‘technologies of entextualization’ (Jones 2009) to construct ‘a new self’ — whether it be Lizz H.’s ‘textual self’ or Kevin Krejci’s ‘data double’. In both cases, this ‘new self’ is perpetually unfinished, a ‘work in progress’. These narratives, then, serve as canvases upon which the negotiation between the past self, the present (better) self and a future (even better) self is enacted (Bode and Kristensen 2015; Hawkes 1977). In this regard, one of the most important things about the discursive construction of self-care that these two stories illustrate is the role of ‘technologies of the self’ in bridging the gap between epistemology and ontology —the way we come to know ourselves and the kinds of selves we are able to be. In both of these examples, the relationship between knowing and being is reciprocal and mediated through technologies which allow us to construct ourselves as objects of knowledge and to construct from that knowledge new ways of being. As Bateson (1972: 113) puts it:

In the natural history of the living human being, ontology and epistemology cannot be separated. His (commonly unconscious) beliefs about what sort of world it is will

determine how he sees it and acts within it, and his ways of perceiving and acting will determine his beliefs about its nature. The living man is thus bound within a net of epistemological and ontological premises which—regardless of ultimate truth or falsity—become partially self-validating for him.

Where these two stories differ is that, while for Lizz H., the process of constructing a textual self facilitates a *dismantling of the illusion of agency*, for Kevin and his fellow quantified-selfers, the process of constructing data doubles is portrayed as helping them to *regain a sense of control* over their bodies and their lives. While, the ‘textual selves’ AA members create provide for them a new way of *being*, the data doubles that quantified-selfers create provide for them a new way of *thinking*. Finally, the communities which provide these technologies and into whose practices the narrators are socialized are construed very differently. Whereas the Quantified self-movement is a source of resources for self-care, the AA community is itself a resource, itself a technology upon which members draw upon in their recovery.

Despite these key differences, both of these stories reveal that self-care is not just an individual practice, but a *social* practice. Even in the context of the individualistic, libertarian philosophy of the Quantified Self movement, self-care depends crucially on the kinds of technologies that are made available to individuals by the communities they engage with and the ways they are socialized into the *discourses of technique* that signal membership in these communities.

‘Technologies of self’ are ultimately technologies of society, which function to integrate individuals into systems of discourse, and to construct and maintain communities of practice.

It has not been my purpose in this article to make judgements about either Alcoholics Anonymous or the Quantified Self movement in terms of the practices of self-care their members engage in or the relative benefits of these practices. I have no doubt that both Lizz H. and Kevin Krejci have benefited a great deal from the practice they describe in these stories, as have many other members of these communities. I also do not wish to equate the challenges of alcoholism with those of Parkinson's disease. They are very different conditions requiring very different sorts of interventions. Finally, while I believe both of these stories are broadly representative of the kinds of narratives typically told in these two contexts, the purpose of this analysis is not to make generalizations about 'AA stories' or 'QS stories', or about the practices of self-care members of these two communities typically engage in. Rather, it is to highlight, in line with several other articles in this issue, ways that the social identities of 'expert' and layperson' are becoming blurred in many contemporary practices of medical care, and to closely examine two specific 'sites of engagement' at which specific people, specific technologies, and specific discourses come together to make certain kinds of actions and certain kinds of identities possible (Scollon 2001).

Notes

¹ The story of Lizz H. is available at: <https://www.youtube.com/watch?v=U33NJ7qyYSY>
The story of Kevin Krejci is available at: <http://quantifiedself.com/2014/02/kevin-krejci-tracking-parkinsons/>

References

- Archer, M. S. (2007) *Making Our Way through the World: Human Reflexivity and Social Mobility*. Cambridge: Cambridge University Press.
- Ahearn, L. M. (2001) Language and agency. *Annual Review of Anthropology* 30 (1): 109–137.
- Arduser, L. (2014) Agency in illness narratives: A pluralistic analysis. *Narrative Inquiry* , 24 (1): 1–27.
- Barta, K. and Neff, G. (2016) Technologies for sharing: Lessons from Quantified Self about the political economy of platforms. *Information, Communication & Society* 19 (4): 518–531.
- Bateson, G. (1972) *Steps to an Ecology of Mind*. Chicago: University of Chicago Press.
- Bode, M. and Kristensen, D. B. (2015) The digital doppelgänger within. A study on self-tracking and the quantified self movement. In R. Canniford (ed) *Assembling Consumption:*

- Researching Actors, Networks and Markets*, 119-134. London: Routledge.
- Boesel, W. (2013, May 22) What is the quantified self now? *Cyborgology*. Retrieved from <http://thesocietypages.org/cyborgology/2013/05/22/what-is-the-quantified-self-now/>
- Burke, K. (1969) *A Grammar of Motives*. Berkeley, CA: University of California Press.
- Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* 4 (2): 167–182.
- Bury, M. (2001) Illness narratives: Fact or fiction? *Sociology of Health and Illness* 23 (3): 263–285.
- Cain, C. (1991) Personal stories: Identity acquisition and self-understanding in alcoholics anonymous. *Ethos* 19 (2): 210–253.
- Candlin, C. (2012) Discussant comments. Presented at Rethinking Wellbeing: Perspectives on language, education and health, Adelaide, South Australia, 3 December. Available at: <https://www.youtube.com/watch?v=quypCb1LZCM>
- Foucault, M. (1988) *Technologies of the Self: A Seminar with Michel Foucault*. Edited by L. H. Martin, H. Gutman and P. H. Hutton. Amherst: University of Massachusetts Press.
- Foucault, M. (2003) Technologies of the self. In M. Foucault [edited by P. Raboinow] *Ethics, Subjectivity and Truth*. New York: The New Press.
- Frank, A. (1995) *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.
- Giddens, A. (1984) *The Constitution of Society: Outline of the Theory of Structuration*. Cambridge: Polity Press.
- Goetz, T. (2011) Harnessing the power of feedback loops. *Wired*, June 19. Retrieved from www.wired.com/magazine/2011/06/ff_feedbackloop/al 1/1

- Hawkes, T. (1977) *Structuralism and Semiotics*. Berkeley: University of California Press.
- Humphreys, K. (2000) Community narratives and personal stories in Alcoholics Anonymous. *Journal of Community Psychology* 28 (5): 495–506.
- Hutchins, E. and Klausen, T. (1996) Distributed cognition in an airline cockpit. In Y. Engeström and D. Middleton (eds) *Cognition and Communication at Work*, 15-34. Cambridge: Cambridge University Press.
- Iedema, R. (2001) Resemiotization. *Semiotica* 137 (1-4): 23-39.
- Jones, R. H. (2009) Dancing, skating and sex: Action and text in the digital age. *Journal of Applied Linguistics* 6 (3): 283–302.
- Jones, R. (2013) *Health and Risk Communication: An Applied Linguistic Perspective*. London: Routledge.
- Jones, R. H. (2015) Discourse, cybernetics and the entextualization of the self. In R. H. Jones, A. Chik and C. A. Haf Badner (eds) *Discourse and Digital Practices: Doing Discourse Analysis in the Digital Age*, 28-47. London ; New York: Routledge.
- Jones, R. H. (2016a) *Spoken Discourse*. London: Bloomsbury.
- Jones, R. (2016b) The discursive construction of knowledge about genetics on YouTube. A paper presented at the Annual Meeting of the British Association of Applied Linguistics (BAAL), Cambridge, September 1-3.
- Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. Basic Books: New York.
- Labov, W. and Waletzky, J. (1966) Narrative analysis: Oral versions of personal experience. In I. Helm (ed) *Essays on the Verbal and Visual Arts. Proceedings of the 1966 Annual Spring Meeting of the American Ethnological Society*, 12–44. Seattle, WA: University of

Washington Press.

Lapum, J., Angus, J. E., Peter, E. and Watt-Watson, J. (2010) Patients' narrative accounts of open-heart surgery and recovery: Authorial voice of technology. *Social Science & Medicine* 70 (5): 754–762.

Latour B. (1991) Society is technology made durable. In J. Law (ed) *A Sociology of Monsters. Essays on Power, Technology and Domination*, 103-131. Routledge: London.

Lave, J. and Wenger, E. (1991) *Situated Learning: Legitimate Peripheral Participation*. Cambridge: Cambridge University Press.

Lupton, D. (2014) *Digital Sociology*. Abingdon, Oxon: Routledge.

Norris, S. and Jones, R. H. (2005) *Discourse in Action: Introducing Mediated Discourse Analysis*. London: Routledge.

Pennebaker J. W. and Seagal, J. D. (1999) Forming a story: The health benefits of narrative. *Journal of Clinical Psychology* 55: 1243–1254.

Reissman, C. K. (1990) Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science and Medicine* 30 (11): 1195–1200.

Reissman, C. K. (1993) *Narrative Analysis*. Newbury Park, CA: Sage.

Ruckenstein, M. and Pantzar, M. (2015) Beyond the Quantified Self: Thematic exploration of a dataistic paradigm. *New Media & Society* 19 (3): 401-418.

Scollon, R. (2001) *Mediated Discourse: The Nexus of Practice*. London: Routledge.

Scollon, R. and Scollon, S. W. (2004) *Nexus Analysis: Discourse and the Emerging Internet*. London: Routledge.

Topol, E. (2012) *The Creative Destruction of Medicine: How the Digital Revolution Will Create better Health Care*. New York: Basic Books.

- Verbeek, P.-P. (2011) *Moralizing Technology: Understanding and Designing the Morality of Things*. Chicago: University of Chicago Press.
- Vygotsky, L. S. (1962) *Thought and Language*. Translated by E. Hanfmann and G. Vakar. Cambridge, MA: MIT Press.
- Wertsch, J. V. (1993) *Voices of the Mind: A Sociocultural Approach to Mediated Action*. Cambridge, MA: Harvard University Press.
- Wiener, N. (1948) *Cybernetics: Or the Control and Communication in the Animal and the Machine*. Boston: MIT Press.
- Wolf, G. (2010) The data driven life. The New York Times, Online. Retrieved 6 June 2014 from <http://www.nytimes.com/2010/05/02/magazine/02self-measurement-t.html?pagewanted=all>
- World Health Organization (1983) Health education in self-care: Possibilities and limitations. Report of a scientific consultation. Geneva, Switzerland: World Health Organization.
- Ziguras, C. (2013) *Self-care*. London: Routledge.