

Lessening the Evils, Online: Embodied molecules and the politics of hope in Parkinson's disease

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Virtual communities are an especially rich subject for social scientists studying the dynamic and multifaceted ways that groups negotiate health-related knowledge. What are the forces shaping the health information that virtual community members circulate, evaluate and incorporate? This article explores health information circulating on an international, though mainly North American, email list for people suffering from Parkinson's disease. The dual purpose of the list—of support and knowledge exchange—is shaped by a particular politics of hope, which channels knowledge and projects it into the future. This politics of hope is, at least partly, based on what I want to call “embodied molecules”—the effectiveness of medications created by the list’s “cyberbody.” Cyberbodies, in this article, are created through the virtual community members’ embodied learning.

Keywords: Parkinson's disease, pharmaceuticals, embodied molecules, politics of hope, biolearning, Internet

*To such researches the healing art is... much indebted for the enlargement of its powers of lessening the evils of suffering humanity. Little is the public aware of the obligations it owes to those who... have devoted themselves to these pursuits... (James Parkinson, *An Essay on the Shaking Palsy*, 1817; emphasis added)*

Ideally, the standardization of medications helps guarantee patient safety in the face of the ever growing complexity of medication management in most countries. Studies about medication safety often ignore the

social and cultural embeddedness of standardization procedures. In his recent study on pharmacopolitics Arthur Daemmrich (2004:160) argues, that “the authority to govern, that is, to set standards...derives as much from the ability to classify and characterize people as it does from the ability to order human relations. This authority is no longer situated solely in the state or medical profession, but instead is spread across a network of actors.” In fact, as Daemmrich (2004: 11) shows, “each of these actors draws upon smaller and tighter networks to articulate policy positions concerning medical issues.”

This article is about one such network. By analyzing how patients and their caregivers struggle for good treatment, my intention is to call attention to the *embodiment of information* that becomes, at least partly, the basis on which truth claims are legitimated. This bottom-up focus, while rarely used in studies of standardization, is important because patients and, especially patient groups, increasingly influence and shape all phases of the social life of health technologies such as medications (Oudshoorn and Pintch, 2003). While patient groups and their activism is a common topic in social science studies in medicine (Barbot and Dodier, 2002; Epstein, 1996), embodied experiences in patient activism have received little attention. This article studies medications and embodiment focussing on one specific scenario: an Internet-based patient group.

It is well documented that, with the Internet, access to medical knowledge has become more democratic (Charland, 2005), leading to more informed patients having access to multiple sources of information. However, Internet searchers are sometimes overwhelmed by information, decision-making and loneliness (Hoffman, 2005) or are in danger of uncritically using self-prescribed health interventions (Harmon, 2005). This is true in richer nations, and increasingly in developing countries (World Bank, 2006), and among older people who, in many countries, no longer shy away from computer technology (Kaiser Family Foundation, 2005; see Goldman, 2001 for Brazil).

The importance of the Internet for finding information on current health issues has led to a growing number of virtual communities constituted around particular medical diagnoses.

These communities are an especially rich site for social scientists wanting to study the dynamic and multifaceted way members integrate knowledge into health-related practices (Wilson and Peterson, 2002).¹ For their members, the online communities can provide information, emotional support, a temporary normalization of stigmatized experience; and, to a certain extent, online communities allow participants to transcend mundane restrictions of time and space, in the sense that: people living geographically apart can connect, people with mobility problems can be part of such a community, and information is constantly available and not restricted to fixed hours of consultations with doctors or self-help groups meeting offline (Cotton and Gupta, 2004; Hardey, 2002; Lasker et al., 2005; Seale et al., 2006; Ziebland, 2004).

But how are knowledge and truth on such lists negotiated? What are the forces that literally filter the huge amount of information on Internet—something Scott Lash (in Malik, 2005) has called “the out of control anarchy of information diffusion”? Some of those social forces, that one might call vectors, following Ian Hacking (1998),² have been documented. For example, the influence of the pharmaceutical industry on the production of a range of health information has been repeatedly elucidated (Blech, 2003; Healy, 2004; Hemminki et al., 2004; Hogle, 2002; Leibing, 2009 a,b; Rasmussen, 2004).³ Sarah Nettleton and colleagues (2005: 976) question the purported diversity of information on the Internet, by showing that search engines influence the ranking of the most popular sites. The websites listed first in results of health-related searches are overwhelmingly “charities, medical institutions and pharmaceutical

companies” and since people most often click on the first results displayed, these have the greatest impact. Additionally, Nettleton and colleagues (2005) identify six implicit rules that people apply in deeming a website trustworthy: 1. the reputation of the organization behind the website (e.g., WHO); 2. the professionalism of the organization; 3. the website’s nationality (preferably that of the user); 4. the website’s source of funding (non-commercial preferred); 5. the user’s self-perception as sensible and careful; and 6. the repetition of information on the web. This article does not focus on the multiple sources of knowledge as does, for example, the excellent study by Barbot and Dodier (2002); the focus is more specifically on the incorporation of knowledge regarding the treatment of Parkinson’s disease.

Parkinson’s, a progressive neurodegenerative disease, mostly affects people over 60 years old, although there is also a ‘young onset’ group. The disease was named after James Parkinson’s 1817 description of ‘shaking palsy’ (see Roberts, 1997). Parkinson’s is caused by cell degeneration and loss of neurons in the brain, specifically in the part of the brain called the *substantia nigra*, which is involved in the control of movements. Today, most experts say that the disease is caused by a combination of genetic and environmental factors. There are different forms of Parkinson’s, some more virulent, others causing decline more slowly. The most common symptoms are muscular rigidity, postural abnormality and tremor.

As of yet there is no cure for Parkinson’s disease, although its symptoms may be mitigated—temporarily—by pharmacological and surgical treatment. Current pharmacological treatment for Parkinson’s stems from studies done in the 1950s by Oleh Hornykiewicz

of the University of Vienna, and basically consists of using dopamine in combination with a number of other drugs, with the combination individually tailored to each patient. The effects of dopamine treatment generally last for up to 10 years. At the end of this period, the treatment’s side-effects such as dyskinesias (involuntary movements) and dystonias (painful contractions of certain muscles) are so disabling that the treatment must be withdrawn. Two surgical interventions are possible: ablative surgery (the destruction of a selected region of the brain) and deep brain stimulation (DBS), the more common one (Freed and Levay, 2002). The Parkinson List members were extremely apprehensive of DBS, and some found the procedure highly traumatizing (see also Anonymous, 2005).⁴ These surgical interventions may be used as alternatives to medications, or when medications have ceased being effective. None of these interventions cures; they only delay the final phase of Parkinson’s disease, although this delay is sometimes for many years (Correia et al., 2005). An important discussion among the Parkinson list members is when to start medications and how to avoid surgery. Much of the information circulating on the list about other treatments, for example about alternative medicine, has to be seen as embedded in these discussions of how to delay the use of last, medical resorts.

The Study Design

The list studied in this article is an unmoderated e-mail list service. It is predominantly for people suffering from Parkinson’s disease (“we Parkies”) but is also, to a lesser degree, for their family members and caregivers. Members send approximately 10-20 messages to the

list daily. The list is designed to provide a forum for knowledge exchange and mutual support relating to personal difficulties arising from living with and treating Parkinson's disease. The list members were notified of my intention to write an article. Except for three members who did not wish to be quoted, there was nobody opposed; some of the members even encouraged me to write this article about their struggle. Nevertheless, to maintain anonymity, no name or geographical location is reported in this article.

During one year (2005-2006) all communications were collected and, following some of the principles of content analysis, the main themes, issues, and information listed. Thematic analysis showed that "treatment" was by far the most important issue on the list and all postings related to treatment were then separated. The material on treatment was analysed by indexing it into subcategories that resulted from the importance given by the list members to the following issues: the right dosage, effect on the body (including side effects), and hopeful (future-oriented) practices. Data was put into context— as much as this is possible online (Pearce, 2008)—by following the discussion threads (and not just isolating them as categories) and, by identifying core voices that seem to express their opinion with more authority than others. The following quotes were taken from this material.

The Parkinson Cyber-community and its Negotiations of Pharmacological Knowledge

Social scientists have used terms such as 'biosocialities' (Rabinow, 1996), 'biosocial groupings' (Rose and Novas, 2005), and 'emergent concerned groups' (Callon and

Rabeharisoa, 2008) to describe people grouped around a specific pathology or biological marker. Such communities constantly reshape how people position themselves towards the world in which they live, and how people are seen by other individuals and groups. Actor Michael J. Fox's initial, still incredulous reaction to his diagnosis of Parkinson's disease reflects what such a positioning, a disease-linked identity, can entail: "If I had this disease, then I would forever be locked into a prognosis, and with that, an identity I'd had no part in creating. I'd be tracked and studied, compared against others *just like me*, ... to see how I varied from the norm" (Fox, 2002: 146; emphasis in the original; see also Anonymous 2005).

Medications are important factors in what one might call identity work. The moment Parkinson medications work, patients might not only feel healthier again, but also regain a sense of normalcy or dignity: "I could walk in the street again with pride," said a German woman after one week of taking her Parkinson medications (Dinklage, 2002). It is not surprising that many postings on the Parkinson's list are about finding a temporary normalcy through the right medications. Such postings frequently feature a complex weighing of dosing and drug combinations in light of numerous, sometimes devastating effects and side-effects. Some postings provide very detailed descriptions of medication-taking. These descriptions of dosing and experience can then be compared and contrasted with those of other List members:

After the addition of Amanadine and Trihexphenidy (generic) twice a day I have cut back on the Sinemet from 4 doses of 50/200 CR to 1/2 of that. I take a quick release

25/100 and one 1/2 a dose of the CR to start the day. Then space out the other 1/2 doses of CR to fit my schedule.... (man with PD⁵).

Trusted knowledge is generally the result of a combination of information provided by experts (e.g., researchers) with the equally important individual bodies of Parkinson patients having experienced the drugs. The following example dialogue shows the addition of new information (from a scientific article) to the group's collective knowledge, and the relativizing of that new information through the List member's own experiences with certain substances:

Has anyone tried this? (She quotes from an article by Mally and Stone, 1994):

"Adenosine is known to inhibit the release of dopamine from central synaptic terminals... Fifteen parkinsonian patients were treated for up to 12 weeks with a slow release oral theophylline preparation The patients exhibited significant improvements in mean objective disability scores and 11 reported moderate or marked subjective improvement" (woman with PD).

Please keep in mind that Theophylline can be deadly. The drug is used to treat asthma, so perhaps someone who has used it for that purpose could let us know if their PD symptoms decreased. At any rate, folks with cardiac arrhythmias, coronary artery disease or a past history of heart attack would be well advised to avoid this drug. It is not a benign medication. God bless (woman caregiver).

It also has a nasty side effect of giving stomach aches. It can be a serious

stomach irritant, so caveats to anyone with digestive disorders. I know because I've taken it for asthma, as has my son. The stomach aches are most uncomfortable (woman caregiver).

This example shows that notions such as expertise and lay knowledge (e.g. Naiditch, 2007) need to be rethought in the light of a constant merging and re-evaluation of different authorities. The patient's body ("stomach aches") is the primary ground on which such notions are evaluated and lived. It further shows that the private and the public are not exclusive domains: the postings, often containing personal matters, are accessible to a large number of readers, but also the experiencing individual body merges in some moments with the bodies of other List members, when learning medications becomes a collective matter, as will be shown below.

In fact, many postings reveal the importance and the authority the List has for its individual members—an authority that at least sometimes surpasses that of 'traditional experts', such as doctors or researchers. The discussions of what is a good treatment often question health authorities and favour the opinions expressed on the List. As Manuel Castells has argued, the 'power of identity' in 'network societies' is often manifest in communities of resistance (Castells, 2004: 30; Stratton, 2000; see also Hardey, 1999). This is also the case, *grosso modo*, for the Parkinson List.⁶

My neurologist prescribed "Neurontin" to help with the nerve/muscle pain. I took it for awhile but eventually decided to quit taking it. I was hearing too many negative reports about it [here on the web](#). I now take "Naproxen" for the pain and I think it helps" (man with PD; emphasis added).

I visited my neuro last week. The intern that saw me for almost 40 minutes was trying to push sinemet [the most common Parkinson medication; A.L.] on me very hard. He sounded worse than the medical sales reps. He insisted that sinemet does not cause dyskinesia! When I told him that Cox-2 inhibitor is important for slowing the progression of PD, he didn't even know about it. That is the kind of younger generation of doctors we are training!...To cut the long story short, I still was not convinced enough to take sinemet. I have determined to stay out of it as long as I can manage (man with PD).

The List community members often unite to achieve their common goal, ideally a cure. Rather than fighting one enemy ('big pharma', 'the' doctors), this Parkinson group, or, community of resistance pragmatically weighs different kinds of alliances that are deemed helpful. The example of voting for the democrats in the USA in favour of the legalisation of stem cell research by patients, who are otherwise republicans, shows the pragmatics of choice:

I certainly hope Bush's program (as much as I like him, I would have to disagree with him on this), doesn't affect that [stem cell research] because many lives would be lost. I wish he had a neurologist on his staff (woman caregiver).

These examples show that expertise is constituted of practices in direct relation with the experiencing bodies. The common (and disembodied) analysis of patient groups and their "dual detour" (the successful pushing for their interests through research combined with political

activism; cf. Callon and Rabeharisoa, 2008) therefore needs to be enlarged: I want to do this by introducing the analytical tool of *embodied molecules*.

Embodied Molecules in critical pharmacology

The concept of embodied molecules is tightly linked to the field of critical pharmacology. This sub-field looks at medications as historically embedded. More specifically, the field approaches medication's molecules assuming these molecules provoke a reaction (effect) in a culturally situated body (affect). It is possible to argue that all molecules are embodied, since bodies are made of molecules. Nevertheless, this critical pharmacology of which I am an advocate uses the term 'embodiment' to emphasize two things: the situatedness of medications (here: the Parkinson group), and the interrelatedness and inseparability of culture and body (e.g., Lock and Farquhar, 2007). Embodied molecules, therefore, cannot be reduced to the molecules of the body alone, but can only refer to *encultured* molecules, as I will show in a moment.

It is the molecules—the small particles of the chemical compounds of medications—which act on the body, but not in a uniform way. In this regard Andrew Barry's (2005) observation regarding 'pharmacological matters' is of importance. Barry, referring to Bensaude-Vincent and Stenger's notion of 'informed materials', argues that molecules embody information and change identities in different environments: "molecules should not be viewed as discrete objects, but as constituted in their relations to complex *informational and material* environments" (Barry, 2005:52; emphasis added). The insistence on the

interrelationship of molecules and their different environments finds a parallel in Georges Canguilhem's cell theory. Canguilhem, in his article *La théorie cellulaire* from 1945, insisted that the cell is always a center that structures its environment; the same principle applies to different degrees when moving from the cell to the person and from the person to society. The molecules of a medication, depending where they 'bind' in the human (or animal), act on different bodily systems. Additionally, people respond differently to the same drug, a fact which might be partially explained by individual genetic makeup (cf. Aldridge, 1998) in combination with the individual 'learning' of bodily sensations (see below).

Much has been written about 'embodiment' in the social sciences. This is not the place for reviewing the abundant literature on this topic (see for example Csordas, 1990; Hughes and Lock, 1987; Scheper-Nichter, 2008 for an overview). Roughly, social scientists using the concept of embodiment can be divided into those focussing on the pre-conscious, following authors such as Merleau-Ponty and Bourdieu, and those who emphasize the interrelatedness of culture and biology. The concept of embodied molecules provides a framework closer to the second approach of 'embodiment' in the social sciences, an approach that is captured by what Margaret Lock writes about 'local biologies' (2001: 483): "the way in which the embodied experience of physical sensations, including those of well-being, health, illness, and so on, is in part informed by the material body" (see also Leibing, submitted).

Hope is directly embodied (or, in this case, also disembodied), for instance in biobanking, when parents store their newborn's cord blood for future use (cf. Brown, 2005). I want to look at embodied

hope from a slightly different perspective. One way of explaining the cultural shaping of what molecules do to people is through 'learning'. Learning is generally understood as a cognitive process of in- and output of information. However, some scholars in the pedagogical sciences now speak about situated learning, which looks at the sociocultural aspects of cognition and learning in a specific context (Lave and Wenger, 1991). Additionally, learning results in structural modifications in the brain, and processed information leaves a physical 'trace' of its passage in the brain. Both learning and the taking of the medications do something to the individual's body—a process that transcends the individual and his or her environment.

Learning is certainly linked to personality traits, which, as Laurence Kirmayer (2002) outlines, differ cross-culturally and affect what drugs do to people and how people 'read' drug outcomes, effects and side-effects. Furthermore, social scientists have long demonstrated that our bodily sensations are, at least in part, shaped by our social environment. Howard Becker's classic study "Becoming a Marijuana user" (1953) shows that the effects of marijuana, its felt bodily sensations, are learned through an initiation that generally takes place in a group. "An individual will be able to use marijuana for pleasure only when he (1) learns to smoke it in a way that will produce real effects; (2) learns to recognize the effects and connect them with drug use; and (3) learns to enjoy the sensations he perceives" (Becker 1953: 35). More recently, Bruno Latour (2004), in his article about the normative dimension of talking about the body, also describes how the senses are "trained" to feel certain sensations. Bruno Latour (2004: 206) goes so far as to define the body as "an interface that becomes more

and more describable as it learns to be affected by more and more elements". He gives the example of an odor training program (e.g., for fragrances), which allows the trainee to acquire "a nose", to be affected by odors that untrained others would not discern. The training kit "has taught them to be affected, that is *effected* by the influence of the chemicals..." (Latour 2004: 207; emphasis in the original). The body becomes articulated through this kind of training of the senses and, as Latour argues, does something to the odors themselves. In a similar vein, I have argued elsewhere regarding the controversial exhibition of plastinated corpses called "BodyWorlds" (Leibing, 2006), that sensations as different as disgust and joy can be felt regarding the same kind of object, depending on the learning process involved.

These findings imply that learning new facts, as in the case of Parkinson research, is not exclusively cognitive; at the same time these findings imply that symptoms are not exclusively biological. Experience entails the embodiment of knowledge through the *communal* negotiations of sensations. When discussions of treatment optimization occur on the Parkinson List, an individual's bodily sensations of effect and side effect are shaped through email exchange with other evaluators. Mainly North American values and cultural scripts structure the perception, interpretation, and discussion of bodily sensations.

The following example discussion about the medication Azilect (rasagiline, a monoamine oxidase inhibitor to treat PD)—shows once more how the body evaluates and shapes information found online (here from the pharmaceutical industry). Other List members can now compare their own bodily experiences against the announced side effects—effects they previously might not have

been aware or attributed to other sources. Or, other List members can now dismiss, as temporary, their own experiences of side effects after reading that a woman did not experience the much-feared side effects, and other List members may even dare to take a medication they had previously avoided because of fears of counter indications:

Would someone in the USA who takes Azilect kindly email me a package leaflet? I am told that it is different from the leaflet that is enclosed with the medication in Europe. The US version deals with contra-indicated foods; the European one doesn't. (man with PD)

Here's some info to start with. ...(cites from the Azilect website) "In order to prevent a dangerous increase in blood pressure when patients are taking AZILECT(r), they should avoid thiamine-rich foods and beverages such as aged cheeses, air-dried meats, pickled herring, yeast extract, aged red wines, tap/draft beers, sauerkraut, and soy sauce. Symptoms of this reaction include severe headache, blurred vision, difficulty thinking, seizures, chest pain, unexplained nausea or vomiting, or symptoms of a stroke. Patients should seek immediate medical attention if any of these symptoms occur." (man, unknown PD status)

I started Azilect about a month ago and it helps with my slowness a lot. I am doing much better on it along with mirapex 1 mg. I was afraid to try it because of the side effects but I have had none. (woman with PD)

One could speculate now that the woman, who took Azilect although she

was afraid of doing so, was suffering so much that her apprehension was finally superseded by hope (for symptom relief). In fact, an important part of medication-taking consists of practices related to hope. Hope can explain part of what is commonly called the placebo effect; it is also a powerful social force fighting for medications in development; and it can entail taking medications, including those that imply a certain risk, to better health.

Politics of Hope

The politics of hope, the motor of many virtual communities formed around disease categories, are linked to practices that both veil and reveal facts of life (see Leibing and Tournay forthcoming). In other words, hope can function as a blindspot (e.g., not acknowledging dangers), but can also prompt action that less hopeful people do not need or do not dare pursue. As Vincent Crapanzano (2003; 1985) has argued, hope can also lead to a standstill—when hoping means waiting—however, hope more often prompts action (Rose and Novas, 2005). Not all hopeful subjects have the social or biological resources for effective mobilization; the ‘voices’ here cited are the successful ones, ones that can make themselves heard/read. Many people with Parkinson’s disease live alone or are only ‘lurking’ on the List. With this in mind, it is nevertheless instructive to look at the different levels on which these active citizens are expressing and acting out their hopes.

A very first level—hope-giving—happens when List members reach out for each other. While hope often involves a possible future, hope is also a pragmatic force in the present. The postings on the Parkinson list show that when

hopelessness is expressed, it is generally countered by a solution proposed by someone who has gone through a similar experience, even if that ‘solution’ is the acceptance of decline and death:

Well I’m starting to think Dad IS at end stage ... he might not have been before—but the Haldol [antipsychotic medication] catapulted him there now. He pretty much just sleeps all day. He seems to know we are there ...and tries to say a few words here and there but we usually can’t understand him... Please tell me whatever you ca—even if it’s not pretty—so I can prepare myself and the family if this is the case! (woman caregiver).

... You need to have a frank talk with your father’s doctor. Then you and your mother need to weigh things realistically. It’s hard to do what essentially feels like “giving up” on a patient. We don’t want to lose a loved one, but on the other hand, what a wonderful thing it is to be able to avoid prolonged suffering for the patient... (woman caregiver).

A second level of hope is medication tinkering, as already mentioned: recommendations regarding finding the right dose, the right combination, a future, a promising treatment or, as in the following example, reducing the use of Parkinson drugs with their severe side effects and their limited applicability. Great effort is put into postponing or optimizing these drugs generally used as last resorts. Exploring the possibility that so-called alternative medicines (cf. Bates 2000) may delay or obviate the use of common PD medications is an important part of the discussions between List members. List members actively share experiences and stories about substances,

diet, exercise and other interventions. Some of them use alternative options that otherwise they might have feared trying or even never encountered if they had a smaller network:

We live in Europe and heard about a man over here who was diagnosed at least 10 years ago and who has never taken meds and he works everyday at a riding stable. We hear he isn't doing too badly. The person who told us about him says he eats an awful lot of broad beans. I also heard somewhere that the Pope ate a lot of mangoes which are high in a number of beneficial nutrients so thought I'd add those to X's diet. We go for long walks every weekend and I can say that since adding the mangoes he hasn't been dragging his left foot. (woman caregiver)

Have you ever heard of x-medication? A right-wing wacko relative is pushing it on me. I looked it up and it is an anti-aging supplement. (man with PD)

Philosopher Ernst Bloch (2001) has argued that the utopian potential of hope, the desire for change, is a human trait rooted in the most diverse and sometimes unspectacular everyday matters. Through hope one gets a feeling for the future, something that Bloch described as a state of “not yet” —a state that is tightly linked to actions in the present and nourished by past experiences (see also Miyazaki, 2003; 2004). Hope, as a social force, is tied to the sometimes pragmatic, sometimes desperate, search for solutions. It is an important channeling force, helping people to filter and evaluate through the constant influx of information through a combination of utopic and pragmatic

knowledge-gathering. Émile Durkheim's description of religion, which he also conceives as a social pushing force, can be seen as analogical to hope: “La religion n'est pas seulement un système d'idées, elle est avant tout *un système de forces*” (1968: 131; emphasis added).⁷

First of all, hope is then movement in time and space, a ‘social motor’. It is part of today's medical culture, a general value system that suggests that the body can eventually be transformed through technologies (Rose, 2005; Good et al., 1990). Hope pushes medical technologies towards a desired goal (e.g., availability), while there are a number of regulating factors that act against hope: depending on the level of analysis one can look at doubt and uncertainty, laws and regulations, biology and availability. The stronger the necessity for hope's fulfillment—as in the case of life-threatening diseases—the less power regulating forces represent. In these situations, hope might win more easily over apprehension. Sarah Franklin (1997) talks about ‘hope-technologies’ when analyzing assisted conception for American couples: “IVF must be understood in part as a ‘hope-technology’. Even when women *know it is most likely to fail*,... the investment is seen to be ‘worth it’. One answer to this apparent conundrum is that it is ... the occasion for hope, fantasy, romance, heroism or other, non-‘rational’, desires to be satisfied which it offers” (Franklin, 1997: 224; italics in the original).

Hope and apprehension are not equally distributed, but constantly interacting agents of change. Wainwright et al. (2006) see this relationship roughly as a continuum. Their study looked at the translations implicit in UK stem cell research for diabetes “from bench to bedside”. They show that scientists in the lab all had a rather pessimistic view of

stem cell research, while clinicians were much more optimistic and 'enchanted' with the possibilities of such a treatment (see also Kitzinger and Williams, 2005). Nik Brown (2003: 16) observes a similar pattern: "The further we travel from the source of knowledge production, the more colourful and flamboyant become the promissory properties of knowledge." Members of the Parkinson List are certainly closer to the 'hopeful' end of such a continuum, although doubt and uncertainty from different sources constantly challenge and change that position. Several messages dampen other members' optimism, especially when it comes to the hype about medications in development, although optimism generally reigned supreme in the case of stem cell research in particular.

...in the last months, there has been more info about PD in the financial section than in the scientific one. Firms announcing a 'new' drug which was an old one in a new form, or many drugs in phase 1 or 2. Some get lost on the way... All my work is cross-checked (because of my profession X) before going out into the world—critical reviews are vital—though often unpleasant when a flaw is found; it does put the stops on over-optimism (man with PD).

For the members of the List, stem cell research is currently the most promising pathway for a cure. The members actively lobbied US American politicians in the hopes that the Bush government would change the laws and allowing stem cell research to continue:

Embryonic stem cell research holds potential for a cure. Are we to sit by silently and wait for others to decide if we are to pursue or discard

that potential? We have a voice. Our citizenship and our tax dollars give us a voice. My Representative here in X has heard my voice today when I called him to urge him to vote for House Bill: HR 810 (the Stem Cell Research Enhancement Act of 2005) which will be coming to a vote in the next few weeks (woman with PD).

In the meantime ... I will keep calling and writing my legislators to urge them [those who are against stem cell research] to move into the 21st century" (man with PD).

This is why it [the Bible] is relevant to Parkinson's. Too many people who follow it or supposedly do, have already stymied research for 4 years. I know now there will be no progress in my lifetime because those in power call the shots and they are definitely anti-science" (woman with PD).

The South Korean scientist Hwang Woo Suk, who claimed that he had cloned human cells, was a strong carrier of hope for the people of the List, because his technique (had it been successful) could be used to generate healthy replacement tissue for tissue destroyed by PD:

These are auspicious times! The floor vote on HR810 scheduled for May 24th along with the recent announcement of a major breakthrough in stem cell research by geneticist Hwang Woo-Suk of South Korea seems to be a good omen (woman with PD).

I would be willing to go to jail if I could be cured of Parkinson's by going to South Korea, but can't make the \$1 million fine (woman with PD).

When in December 2005 it turned out that the cloning of stem cell lines by Woo Suk was a fraud, hope as a channelling force for truth also became increasingly explicit. As one man (with PD) wrote:

This article [about Dr. Hwang Woo Suk] deals with the many factors that influence research results. There is another factor that deserves attention in our ongoing discussion, that being the hope of the people who are afflicted and those that are caregivers including the professional staff (emphasis added).

And although, after the fraud, those who defended stem cell research were criticized by some, as in the following example, the hope linked to stem cell research nevertheless continued.

For so long we have heard from those who seem to have the loudest voices in this forum how great Korea was in this research and how far ahead of the US they were and what a shame it was. Now we see that it was a complete fraud (woman with PD).

How come politicians tell worse lies in worse causes all the time and not only get away with it, but end up retiring on fat pensions? At least Hwang was trying to help (woman with PD).

There is nothing wrong in hoping research (in whatever field) will succeed. In this case, the cheating and lying scientist will have to give up and retire from his job. I just wish the same would apply to lying politicians (woman caregiver; emphasis added).

The postings regarding stem cell research on the List frame the research as a

political issue. Parkinson patients, their family, and other actors who might gain something from this research push for fulfillment of this possible intervention. The desire for fulfillment is not only linked to the individual's hopes, but also to the general stem cell rhetoric—a rhetoric of hope and utopia, establishing an “economy of loss” for which stem cells would compensate (Franklin, 2005). As Melinda Cooper (2006:3) argues, the discourses of stem cell research are especially relevant for older people, since they provide a “more malleable concept of biological limits”, uncovering a “latent ‘surplus’ life, even in the most worn-out of bodies.”

Dangers posed by stem cell therapy, including side effects and the possibility that the stem cells grow into cancer cells, are only rarely mentioned by List members. The communal maintenance of strong hope in stem cell research overshadows postings from members who are more fearful, for whom stem cell treatments are (still) disconnected from present concerns (see APDA, 2006; Braude et al., 2005). Harro van Lente (1993) has called this “possibility spaces”, where promising technologies create spaces of expectations that reign over apprehensions. The tension created from supporting possible future treatments and its disbelieving, often ironic critics can be located between what Moreira and Palladino (2005) call a “regime of truth” (what is known) and a “regime of hope” (what might be); each regime aggregating different actors of support and talking about different patient subjectivities. The Parkinson List's ongoing debate regarding stem cell research can be explained by what Moreira and Palladino (2005: 73) call a “mutual parasitism” of these two regimes: “Mutual parasitism corresponds to a looping process through

which different knowledge practices ... progressively generate their own epistemic resources by translating each others'" (see also Brown 2005 for an extensive overview of this tension).

In reading the Parkinson List postings, a general impression emerges: medical technologies carrying hope are more positively evaluated by individuals in need of a cure than by people who are less involved. It is nevertheless wrong to imply that hoping people uncritically advocate any resource offered. One of the (many) mechanisms influencing decisions regarding optimal treatment and, concomitantly, interacting with the vector described here as hope, is *the multiplicity* of experience of medications within the group. This experience—a communal cyberbody—would mean the incorporation of a “mutual parasitism”.

Communal Cyberbodies

Cyberbodies are generally described as human-computer hybrids. Social scientists investigating cyberbodies may be “interested in the ‘psychotopography’ of the human/computer relationship, the ways that humans think, feel and experience their computers and interact with them as subjects” (Lupton, 2002:478). Scholars like Donna Haraway (1991) have addressed this relationship as one of the computer-as-prosthesis or *cyborg*. In yet other instances, a cyberbody denotes the creation of a “post-human” body, a “wireless, inorganic entity, made of pure bits of information” (Gaggioli et al., 2003: 77; see Hayles, 1999).

In this article, however, a cyberbody is not conceived as an individual human-machine interaction or hybrid, but as a *collective* material and symbolic body that experiences bodily sensations created by momentary consensus of the Parkinson virtual community. This consensus, generated through a multitude of

experiences by different individuals, has a direct and physical effect back on the individual bodies. This kind of effect can be described as biolearning. In this usage of ‘cyberbody,’ the relationship with the computer is not the focus *per se*, although computer networking assembles a critical mass of persons into a disease-based community. The shaping of the collective cyberbody is influenced by experience (what does medication x do to my body?); expertise and authority, variously attributed (cf. what a List member called “the loudest voices in this forum”), the use and abandonment of information; the politics of science (cf. Gottweis, 1998); and the force of hope, described above.

While the cyberbody affects and effects people, it does not homogenize experience. In fact, what here is called a cyberbody is an extremely fragile momentary state of truth, because new knowledge can always alter the former consensus. Common refrains in postings of List members are that PD is heterogeneous and that the value of ‘the meds’ depends on each person’s specific phenotype. Nevertheless, the evaluation and conceptualization of symptoms and effects are negotiated in threads of discussion through warnings, disagreements and recommendations. What is at stake in the collective cybergroup is not only the way scientific/popular knowledge circulates and is evaluated and integrated into everyday practices by its members (cf. Wyatt et al., 2005), but also the shared experience of medication-taking. The exchange of experiential, embodied knowledge often leads to the question of normality:

His medication during the first few years was primarily sinemat; however, during the last 2 years or so, the doctor has prescribed entacapone (comptan) to reduce the down time. Since then,

symptoms of aggressive behavior, paranoia and hallucinations have profoundly increased. Is this common? What are the alternative treatments? (woman caregiver)

This attention paid to the negative effects, as well as the positive effects, of PD medications is salient because many medications used for this disease have numerous and serious side effects. The Parkinson Society Canada's website (accessed April 2006), for example, describes the most common side effects as dyskinesia, hallucinations, nausea, anxiety and insomnia. List members can read what these medications do to others on the List and compare those experiences with their own:

With my very first dose of Sinemet in 2000 I was "ON", but it never helped again even though I took it for a year CR 4x daily 50/200. I think it was a blue pill. I don't take it at all. Nothing happened when I quit. I tried regular Sinemet and Stalevo after my DBS surgeries in 2003 and neither helped. Stalevo made me nauseated. I know they really help some people, but I think PD meds are very problematic" (woman with PD).

Didn't realize at first, but the Mirapex was causing me to be sleepy all the time, and even more depressed. I finally figured out that myself didn't like this drug, and the doc switched me over to Requip. This made a dramatic difference for me (man with PD).

At the time of the research (2005-2006), neither the Canadian nor US American Parkinson Society website listed the side effect of pathological gambling (but see Dodd et al., 2005). However, members of the List alerted others to that side effect's devastating consequences:

I was treated with Sinemet along with Mirapex, which caused devastating effects on me and my family. We were not informed and did not realize that this medication could cause a gambling behavior, which I was not able to control. This was replaced by Tasmart and Comtan, which made matters just as bad, if not worse. (man with PD)

Furthermore, the medications' side effects may include the development of bodily sensations that otherwise might have been attributed to personality or questions of morality, as in this example:

Someone from the X list had developed the need to gamble, but also homosexual desires (without being inclined to this before); all this while taking Requip. His wife wanted to divorce him; they had to mortgage their house. (woman caregiver)

It would be too easy to conclude that hopeful practices veil, while practices related to embodied molecules reveal. Both vectors interact constantly in a mutual parasitism, following Moreira and Palladino (2005)—a struggle that is grounded in the experiencing body. The following quote from a Canadian caregiver shows the battle of finding the right treatment for a heterogeneous disease like Parkinson's and the "calm after the storm" (the title of her article) experienced through information gathering within a network:

...Because Parkinson's affects every person differently, it was even hard to share experience with others who shared E's diagnosis. Some have tremor, others don't. Some feel like their legs are encased in cement blocks, others still go golfing.... Every

new medication he tried carried its own side-effects, some of which were worse than the symptoms. We were constantly bombarded with questions and decisions... Our faith in God, the prayers and emotional support of our family, our church and our friends, and contact with the Parkinson Foundation in Ontario formed the eye of the tornado... I finally reached the right specialists and learned to ask the right questions. I devoured any information available through books, magazines and the Internet. I developed a team of health care workers and tried to keep them informed as to what was going on... Now we have learned to recognize the subtle and not so subtle manifestations of this new intrusion into our lives... E. is slowly learning how to live in this new body... (Toews, 2002).

Conclusion

This article adds an often overlooked dimension to studies of Internet-based patient groups. Distinct from studies in the sociology of expectation and related fields, (Brown, 2003; 2005; Brown and Michael, 2003) I have put hope, rather than expectations, at the center of my analysis. This is because hope, as Vincent Crapanzano (2004: 98; emphasis added) argues, is “a category of *both* experience and analysis.” Or, following Hirokazu Miyazaki (2004), hope refers to both a method and the politics of self-knowledge. Emphasizing the interconnectedness of these two levels—a methodological framework and the culturally situated (‘learned’) material *effect* of medications on hopeful individual’s bodies—is not opposed to a sociology of expectations, but rather complementary to it.

This article also extends the now common notion that the success of patient groups is based on political activism in combination with knowledge gathering. Here, the very first instance of evaluation is located in the body, as the primary ground of experiencing and defining the world. The use of the term ‘embodied molecules’ calls attention to the hitherto-ignored material aspect of expertise. As I have shown, lay and professional expertise are often intermingled, and in this e-mail list have lost their traditional positions in a hierarchy. The experiential evaluation of medications can be purely individual, but this is the exception rather than the rule. The momentary certainty of taking the right combination or dose of the right drugs arrives through a process of biolearning, of socially-situated, embodied learning. This is comparable to learning to like the effect of marijuana: “The taste for such experience [of marijuana smoking] is a socially acquired one, not different in kind from acquired tastes for oysters or dry martinis”, writes Becker (1991:53).

The concept of a cyberbody would be misleading if the cyberbody was assumed to be as fixed in time and space. It would also be misleading if a collectivity was assumed to be a ‘gray mass’ of people. List members do not leave behind their individualities when they identify with other people on the List (“we Parkies”), nor do they eschew their individualities when experiencing together with other members the effects of medications. While collective learning alters individual perceptions and even concrete individual effects of medications (sometimes called placebo), people maintain ‘what they are’ and their multifacetedness. To take a very general example, men and women evaluate and experience the symptoms of PD differently (Solimeo, 2008); for

instance, (gendered) role continuity shaped symptom experience. This kind of difference creates permanent tensions in every achieved consensus regarding experiences of drug effects and side-effects.

Standardization studies might be strengthened through extending the ambit of their analysis to include emotions such as hope, and effects based on biolearning (the cyberbody). This is true even when the objective of standardization studies is the examination of authority. As Brown and Michael (2002, 259) write, there “are emerging conventions by which ‘suffering’”, or the demonstration of emotion, “evokes ‘authenticity’ in the effort to reach a decision (or assess a risk) and that this ‘authenticity’ is replacing ‘authority’ as the means by which a decision (or risk assessment) is rhetorically warranted.” If Brown and Michael are correct, the *experiencing* (and suffering) bodies and cyberbodies of PD List members are part of this new authority that is based on ‘authenticity.’

Daemmerich, quoted in the introduction to this article, claimed that the authority for standardization is increasingly found in smaller and tighter networks. This kind of authority is not immune to ‘hopeful facts’; particular facts become scientific reality in part because researchers, health professionals and policy makers rarely experience, in a medication-in-body sense, the implications of scientific reality they assert. In the case of Parkinson’s disease, disasters related to pathological gambling, and divorces due to unwanted homosexuality, might have been avoided if the patient’s body had been taken more seriously; in other words, these life difficulties might have been averted if the standardization of such medications had taken another road to success.

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Notes

- ¹ Social scientists, writing about Internet communities, often split into two camps: those who ascribe empowering forces to this medium (e.g., through destigmatization when communicating through the Internet for otherwise stigmatized groups), and those who warn against the negative effects of disembodied relationships, social isolation and “thinned selves” (Willson, 2001) that result when the Internet communications replace ‘real’ social relationships.
- ² Ian Hacking elucidates how the vector, as a concept used in both mechanics and epidemiology, is a metaphor for “a force acting in a direction. When there are several forces acting in different directions”—as is happening constantly on Internet lists—“the

resultant force is the product of the different forces and their directions” (1998: 81).

- ³ In an article recounting how pharmaceutical concerns influence self-help groups, Keller describes several tactics of how these enterprises influence group members to positively evaluate drugs (2005). One reason for these enterprises’ attention paid to self-help groups is that self-help groups may recommend medications on their websites and other printed material, while pharmaceutical enterprises, in many countries, cannot advertise their products directly to the consumer. Examples of mechanisms of influence specific to self-help groups include: selective financing (sometimes only key positions, but never groups eschewing medications); financing and directing publications; sponsoring online and in person group meetings; infiltrating discussion forums with fictive caregivers; and directing the conversation towards a certain drug.
- ⁴ DBS consists of two interventions. In the first intervention, a neurostimulator is inserted into the brain. Surgery is performed through a hole in the skull and the patient is awake during the surgery. In a second surgery, a kind of pacemaker is positioned under the skin (over the patient’s chest). Some weeks after the interventions the “pacemaker” is turned on and its electronic signals are tuned according to the patient’s needs (see NINDS/NIH, 2006).
- ⁵ All the following quotes describe a person from the PD list in question by using qualifiers such as “woman with PD” or “woman caregiver”. Further descriptions are avoided in order to guarantee anonymity.
- ⁶ Resistance is not a characteristic of all Internet lists based on biosociality.

In the case of a French breast cancer group studied by Akrich and Méadel (2002), biomedical knowledge is not challenged by the List members. The authors attribute this to the French medical system, in which professionals often determine the therapeutic strategies without involving the patients.

- ⁷ We discuss the aspect of hope and religion in the introduction to Leibing and Tournay (forthcoming), and show how different thinkers try to split off the utopian part of hope (sometimes called optimism, as in the case of Barack Obama), in order to reach a pure state of hope-without-doubt, just as in many religions hope means faith (e.g., the coming of the Messiah), and doubt means lack of faith.

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