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"Think positively":
Parkinson's disease, biomedicine, and hope in contemporary Germany

Ingrid Metzler, Paul Just

Narratives of hope shape contemporary engagements with Parkinson's disease. On the one hand, a "biomedical narrative of hope" promises that biomedical research will help to transform this treatable but incurable disease into a curable one in the future. On the other hand, a more individual "illness narrative of hope" encourages patients to influence the course of Parkinson's disease by practicing self-care and positive thinking. This article asks how these two narratives of hope interact. It bases its argument on an analysis of data from 13 focus groups conducted in Germany in 2012 and 2014 with patients with Parkinson's disease and their relatives. Participants were asked to have their say on clinical trials for advanced therapies for Parkinson's disease and, while doing so, envisioned their biosocial selves in the present and the future. Three "modes of being" for patients were drawn from this body of data: a "users on stand-by" mode, an "unengaged" mode, and an "experimental pioneers" mode. Both narratives of hope were important to all three modes, yet they were mobilized at different frequencies and also had different statuses. While the biomedical narrative of hope was deemed an important "dream of the future" that participants passively supported without having to make it their own, the illness narrative of hope was a truth discourse that took an imperative form: having Parkinson's disease implied the need to maintain a positive attitude.

Key words: Parkinson's disease, biomedicine, clinical trials, hope, Germany

In this article, we engage with the work that hope performs in the contemporary ordering of Parkinson's disease. We base our argument on data from 13 focus group discussions conducted in 2012 and 2014 in Germany with patients diagnosed with Parkinson's disease. We explored the ways in which participants assembled elements of two distinct narratives of hope—a "biomedical narrative of hope" and an "illness narrative of hope"— when they were asked to share their opinions about clinical trials for advanced therapies and, while doing so, envisioned their biosocial selves in the present and the future. The "biomedical narrative of hope" relates to the expectation that biomedical research will contribute to making Parkinson's disease curable in the future. The "illness narrative of hope" involves

the understanding that individual patients can act on their Parkinson’s disease by practicing self-care and positive thinking. Both narratives are described – and at times prescribed or criticized – by two bodies of scholarly work. With notable exceptions (e.g., Brown, 2005), however, these two bodies are often unrelated. In this article, we wish to bring them into conversation, basing our argument on an analysis of the reasoning of patients with Parkinson’s disease in Germany.

Below we say more about Parkinson’s disease, situate the two narratives of hope in the scholarly bodies of work engaging with them, and discuss our methods. Subsequently turning to the results, we first discuss the three “modes of being patients”, i.e. the ways in which patients envisioned their biosocial selves in the present and the future in relation to biomedicine, which we distilled from the body of data: a first mode as “users on standby”, a second mode as “unengaged” patients, and a third mode as “experimental pioneers”. We show that elements of the two narratives of hope were assembled differently in each of these modes, and we argue that these modes were associated with age and also tied to different understandings of the “objectivity” and disease course of Parkinson’s disease, as well as to patients’ understandings of their “subjectivity” and agency in light of these. Second, we also explore how these modes of being entered into conversation and conflict, discussing the status of the two narratives of hope. We argue that the biomedical narrative of hope was passively shared by all participants but that it did not need to be actively appropriated as one’s own. The illness narrative of hope had the status of an imperative “truth discourse” (Prainsack, 2006) that participants had to make into their own. In the conclusion, we discuss the implications of our findings and suggest that the ways in which different narratives of hope are shared and appropriated also need to be contextualized in socio-political cultures that make some narratives of hope more meaningful than others.

Background

Parkinson’s disease

Parkinson’s disease is a progressively degenerative disease believed to be caused by a loss of brain cells that are responsible for the production of dopamine. First reported by James Parkinson in 1817, biomedical professionals describe this condition as “highly variable” (Bostuma et al., 2016: 546). It is characterized by a number of “motor symptoms”, such as tremors, stiffness of the limbs, or a slowness of movement, and “non-motor symptoms”, such as fatigue, constipation, or depression.

Medications can mitigate Parkinson’s disease symptoms for a while, chemically replacing the substances that afflicted bodies can no longer produce on their own. However, they cannot reverse the underlying process of cell degeneration. Eventually, usually after

a decade, medications cease functioning or begin to produce serious side effects. At this stage, advanced therapies such as deep brain stimulation can relieve some motor symptoms. Pioneered in the 1990s, this now-established therapy involves so-called stereotactic surgeries in which surgeons implant a "brain pacemaker" into the brains of patients, who are awake during these procedures (Gardner, 2013). Hence, Parkinson's disease is a chronic disease that tends to worsen over time. Some of its symptoms can be treated with medication. But, as of today, Parkinson's disease is not curable.

There is, however, hope that ongoing biomedical research can contribute to making Parkinson's disease curable in the future. Over the past decade, such hope has been invested in particular in "regenerative medicine". This research field involves stem cells derived from various sources, such as from aborted fetuses (since the 1980s), from surplus in vitro fertilization embryos, or—most recently—from somatic cells "induced" to behave like "pluripotent" stem cells. The latter, so the expectation goes, could be prepared in laboratories and eventually be implanted in patients' brains to replace the degenerated cells (Barker, 2014), thereby curing the disease rather than merely treating its symptoms.

Hope in biomedicine

With the promissory expectation that ongoing biomedical research will lead to cures in the future, Parkinson's disease is also an instance of a broader trend in biomedical innovation regimes: the flourishing of a language of hope around biomedical innovation projects.

Since the late 1990s, a steadily growing body of scholarship has observed — and at times criticized — the emergence of future-oriented "discourses" (Brown et al., 2000) or "regimes of hope" (Brown, 2005; Moreira and Palladino, 2005) that accompany biomedical innovation projects. Partly institutionalized as a "sociology of expectations", this body of scholarship studies the ways in which a language of hope and the expectations and practices of promising help to gather support in particular for more controversial innovation projects (Brown et al., 2000; Martin et al., 2008), engaging with what we refer to as a "biomedical narrative of hope": the expectation that investments in biomedical research will help make conditions curable.

Patients play a prominent role in this biomedical narrative of hope. At times, they are passively implicated by biomedical professionals or policy makers as those waiting hopefully – or desperately – for biomedical breakthroughs (Brekke and Sirnes, 2011; Moreira and Palladino, 2005). Other studies describe patients as actively contributing to this narrative of hope, joining forces with biomedical professionals and/or pharmaceutical companies in "political economies of hope" (Novas, 2007; Rose, 2006) or investing their bodies into this regime of hope (Brown, 2005). Some patients have also been observed to mobilize their afflicted bodies on public stages, so as to make claims for more financial support for innovative projects or for reduced legislative hurdles on them (Gottweis, 2012;

Rose and Novas, 2005). Parkinson’s disease is a case in point for patients as co-authors of the biomedical narrative of hope. For instance, former actor and patient with Parkinson’s disease Michael J. Fox became a prominent voice in the controversies about human embryonic stem cell research in the United States (Gottweis, 2012). He engaged in US electoral politics, seeking to convince his fellow citizens to cast their vote for a candidate “who shares my hope for cures” (quoted in Gottweis, 2012: 21).

Importantly, however, the biomedical narrative of hope is not the only narrative of hope in which Parkinson’s disease is entangled, nor is the “sociology of expectation” the only body of scholarly work engaging with the work that hope performs in the contemporary ordering of health and illness. Since the 1970s, a more applied scholarship has regarded hope and optimism as emotions, affects, or positive attitudes that can contribute to a patient’s recovery from a condition or coping with a chronic condition (cf. Petersen and Wilkinson, 2015; Petersen 2015), describing and at times *pre*scribing what we here conceptualize as an “illness narrative of hope”. This involves the understanding that individual patients can act on their Parkinson’s disease by practicing self-care and positive thinking.

Similar to the biomedical narrative of hope, this illness narrative of hope is not limited to Parkinson’s disease. Rather, it has been observed to have a powerful presence, particularly in oncological care, where it emerged in the United States in the 1970s in the context of “positive psychology”, before it began to travel to other countries and to other conditions (Delvecchio Good et al., 1990; Brown, 2005).

With important exceptions, the two narratives of hope as well as the two bodies of work engaging with them tend to be separated by disciplinary boundaries. In terms of exceptions, Mary Joe Delvecchio Good and colleagues have linked the particular shape of disclosure practices in oncological care in the United States to what they call a “political economy of hope” (1990: 60). Intriguingly, they also situate this political economy of hope within what they discuss as a particular “cultural context”, arguing, for instance, that the expression of hope and modes of disclosure in American oncology are powerfully influenced by popular American notions of psyche and soma, by a deeply felt cultural conviction that individualized *will* can influence bodily processes. (1990: 75)

More recently, scholars have extended the critical tools elaborated for engagements with the biomedical narrative of hope to shed new light on the illness narrative of hope. For instance, in his book, Alan Petersen (2015) ties the emergence of hope in health to a general “socio-politics of optimism”, as well as to neoliberal policies that see health “as a responsibility of citizenship”, subjecting it “to commodification” (Petersen, 2015: 216). In a related work, Nik Brown (2015) traces the emergence of “hope scales” in oncological research and links this to a “biopolitical culture of affect” and “modes of self-management”.

He notes that emotions are put to "work in the production of an affective mode of morality and a personal ethics of probity and conduct at times of illness." (Brown, 2015: 121)

Partly building on this work, we wish to bring the two bodies of work into conversation, basing our argument on an empirical analysis of the ways in which patients assembled elements of these distinct narratives of hope in practice.

Methods

We base our argument on an analysis of data from 13 focus groups. The focus groups were conducted in 2012 and 2014 at two German biomedical centers that specialize in Parkinson's disease and that were gearing up for two clinical trials. Both the 2012 and 2014 studies were approved by the ethics committees of the hospitals in which patients were recruited. All participants gave informed consent to participate in this study. They were patients with Parkinson's disease or relatives or friends of the patients. A total of 102 individuals participated in the focus groups: 68 were patients (40 male, 28 female); 34 individuals did not have a diagnosis of Parkinson's disease (9 male, 25 female). (See Table 1 for details.) Participants were recruited with the help of biomedical professionals.

Focus group	Number of participants with Parkinson's disease		Number of participants without Parkinson's disease		Total number of participants	Age range	Average age
	male	female	male	female			
FG1	6	0	0	4	10	46-78	73,3
FG2	4	0	0	3	7	69-81	74,4
FG3	3	3	2	2	10	54-72	63,4
FG4	4	1	0	4	9	52-75	67
FG5	4	2	1	3	10	62-88	74,4
FG6	3	3	1	1	8	51-79	68,2
FG7	2	3	1	2	8	55-77	66,4
FG8	3	1	1	0	5	68-78	73,4
FG9	1	4	0	0	5	67-84	75
FG10	4	1	1	4	10	55-77	65
FG11	0	3	0	2	5	47-77	68,4
FG12	0	5	0	0	5	41-69	56
FG13	2	6	0	2	10	61-84	70,9

Table 1: *Table summarizing demographic details of focus group participants. Focus groups 1 to 6 were conducted in the North of Germany in 2014; Focus groups 7-13 were conducted in the South of Germany in 2012.*

Based on the same script, the focus groups were originally designed to provide people affected by Parkinson’s disease with a space within which understandings about two clinical trials about to begin at the two biomedical centers could be shared. These should help social scientists provide empirically grounded advice on the ethical governance of these studies.

The two clinical trials were funded by the European Union’s 7th framework program; both trials involved brain surgery. One trial involved transplanting cells from aborted fetuses into the brains of patients (Abbott, 2014). The other trial involved implanting a pump into patients’ bodies to regularly deliver doses of growth factors into the brain via a conduit. Hence, both trials sought to channel the hope that particular agents — fetal cells or growth factors— would help revitalize dopamine-producing cells, from the bench to the bedside, via the organizational form of clinical trials.

In the focus group discussions, the moderators informed participants about the details of the two “therapies in the making” and contrasted them with therapies already available, i.e. medications and deep-brain stimulation. Subsequently, they asked participants to share their thoughts. A number of participants were keenly interested in these clinical trials. They stated their eagerness to learn more about the “therapies that might arrive in the future” (Herbert, patient, 51 years, in focus group 6—all names are fictional). A consistent number of participants, however, seemed uneasy expressing an opinion about what Astrid, the wife of a patient, dismissed as “far-fetched” (focus group 6). Many participants seemed to find it easier to talk about therapies available in the present rather than future therapies. Diverging from the focus group scripts, they talked about their hope that current medication regimens will continue to work for a while, about the ways in which sports or dancing helped patients “to get a grip on” Parkinson’s disease, as well as about their hope that their effort to “accept” the condition and to “think positively” might eventually mitigate the disease progression. Intrigued by this phenomenon, we wished to understand it better.

We therefore decided to break away from the initial research questions and instead begin a secondary analysis of the data. We approached the focus groups with a constructivist methodology (Kitzinger 1994; Wilkinson, 2011) and analyzed the material following the major tenets of a constructivist grounded theory approach (Charmaz, 2006). Initially, we coded five focus groups extensively, inductively extracting salient themes and issues from the discussion. Subsequently, we switched to a more selective strategy, focusing on “temporal narratives” (Felt et al., 2014) through focused coding, and on the ways in which patients’ understanding of the disease course and the temporality of biomedical research were assembled through axial coding (Charmaz, 2006). We drew positional maps to further support our data interpretation (Clarke, 2005).

In coding the data, we privileged the voices of patients, i.e. those directly affected by Parkinson's disease, over the statements of participants who accompanied them to the focus groups. We followed the constructivist understanding that while focus groups "do not reliably tell us what individuals think or feel" (Hollander, 2004: 628) they can nonetheless help us develop an understanding of "what people say in particular social contexts" (Hollander, 2004: 628). We coded the data in German and later translated excerpts into English. We extracted three "modes of being" through this analysis. We use "modes of being" as a descriptive term, defining it as the ways in which participants situate their biosocial selves in relation to Parkinson's disease and biomedical research. In line with our constructivist understanding of focus group data, our units of analysis were not individual opinions, nor full-blown identities. Distilling "modes of being", we wished to engage with crystallizations of what patients feel they can say meaningfully when they are asked their opinions in the semi-public of focus groups.

Limitations

Reading the data through the prism of how participants placed their biosocial selves in relation to invasive clinical trials in our analysis, we have neglected a number of meaningful differences within these modes of being, such as how gender or the civil statuses shaped participants' understanding of their biosocial selves.

Additional limitations pertain to the original design of the study. First, the focus groups were conducted with participants directly or indirectly affected by Parkinson's disease who were recruited with the help of biomedical professionals. We do not claim that findings from this data can be readily extended to other conditions. Second, the very nature of the advanced therapies discussed in the focus groups is relevant. Both involved brain surgeries, which was a matter of concern to many participants. Participants might have been more willing to make the biomedical narrative of hope into their own if this involved, say, medications, and not operating rooms. Last but not least, the focus groups were conducted in two cities in Germany and hence in a nation that, among others, provides universal access to biomedical therapies and care to patients with Parkinson's disease. While many participants shared complaints about specific care provided by specific doctors, none of the participants criticized the German health care system. They encouraged others to change doctors, but not to challenge the health care system. Participants silently took for granted the reasonability of that system's norms and – as we show below – also partly made them into their own.

Results

Mode 1: Patients as “users on stand-by”

A first mode of being patients was articulated by a number of participants who tended to be between the ages of forty and sixty-five. Other participants referred to them as the “young” or “younger ones”. Some of these were well informed about ongoing biomedical research. They added information to the introductions provided by the moderators. Being attentive to therapies that “might arrive in the future”, it seems, belonged to their mode of being patients.

The biomedical narrative of hope was important to their lives. Many of these participants emphasized that an awareness of the existence of biomedical research enabled them to see potential therapies arriving in the future. However, they did not envision themselves as active protagonists of this narrative. Instead, they deferred their active subscription to this narrative to a conditional future, when, first, their Parkinson’s disease might have advanced to the point that it was causing them to spiral down and, second, when research on these advanced therapies might have advanced further and more evidence on these therapies would be available. For the time being, they saw themselves as attentive yet passive spectators of the biomedical narrative of hope. This is why we refer to them as “users on stand-by”: ready to use such approaches as established therapies in an undesired future.

The time that had elapsed between their Parkinson’s disease diagnosis and the time of the focus groups ranged from two years to approximately ten years. Most of the participants articulating this first mode had been on medication regimes since their diagnoses, and many noted that they “coped with this [situation] pretty well” or felt “well regulated”. They emphasized their uncertainty about how long this relative well-being would last. For the time being, however, this was given as a reason for not wishing to participate in clinical trials for advanced therapies. For instance, Michael, a 46-year-old patient, shared the following thoughts:

> *Michael (male patient, 46 years): I appreciate research. But at the moment …*
>
> *Hannah (female relative, 73 years): This [advanced therapy with growth factors] has not yet been sufficiently studied.*
>
> *Michael (male patient, 46 years): At the moment, [this is] not for me, but if it is necessary (focus group 1)*

Like many other participants, Michael was dissuaded by the fact that both clinical trials required undergoing brain surgery. Nonetheless, most of the patients articulating

this first mode of being did not exclude that they might eventually use such advanced therapies in a conditional future, namely if their Parkinson's disease worsened drastically and if research on such advanced therapies had by then progressed. Recognizing the possibility of such a future without desiring it, they said that in that case they might then make use of advanced therapies, consuming and using them as established therapies. However, these experimental advanced therapies were imagined as entailing "grasping at straws" or "last resorts" in an undesirable future; or in the words of Michael,

> *Well, as long as I cope [with medications], I would not do this. But if things get dramatically worse, I would take this into consideration (…).*

And he added:

> *I would also inform myself on the state of the art. I would not act on the basis of a mere smokescreen. (focus group 1)*

In the meantime, biomedical research was not the only source of hope for these "users on stand-by". They hoped that they could contribute to getting "a grip on Parkinson's disease" through other things that can – or could – be done in the meantime: such as tinkering with medication dosages and timing to optimize their performance, undertaking regular physical activity, using complementary medicine, participating in self-help groups, and, not least, accepting their condition and maintaining a positive attitude. This was not always easy, as aforementioned Michael (PD patient, 46 years, in focus group 1) explained. Recalling his shock when he was diagnosed with Parkinson's disease at the age of 45, he explained that

> *in the first six months, it was not easy, of course, I could not stand many people around me. But now (...), I am open about it. [I try] to make the best out of it — anyway, there is no other choice.*

A particular understanding of what Parkinson's disease is as a condition as well as a patient's speculation about how it might develop in the future seemed to provide fertile ground for the elements of the illness narrative of hope. Many participants maintained that they were well aware that Parkinson's disease progresses in stages, and that after the first period, in which symptoms can be kept under control with medications, Parkinson's disease might progress and medications might trigger side effects. And, yet, importantly, neither the temporality of the disease progression nor the severity of it seems to be preprogrammed. For instance, Helga, wife of a patient, noted that she found it "comforting" to know that current research might bring more therapeutic strategies in the future, so she could "keep in mind [that] there is still something if it really goes from bad to worse" (focus group 2). Yet, her husband, Friedrich, a 72-year-old patient, added:

Friedrich (patient, 72 years). Well, I hope that it will not be that bad.

Helga (relative, 71 years): That it will not be “that bad”, right.

Horst (patient, 72 years): This is what we all hope, don’t we? (focus group 2)

Hence, in this first mode of being patients, Parkinson’s disease was a terrible condition expected to become worse. And, yet, these participants did not frame Parkinson’s disease as stabilized by a predetermined trajectory, nor did they conceptualize themselves as passive victims without agency. Similar to the subjects that Ulrike Felt and colleagues described in a study on the temporality of obesity, patients articulating this first mode “personalized” the Parkinson’s disease course (Felt et al. 2014, 654–655). In so doing, participants referred to the plethora of symptoms and to the “many faces” of Parkinson’s disease. The ambiguity, uncertainty and unpredictability of the conditions were transformed from a matter of concern into a fertile ground for the illness narrative of hope. In their understandings of themselves in relation to the Parkinson’s disease trajectory, the future was one that was uncertain and therefore able to be influenced and acted on by practicing self-care and positive thinking.

Mode 2: Unengaged patients

A second mode of being patients was articulated by a number of participants who tended to be over the age of 70. All of them had lived with Parkinson’s disease for a while, some of them for a couple of years and others for more than a decade. They were at different stages of the disease course. However, they all tended to conceptualize themselves as “too old” to contribute to or benefit from incipient biomedical research.

Similar to participants articulating elements of mode 1, these “older” participants conceptualized the planned clinical trials as incipient materializations of what might eventually become established therapies. Yet, they did not expect this to happen during their lifetime. The research possibilities were framed as “dreams of the future” (Angelika, patient, 67 years, in focus group 9). They thought that such research was important and ought to be done; however, it was not for them but for the “younger ones” or for the “next generation”. Hence, they neither saw themselves as protagonists of the biomedical narrative of hope nor did they envision themselves as its target audience. Being less attentive to the biomedical narrative of hope from which they did not expect to be able to benefit as eventual users nor to contribute as producers, they articulated an “unengaged” mode. In their modes of being patients, biomedicine was present in terms of daily medications. But biomedical research in the making was a fairly remote reality.

When it came to envisioning themselves in relation to these ongoing clinical trials, participants referred to the risks entailed in brain surgeries, often supporting their concerns with anecdotes about other patients. Moreover, they cited their age as the reason they did not wish to participate in clinical trials in either the present or the future. For instance, in focus group 9, Walter, a 82-year-old patient, explained:

> *Well, I would give it a good deal of thought [before participating in a clinical trial], because I am coming closer to the end of my life, right? It is not the case that I can say, "I still have 20 years to look ahead to", right? I am not Heesters [a German actor famous for his age], who became 108 years old or so.*
> *(focus group 9)*

"Age" was not merely referred to in "subjective" terms – i.e. in terms of "feeling too old" to participate; some participants also noted that they would not be eligible for surgeries in any case and would be excluded from these clinical trials. Remarkably, however, this presumed lack of entitlement—at the time of the focus groups, the enrollment criteria of the two clinical studies had not been defined—was not referred to as a "matter of concern". Instead of unpacking or questioning this, participants referred to this as a matter of fact that they incorporated into their own moral reasoning: they could not participate.

The ways in which they envisioned their biosocial selves in both the present and the future were enmeshed with their understanding of their limited life expectancy. Moreover, a number of participants also noted that at an advanced age, Parkinson's disease ceased to be the only health condition one was coping with. Other conditions and physical symptoms added to it, at times making it difficult to differentiate between which condition was causing what symptom.

> *Stefan (patient, 76 years): Of course there is one thing that we should not forget, we are all getting older and (…) at the age of 70, the body does no longer function as it did at the age of 30 and I hold the opinion that Parkinson's cannot be blamed for all of these complaints.*
>
> *Interviewer: I see, so you think it is incorrect to solely blame Parkinson's for your health concerns?*
>
> *René (patient, 73 years): It is not always [due to] Parkinson's.*
>
> *Timon (patient, 65 years): You cannot discern "is this due to Parkinson's or to another thing". As in my case, I, I had two surgeries, now I have pain in my back. Is this a result of Parkinson's or something else? I cannot gauge this.*
>
> *René: How would you feel without Parkinson's?*

(Several participants speak at once.)

Timon: If we did not have Parkinson’s, we would have other complaints, this is how it is, and as said, with increasing age, other complaints arise.

Stefan: Yes, we just all get too old. (focus group 13)

Hence, in this mode of being, Parkinson’s disease, and its symptoms were entangled with the side effects of medications, symptoms of other conditions, and signs of an aging body. Ultimately, the patients expressed that they no longer merely viewed their bodies as ill-functioning *because* of Parkinson’s disease, but they saw their health complications instead as “signs” of bodies that were aging and about to reach their end. Thoughts about the “disease course” were not absent; yet, they were enmeshed with thoughts about their “life course”, which relativized the prominence of Parkinson’s disease in their ways of thinking about their biosocial selves.

Underlining that the biomedical narrative of hope might be important for others, but not for them, did not mean that participants articulating this mode were desperate. In contrast, interestingly and tellingly, these participants tended to change the subject, shifting discussions on clinical trials for advanced therapies to “the many other things that can be done”, such as sports. For instance, 78-old Peter, who had Parkinson’s disease for 12 years, interrupted a discussion about brain surgeries:

The best thing is a lot of sports, a lot of movement. This is mitigating, as then you can grow old with [Parkinson’s disease]. (focus group 1)

Hence, they shared many of the elements of the illness narrative of hope with participants who articulated mode 1 and underlined the variety of social and physical activities they pursued. Many of these patients had learned to live with Parkinson’s disease, appreciating the things they were still able to do. For instance, Thomas, a 77-year-old patient, highlighted that there were still a number of things he could do on his own, and that others helped him with those things his ailing body did not allow him to do. Far from being desperate, Thomas felt that he did not wish to put this at risk.

Mode 3: Patients as “experimental pioneers”

A third mode of being was articulated by just one participant. Gisela, a 41-year-old woman, supported experimental research for advanced therapies in theory and in practice. She made the biomedical narrative of hope into her own, framing the possibility of contributing to biomedical research on Parkinson’s disease as an “experimental pioneer” as the only way to regain the moral agency that Parkinson’s disease had wrested from her.

Gisela had been diagnosed with Parkinson's disease at the age of 40. She immediately knew that she did not want to take the path of established therapies, recalling that she told herself, "[if] you do this now, that's wrong, because then my father's history repeats itself." Unlike many other participants, who were often uninformed about Parkinson's disease until they were diagnosed with it, Gisela knew the condition all too well because her father had been diagnosed with it at her age and had already passed away. Now her father's destiny was about to repeat itself, consuming her body and life. Thus, unlike other participants, Gisela did not see Parkinson's disease as an ambiguous condition with an unpredictable future. In light of her family history, she saw it as a distinct disease with a predictable future, and she saw herself as the passive victim captive to this disease trajectory. Transforming the biomedical narrative of hope into a script for her life, and subjecting herself to untested, yet promising therapies, was her way to regain moral agency.

Determined not to repeat what happened with her father, Gisela reported that she began to "look for alternatives". She found comfort in a biomedical professional who helped her "participate in a study" that "tests a new drug, which is said to regrow cells in the brain" (focus group 12). Questioned by other participants, who thought that it might have been better if she had waited for more evidence on this experimental research, she noted that there was no point in continuing to "bear up" until more evidence arrived. Notably, Gisela was also not deterred from responding as an "experimental pioneer" when the moderator asked participants what they thought about "sham surgeries" in clinical trials. At that point, participants, including the more silent ones, unanimously exclaimed that they would not allow others to "drill a smallish hole in [their] brain" for nothing, particularly since doing so put their current therapeutic regimen at risk. Yet, for Gisela, participation in research was not pointless, even if she might not gain personally. "In our case," she explained, "Parkinson's runs in the family — my dad had it, and I have two children, my sister has two children. I would also take this [risk of ending up in a placebo group] if it serves research" (focus group 12).

Hence, in this third of mode of being patients, Parkinson's disease was imagined as a coherent condition in the present with an inevitable future – there was neither an acceptable future with Parkinson's disease nor any agency in the present in light of this unbearable future. There was no point in investing hope in one's own disease course or in available therapies. For this participant, biomedical experiments promising to heal Parkinson's disease altogether were the only space to invest one's hope in a situation otherwise full of despair. This was the only way to regain agency, helping to transform what seemed a terrible family destiny into future past history.

Dynamics between the three modes

Elements of mode 1 — the “users on stand-by” — and mode 2 — the “unengaged” one — were uttered more frequently than mode 3 as “experimental pioneer”, which was articulated by only one participant. In the focus groups, modes 1 and 2 also proved to be more legitimate.

While participants articulating either mode 1 or mode 2 had different attitudes toward the biomedical narrative of hope, they tended to peacefully co-exist. Indeed, they shared a common ground. By framing Parkinson’s disease as uncertain and by letting power and agency rest with the patients, they shared elements constitutive of the illness narrative of hope. The understanding that Parkinson’s disease was amenable to be acted on through practices of self-care and positive thinking was their common ground. This became visible in particular when Gisela, the participant articulating mode 3, disrupted the shared common ground. Her way of envisioning herself as an “experimental pioneer” was the exception that helped make the norm visible.

Gisela was allowed to speak for a long time in the focus group she was in. Other participants noted that they could understand her way of reasoning, even though they thought differently. However, this supportive attitude disappeared at the very end of the focus group, when Gisela mentioned that she was also for “assisted suicide” for those cases in which Parkinson’s disease made patients bedridden and, as Gisela said, made their lives meaningless. At this point, other participants began to criticize her attitude. In particular, Heide, a 69-year-old patient in this focus group, told Gisela that she must not think that way. Other participants began to join forces with Heide, asking Gisela “how long” she had been living with Parkinson’s disease. Learning that Gisela had been diagnosed only six months before, Heide noted that that was “no time. Obviously, you haven’t gotten used to it.” When Gisela noted that her symptoms have become more severe during the six months, Heide explained, that this was “evident: if you have such a negative attitude, then it becomes way worse. [So] think positively”. Although conceding that this was more “easily said” – as other participants interjected – than done, Heide insisted that “it is the only thing that helps, I know this from my own experience, it is the only thing that helps.”

Hence, Gisela was a young patient in two ways: first, she was one of the few participants who had been diagnosed with Parkinson’s disease in their forties instead of at an older age. Secondly, she had been diagnosed only recently and not yet learnt to live with Parkinson’s disease, accepting the condition. She had not internalized the individual narrative of hope, disrupting the common ground of others.

Discussion and conclusion

In this article, we explore how patients assembled elements of distinct narrative of hope when they were asked their opinion of clinical trials for advanced therapies. We describe three modes of being patients — a mode of being as "users on stand by", a second one as "unengaged patients", and a third mode as "experimental pioneers". In all modes, hope carved out spaces of power and responsibility of human actors in shaping biology. Yet, how human agency and biology were understood in practice differed for each mode.

The uneven frequency of these modes showed that the biomedical narrative of hope and the illness narrative of hope each had a different status depending on the patient mode. The biomedical narrative of hope was deemed important and in need of passive or at least tacit support – if not yet (in the case of the first mode of "users on stand-by") or no longer (in the case of the second "unengaged" mode) for oneself than as a form of solidarity with other patients. However, with the exception of mode 3, this narrative was not actively endorsed. Instead, participants imagined themselves as more or less attentive passive audiences of a biomedical experiment to be performed by others.

The illness narrative of hope was more frequently invoked and retold. Many participants had made elements of this narrative into their own. During the interactions in one of the focus group discussions, it also became evident that this narrative took the form of a "truth discourse" (Prainsack, 2006). This illness narrative of hope was not amenable to be negotiated; the understanding that Parkinson's disease is more than a tragic destiny and instead is actionable through practices of self-care and positive thinking took an imperative form.

The illness narrative of hope also prepared the ground for circulation of the biomedical narrative of hope: a passive confidence that better therapies would eventually arrive made the adoption of positive attitudes in the present more feasible. Importantly, however, the salience of the illness narrative of hope also worked against an active subscription to the biomedical narrative of hope in the present. The biomedical narrative of hope was allowed to add to the illness narrative of hope, but it was not allowed to replace it.

Interestingly, hence, the ways in which participants envisioned their biosocial selves in the focus groups in Germany was not reminiscent of the subjectivities described in a consistent body of social science literature engaging with the biomedical narrative of hope. Most of participants' reasoning was more akin to those self-managing subjects envisioned in the literature on "once-hope" analyzed by Nik Brown (2015). Clearly, many of the participants subscribed to an understanding that they *had* to take care of themselves and that "there was no alternative" to seeking to keep a positive attitude. They felt that it was their duty to take care of themselves at the gym, and to refrain from desperately seeking salvation in the operation room.

What, then, do these findings imply beyond the particular focus groups? Let us start by emphasizing what we do *not* wish to identify as a takeaway of this study. We do *not* read our findings as taking the merits away from social science research that documents the salience of the biomedical narrative of hope for other (modes of being) patients. Clearly, there are various modes of being patients around the globe, and these modes co-exist. However, we *do* think that our study implies that all of these modes of being patients ought to be situated in relation to particular contexts, from which they should not be rashly extracted.

Here it is helpful to return to what we describe in the methods section as the limitations of this study. The very same elements can also help us understand how the particular configuration of hope described in this article became meaningful. First, the salience of the illness narrative of hope – and therewith – the belief in patients’ agency and responsibility was tied to an understanding of Parkinson’s disease as an elusive condition that was amenable to be influenced and acted upon. Hence, the work that hope performs in the ordering of conditions is tied to the ways in which the ontologies and disease courses are understood. Moreover, second, patients may well be more willing to embrace a narrative of hope that is materialized through medication such as a pill, which is perceived as less risky and less permanent, than a narrative materialized through brain surgery. And, yet, neither the first nor the second element alone can help us understand the prominence of the illness narrative and the difficult standing of the biomedical narrative of hope in the focus groups in Germany. As the case of Michael J. Fox illustrates, patients with Parkinson’s disease do fight for the very same kind of interventions that the patients in the focus groups found so troublesome in other contexts. This is why, third, we also believe that the location of the focus groups — or in more abstract terms: the cultural and political contexts of modes of being patients — matter.

In their path breaking study, Mary Delvecchio Good and colleagues (1990) interpret the “political economy of hope” in oncological care not so much as an instance of then-contemporary trends in biomedicine, but as an expression of US culture. It is certainly problematic to upscale findings from two biomedical centers *in* a nation to statements *on* a nation, but we think that Delvecchio Good and colleagues did raise an important point. In the absence of comparative data, that would help us to solidify this point, we tend to read our findings also as an expression of legitimate modes of being patients with Parkinson’s disease in the political culture of Germany. There is both evidence external to the focus groups as well as internal hints. By way of external evidence, Germany is well-known for its controversies related to biomedical technologies (Herrmann, 2009). But Germany is not well-known for individuals or groups of individuals who mobilize their bodies and biologies on public stages in order to call for more biomedical research or to make claims for rights on the basis of their biologies. The absence of contestations of the health care

system, which we note in the methods section, as well as the salience of "age" as a reasonable criterion that sets apart those who might be entitled to participate in a study from those who are not, provide some evidence from within the focus group discussions for the claim that patienthood in Germany tends to take a more "private" form of taking care of one's body and soul. The strong salience of the illness narrative of hope, in turn, might help us understand the stability of this political culture.

By situating our findings and by underlining the importance of the politico-cultural contexts of configurations of hope in biomedicine, we do not wish to say that our findings are unique to patients with Parkinson's disease in Germany, or that political-cultural contexts are forever set in stone. In contrast, the similarity of the reasoning of these patients to the visions of biomedical professionals in the field of oncology in the United States shows that hopes, narratives of hope, and practices of hope can and do travel. The strong salience of the illness narrative of hope in this body of material and the less prominent standing of the biomedical narrative of hope, however, also suggests that we cannot take it for granted that all narratives of hope travel, from condition to condition, from expert group to expert group, and from country to country. How they travel and what is lost—or gained—in translation is something we need to explore empirically. Following these configurations might also help us to develop a better understanding of those socio-political contexts that make particular narratives of hope both salient and meaningful.

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