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| Pateraki M. Tauhe multiple temporalities of deep brain stimulation (DBS) in Greece. Med Health Care Philos. 2019;22(3):353-62. | |
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| it places them in the position of beneficiaries of the Greek National Health Care System (ESY). In other words, they become enmeshed in a complex socio-technical-bureaucratic complex made up of health committees, hospital administrators, medical teams, and health equipment providers, all of whom condition the patients’ access to the technology. And, although they have been expecting an easy resumption of their lives, they often find themselves subjected to not linear but broken temporalities; they face an array of bureaucratic hurdles, only worsened by the financial crisis currently engulfing the ESY.  The financial crisis has weighed heavily on DBS implantation processes. Severe restrictions on healthcare spending have had two impacts on DBS procedures. Implantations are subjected to a more complicated bureaucratic process, in order to filter out any “unnecessary” costs, and even operations that are formally approved are subjected to the final decisions of the hospital administrators. The chronic shortage of equipment in public hospitals, results in an unnecessary waste of time. For example, an implantation procedure may be split into several surgical operations occurring over an interval that may last for days, weeks, or even months.  The hospital administrator assumes gatekeeper functions in decisions concerning the allocation of the hospital’s budget, often rejecting or delaying demands concerning DBS implantations.  For example Mr. Nikos’s implantation was performed in two stages, and during multiple hospitalizations, due to funding problems:  *I went in [to the hospital] in February and I did the first operation [the implantation of the leads] and they reopened my head a second time to do the connections. Because they told me that they couldn’t cover the whole expenditure at once… I went four or five times to the hospital because they did not have the materials, and each time I was hospitalized for two to five days, expecting to be implanted. (…) They told me that the device [the pulse generator] was too expensive... Finally, after a great deal of hardship, and after I was hospitalized five times, in May the device was installed and began to be operational (interview with Mr. Nikos, PD/DBS patient).*  Ms. Zoe, a 46-year-old woman, had to wait for over a year after the initial approval, until the director of the hospital processed and scheduled the intervention. She was finally hospitalized, and was prepared for the intervention. Her head was shaved, but then the staff realized they did not have the materials required. Finally, after a long week, Ms. Zoe was readmitted and the operation was performed. I met her in a big hospital in Athens, together with her husband Yannis, who acts as her caregiver. He explained:  *The operation was approved one year ago [2014], and the hospital wasn’t performing it for financial reasons, because it’s a costly operation. They [the hospital administration] preferred doing other things, they prioritize cheaper things. They left the others aside, not regarding how they affected patients’ lives. And then they did not have the proper materials and equipment in the surgery, while [my wife] had been shaven and anesthetized. Psychologically, this was madness (interview with Yannis, caregiver).*  Ms. Olga, a 64-year-old woman, also had to wait for over a year after the initial approval until she underwent the surgery; she claims that this delay subjected her to severe psychological stress, and that in her opinion, the operation “did not help.” If she could return to the past, she said, she wouldn’t do it again.  *I waited a very long time. One, one and a half years, and probably even more. I got the approval in August, and the procedure took place in April, almost two years later. Twelve, sixteen, eighteen,*  *almost twenty months. And during that time, I was getting worse. The results of this waiting caused me a great deal of harm (interview with Ms. Olga, PD/DBS patient).*  But in 2015, his second battery expired, and replacement procedures were delayed for 9 months. As Mr. Achilles claimed, his life deteriorated; trembling resumed again and he had to stop his courses of speech therapy and physiotherapy. The waiting time for battery replacement took a heavy toll on his health.  *All went well until 2015, when I started waiting for the battery. From then on, things went downhill. And I became a worse mess. See, now my hands are shaking; whereas before, they didn’t; they had stopped (interview with Mr. Achilles, PD/DBS patient).*  Ultimately, the quality of the patient’s care was downgraded. While initially the approval was granted for an improved rechargeable battery that included a recharging vest, in the end the hospital provided him with a standard battery. And not only that; after the replacement was made in 2016, his neurologist programmed the device to a very low setting, in order to extend the battery’s life.  Afterwards, many motor symptoms that DBS was supposed to improve returned, or even worsened. In this case, the results of the financial restrictions led to disability, partially undoing the technological effects.  But Ms. Martha faced an experience similar to that of Mr. Achilles; after her battery expired, she had to go to another hospital, different from the one where she initially underwent surgery, to follow her prescribing physician. There, the hospital administrator rejected her requests for battery replacement for a long time, due to the high cost of the replacement device. This resulted in a period of waiting time marked by intense anxiety and suffering for the patient  This waiting, to have reached the end, and to say: *‘In a while, I won’t be able to walk.’ Because these are the symptoms that DBS causes in you, when it’s not functioning, and you’re OFF. If you go OFF by accident, you remain so. That is, you are [like a piece of] marble, you can’t do anything. And it’s painful from this point of view. When I got the approval, I was subjected to a change of the pacemaker, but then I had other problems (interview with Ms. Martha, PD/DBS patient).*  Similarly to Mr. Achilles, the limitation of the specific technological artifact became a limitation of Ms. Martha’s body, and this became visible and more intense, due to the organizational and financial condition of the ESY, which impeded a seamless continuation of DBS treatment. But Ms. Martha, unlike Mr. Achilles, was fitted with the rechargeable battery her doctor requested. To recharge the battery, she must sit, immobilized, for an hour and a half, every 2 weeks. She finds that boring. This cyborg relation subjects her to the device’s needs, demanding the creation of a new imposed bodily habit, and she resents that.  Moreover, Ms. Martha experienced further problems linked to the body/technology fusion. After her battery change, she developed adhesions, making her suffer and exposing the vulnerabilities of the juncture between the biological and machine elements.  *The device was making adhesions in my body, and my body wasn’t accepting that. As a result, I was in pain, I was suffering. (…) Then we couldn’t find medication; that is, antibiotics. That was during the height of the crisis, while all hell broke loose [tears] (interview with Ms. Martha, PD/DBS patient).*  Every time Ms. Martha lies down to sleep, she feels the pulse generator in her body, and that makes her feel uncomfortable.  In another incident, Nikos’s device started malfunctioning, seemingly because it was interacting with a wet and electrified environment. Time thus was shattered, as the DBS device overtook his motor functions. Briefly, he lived an almost lethal experience:  *Two months after the device was initialized, I went with my best friend, a tiler and marble technician. He was polishing marble with a big electric machine. I was with him to spend my free time, because I was retired, so to speak. And suddenly I started having convulsions in my body. My arms and legs were shaking, and I could not control my body in any way. I started rotating on the floor, spinning, and I was helpless. I waited two hours for the ambulance to arrive. I almost died. I was hammering myself on the floor, my arms and legs were hurt, [everything] besides my head… when the rescuers came, supposedly to help me, when they saw me from a distance, they thought I was crazy. I was in the water and spinning and I was hurt everywhere besides my head. My friend was holding me, otherwise I would be dead. I might even have sprung outside. I went to the hospital where they shut down my DBS, and immediately the body calmed down. (…) Perhaps because the marble-polishing machine was too powerful and partly immersed in water, because when you polish marble, you have to keep the floor wet. (…) I was in the water and perhaps my body acted like a conductor of electricity (interview with Mr. Nikos, PD/DBS patient)* | |