

Experiencing DBS in Greece: Parkinson's Disease Temporality and Patients' contradictory voices

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«Patients' lived experience: what it means and what it implies»



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Three main features of the Greek Health Care System

- 1. Late creation (1983)

Law 1397/83 providing “universal Healthcare, creates ESY (National Healthcare system)

- 2. Shifting Policies

Changes in overall policy in 1992 (towards privatization), 1994 (towards socialization), 2004 (towards privatization)

- 3. Financial Crisis (since 2010)

Drop of public expenditure on health to below 1000€/year per capita

“Persons with disability” (ΑμεΑ)

- PD patients are considered as ΑμεΑ
- The legal status of ΑμεΑ has improved in the last decades, partly in compliance with EU guidelines (law 3304/2005)
- ΑμεΑ persons benefits:
 - -reduced municipal taxes
 - -reduced electricity bills
 - -discounted public transport
- In order to obtain the status of ΑμεΑ, people have to be examined by a special committee and obtain a “disability rate” superior to 67%, in order to be eligible to the provisions of the law
- Cutbacks in benefits have been recently dubbed by ΑμεΑ groups as “social euthanasia” (3/12/2016)

Centers performing DBS in Greece

Thessaloniki

Athens

Public Hospitals

1. Evangelismos
(since 2003)
2. Attikon +
251 HAF

Private Hospitals

1. Ygheia
2. Metropolitan

Thessaloniki

3. AHEPA

Patras

4. PGNIP

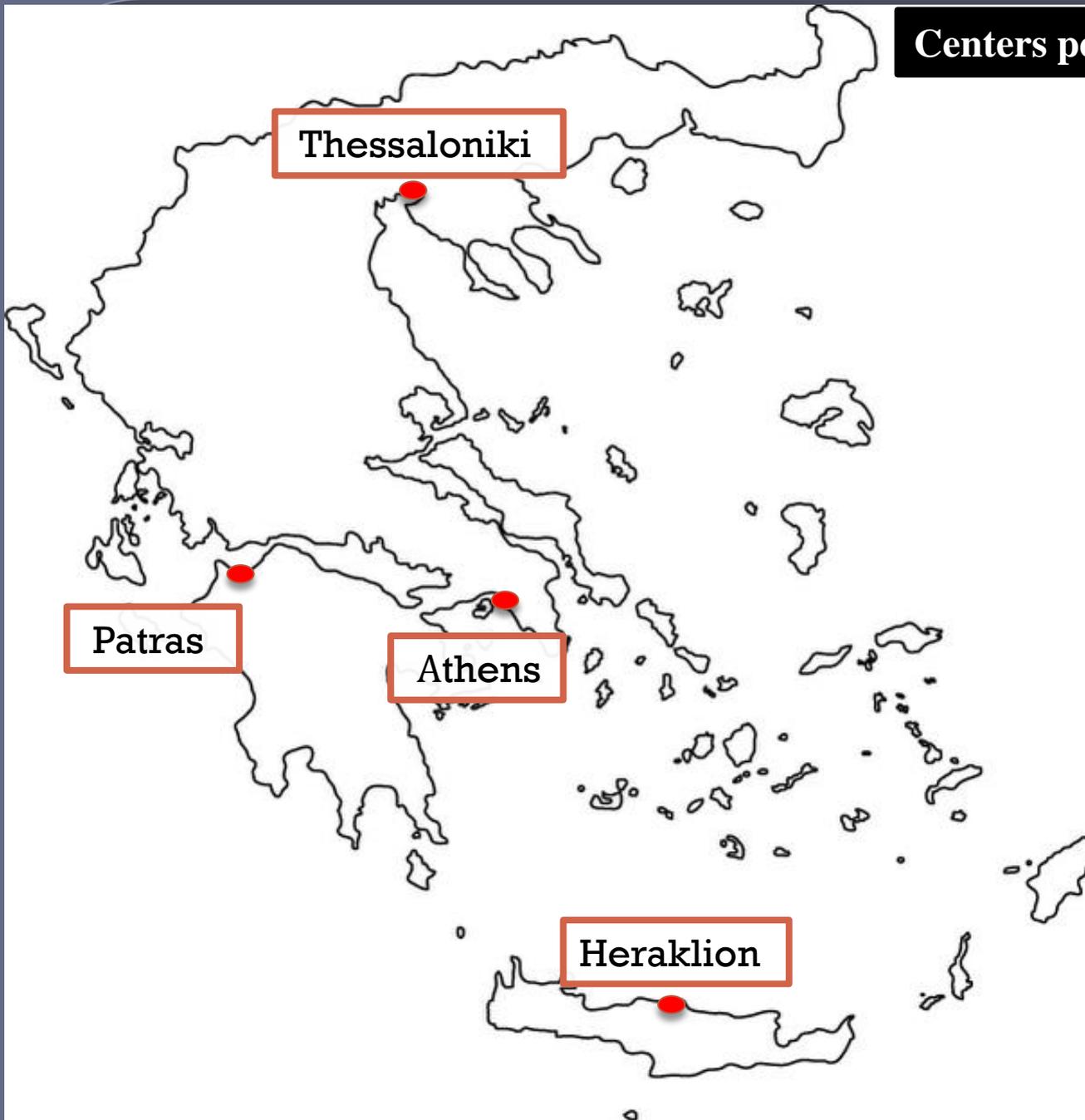
Heraklion

5. General
University Hospital
of Heraklion
(intermittently
constituted)

Patras

Athens

Heraklion



Parkinson's Disease Communities

1. *Patients' Society of Parkinson's Disease* (Athens, cr. 2011- in bankruptcy)
2. *Association of Parkinsonians Patients' and Friends of Northern Greece* (Thessaloniki 2009-), EPDA
3. *EPIKOUROS kinisi* (Athens, 2006-, NGO, presided by a DBS neurologist)- EPDA

Lived experience of Time

Linear time of PD

“After DBS, a patient will not be disabled, but will remain active. Therefore, if he is young, he will not lose his job; if he is old, he will not be institutionalized or confined to a wheelchair.—As a result, the health system will save funds. In my opinion, this operation must be liberalized and all public and private hospitals having the qualified personnel should to perform it. It should become something like, to say, appendicitis. If I have appendicitis, I will not die, but I will undergo a simple operation. and [instead of dying I will be operated]. If I have Parkinson’s, I will be disabled, not tomorrow but in the next five years. In order not to be [disabled] I must be operated now. That point is not understood, even by patients. Many are afraid to be operated and prefer to become disabled. I faced that too” (Interview, 46 years old, male neurologist, expert on DBS)

Time Dragging

“I went inside [the Hospital] in February and I did the first operation 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 at the hospital because there had not the materials and each time I went inside for two to five days and I was expecting to be operated. (...) They were telling me that the device 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, Nikos, male 52 years old, 16 years PD, three years DBS)

“They were supposed to implant me all the parts in the same day, but the machines crashed. The problem started in the morning with the CT, who couldn’t transmit more than a hundred pictures. (...) The problem started there, and at midday, when they were about to implant me the leads, they noticed that there was no communication with the machines, the computers, the neurologist’s laptop... Anyway they stitched me and they left me there void... And [after the weekend] I went back. On Tuesday the operation was performed again, they put me the neurotransmitters, and they took their time, I stayed six hours at the operating room. (...)” (Interview, Adam, male 53 years old, 16 years PD, one year DBS)

“Ten-twelve hours I was standing still and awoken. No dizziness, no nothing, and no medication. You think you are coming apart. I cannot explain this, but you think you are going to be absorbed by the chair in which you are sitting on, so to speak. That you are going to be liquid, or a jelly. [laughter]” (Interview, Adam)

“Two months after the initiation of the device, I went with my best man, who was a tiler and marble technician and he was rubbing marble with a big motorized machine. I was with him to spend my free time, because I was, so to say, a pensioner. And suddenly I started having convulsions in my body, to shake my arms and legs and I could not control my body in any way. I started rotating on the floor, spinning and I could not function. I was waiting two hours for the ambulance to arrive. I almost died, it is, I was hammering myself on the floor, I had my arms and legs hurt, [everything] besides my head... when the rescuers came, supposedly to help me, when they saw me from afar they thought I was crazy. I was in the water and spinning and I was hurt everywhere besides my head. My best man was holding me, otherwise I would be dead. I might even had sprung outside. I went to the Hospital where they shut down my DBS and immediately the body calmed down. Simply I have never had an answer as to why this incident happened. [the neurologist] was at odds and so my attending neurologist. Both told me it was the first time that such thing happened; (...) Perhaps because the engine of rubbing the marble was too powerful and partly immersed in water, because if you scrub marble you have to pour water on the floor, (...) I was in the water and perhaps my body acted like a conductor of electricity.” (Interview, Nikos)

Lived time and Stigma

“Sometimes they stare at us in a funny way in buses. Once I was inside a bus, and I sat next to a young man and he talked loudly [at me]. Meanwhile, I just got out of the court and I was shaking very much, and he says to me: ‘Lady, do you have Parkinson’s?’ loudly in the bus. I said yes, I have Parkinson’s. ‘And you are wandering on your own?’ I said, yes alone. ‘Be careful and go only to the church and at home, and nowhere else’. I said, why my lad? Are we in shortage of pubs and taverns? And the whole bus laughed at the young man.” (Interview, Helen, 69 years old, 17 years PD, member of patients’ Association)

“...I couldn't stroll on the streets, [because] people were staring at me. Because people can't understand that you are in a state of illness. They thought I was a junkie, or even a homeless. I might have been well dressed but I couldn't move, I tried to hold myself here and there in order to stay afoot. Some people thought I'm an outcast and were staring at me.” (Interview, Nikos)

“With DBS I never freeze on the road completely, I still can be in OFF periods during the day, but OFF periods are shorter and milder. They are not so intense as before.” “With DBS things are better, OFF periods are shorter and fewer during the day. I might even spend five days without any OFF period. (...) When the DBS was properly configured last summer, in May, I started doing more things, when the device setting was in order. That is, the device was put in good use on my body.” (Interview, Nikos)

Lived time: technological expectations and future versus presenteeism

“I believe that this technology is at its beginnings, meaning that this device has not been tested for many years, and reasonably there are still problems. And I believe that there will be an evolution of the device.” (Interview, Nikos)

“The disease follows its own rhythm. [Since] 17 years that I am patient I had to show great courage and patience. The disease follows its own path. There is no way to stop it. Since it's incurable, there is not a chance that it can be stopped.” (Interview, Helen)