ding ding dong

Institut de co-production de savoir sur la maladie de Huntington

Being Huntingtonian.

A Multidisciplinary Experiment in the Creation of Knowledge about HD.

How to translate what we are really feeling?
HD is an enigmatic entanglement, first of all for ourselves.
Whatever questions we might ask about this sickness, they first of all concern life itself – rather than symptoms.

Dingdingdong is an Institute for the Co-production of Knowledge about HD. In this Institute, "we" corresponds to a group of people who are in one way or the other personally concerned by HD:

- be it because we are at-risk, carriers, carers, sick, or part of the direct environment of one of them
- be it because we feel concerned by the very specific issues, problems and opportunities that HD brings into Society.

Dingdingdong is founded on sharing and enriching perplexity.

One of these perplexities concerns the frequent assertion (by doctors, psychologists, carers as well as by families and friends of the sick persons) according to which *Anosognosia* and *Dementia* are part of HD's.

Concrete experiences with HD patients gave birth to a suspicious attitude with respect to these two central elements of its medical definition.

We decided to take these enigmas as starting points for our inquiries.

First enigma: is the Huntingtonian anosognosiac?

Anosognosia (encyclopedic definition): (from the Greek words *nosos*, "disease", and *gnosis*, "knowledge", with *an-* or *a-* as a negative prefix), is a condition in which a person who suffers a specific disability seems unaware of the existence of his or her disability. Unlike denial, which is a psychological defense mechanism, *anosognosia* is rooted in physiology (for example, damage to the frontal or parietal lobe due to illness and disease). This may include unawareness of quite dramatic impairments, such as blindness or paralysis.

Second enigma: is the Huntingtonian dement?

Dementia (encyclopedic definition): (taken from Latin, originally meaning "madness", from *de-* "without" + *ment*, the root of *mens* "mind") is a serious loss of global cognitive ability in a previously unimpaired person, beyond what might be expected from normal aging.

Considering that there is no perfect correlation between what is shown/told/felt by the sick persons that we know and the neurological definition of anosognosia/dementia, we will re-consider this notion from the patient's perspective instead of from the doctor's.

As we are doing so, we'll never forget to pay attention to the theoretical and practical consequences generated by this de-construction/re-qualification process – consequences regarding for instance the relationships between the patient and his family, social and medical environment, and his care in general.

Other issues frequently evoked which we'll explore subsequently:

- Aggressiveness,
- des-inhibition,
- sexuality,
- moral and physical suffering,
- suicides,
- Huntingtonian's specific needs etc.

Tiebreaker-question: How to proceed in order to define a disease whose first characteristic is to be extremely *variable* from one case to the other, in terms of the time of onset, as well as of the symptoms' nature and their developments: involuntary movements, extreme variability of psychiatric, mood and cognitive difficulties?

What if this ***variability*** was the only stable feature of HD? Aren't we missing something crucial when insisting to define and freeze it in a classical nosology? One could even ask, whether it is not precisely the difficulty of capturing something as volatile as HD in an adequate way that frightens those who are confronted with it?

Our bet is to consider that, concerning HD, not everything is determined in advance. On the contrary, it is precisely the way we are going to deal with it that will be decisive for what it turns out to be from one instance to the other. In short, our ways of dealing with HD are decisive, they *influence* its shape and progression.

Main constraint and methodology: To achieve these inquiries about the Huntingtonian enigmas, we need the collaboration of the carriers, sick persons and their carers in order to build a subjective, subtle, progressing and dynamic knowledge about what they are really experiencing. Until now, the sick persons are not – or nearly not – solicited as producers of knowledge about HD. How to build specific set-ups that will enable us together to transform them into co-producers of the knowledge about their disease?

This question can't be answered without a preliminary work of empirical inquiries. Such inquiries need the elaboration of *ad-hoc* instruments able to gather and tell *motions* or *trajectories* rather than static states. Because we believe that sickness-stories are part of life more than of anything else, Dingdingdong notably assembles artists and social scientists that try to tell those stories in the most loyal and concerned ways possible.

Instead of freezing the descriptions at a moment *n*, we'll gather *stories*, and thus never separate the expression of HD from the biography of the concerned person. Those stories will be collected by several calls to huntingtonian people and communities (via Dingdingdong's website, HD's associations, forums, congress such as EHDN and EHA's, "word of mouth", specialists networks etc.). Also, an ethnologist will be charged with the fieldwork among carriers, sick persons and their carers.

The team

A multidisciplinary team is constituted to achieve our inquiries concerning various issues and methodologies that we believe crucial for HD's comprehension:

Vincent Bergerat is an artist. He founded the Secret's Service of Dingdingdong. This department deals with the specific needs of discretion/anonymity for those who are concerned by HD. He is the French translator of the first description of HD by Georges Huntington in 1872 (soon to be published by DDD's edition).
Liisa Cervières is an artist. Her main concern and body of work is dealing with events - from the daily trivial to the most dramatic - and how they shape our lives.
Anne Collod is a contemporary dancer and choreographer. She is producing "choreographic portraits" of persons with HD, taking note of their particular trajectories and motions with Laban's method. She will use dance and choreography as an experimental set up to approach the body's uncontrollable aspects of HD.
Alexandra Compain-Tissier is a painter specialized in portraits. She is painting the portrait of all the persons who are contributing to Ddd's project.
Didier Debaise is a philosopher specialized in Pragmatist and Speculative Philosophy. He focuses on the experimental aspects of Ddd.
Vinciane Despret is philosopher and psychologist. She is a special contributor for methodological aspects of Ddd, in order to design the experimental settings necessary for the project and to invent specific methodological paths.
Emilie Hache is a philosopher. For Ddd, she concentrates on the HD's communities.
Emilie Hermant is a psychologist and a writer. She is writing the encyclopedic adventure of Ddd. She co-coordinates Ddd with Valérie Pihet. She also works on the Moss/Foam/Mousse Dept., to learn how to produce a lot of contents and effects when you start from very little.
Bruno Latour is philosopher and sociologist, specialized in Sciences and Technology. For Ddd, he is special counselor.
Valérie Pihet is the director of The Programme of Arts and politics at *Sciences po* (Paris). She is the main coordinator of Ddd. She will also work on the HD's communities and do field work to sketch and translate peoples' everyday feelings about their disease.
Fabien Siouffi is an on-line video games and virtual communities editor. For Ddd, he works on the elaboration of a video game inspired by HD.
Katrin Solhdju is historian of Science. For Ddd, she is conducting a comparative analysis of the HD's contemporary practices, especially concerning the presymptomatic test.
Stéphanie Soudrain is an artist. For Ddd, she will record some testimonies of persons with HD, using media such as writing, audio and video recordings.
Isabelle Stengers is philosopher, specialized in Sciences. She is the Godmother of Ddd.
Fabrizio Terranova is a filmmaker. For Ddd he will focus on possible ways of producing speculative narrations. This approach insists to get inspired by fiction as well as by reality.
Sophie Toporkoff is an artist and the Art Director of Ddd, rendering the shape and the appearance of things as important as their contents.
Katia Youssov is neurologist specialized in HD. For Ddd, she is our medical counselor.

Founded in France/Belgium in 2012, our working group is organized in nine departments and is framed by an "Association Loi 1901", which also includes persons who are affected by HD. For confidentiality reasons, these persons appear under pseudonymes.

For further descriptions or if you would like to participate, go to:

www.dingdingdong.org

Theoretical environment and major inspirations:

• Pragmatist Philosophy: **"Faith is synonymous with working hypothesis."** William James, American philosopher, 1842-1910.

• Narrative Psycho-Neurology, such as Oliver Sacks' approach: **"Neurological patients are travellers to unimaginable lands."** Oliver Sacks, English neurologist born in 1933.

• Narrative Philosophy such as Donna Haraway's approach (American philosopher): **"Stories are much bigger than ideologies. In that is our hope."**

• **Speculative Narration**: a speculative approach aims at using the power of "possibilities" that HD contains versus its "probabilities".

• **Other patient's associations** such as Hearing Voices Network, communities linked to the notion of *Neurodiversity*, Parkinson's Movement, HDN's, AFM (French Agency against the Myopathies), Act up…

Theoretical outcomes:

- To refine the actual definition of HD
- To encourage the emergence of innovative ideas on this disease and on genetic diseases in general
- To contribute to a renewal of the traditional representations of HD that are mostly frightening
- To transform a predicted disease into a source of inspiration for Philosophy, Social Sciences and Arts, as well as for the Society

Practical outcomes:

To construct some tools capable of increasing the awareness of the at-risk and sick people, the carers, professional or not, about the disease, and to enhance the care of carriers and sick people, such as:
- the publication of the first HD's description by Georges Huntington, translated into French
- setting up a working clinical group with sick persons, psychologists, doctors and social workers
- to organize training sessions about the disease for professionals, for instance in psychiatric and geriatric services
- to help the at-risk persons in their own hesitation concerning the pre-symptomatic test, and to help the professionals that have to deal with this test
- together with a specialized lawyer, to explore the law about at-risk persons, carriers and sick persons.
- etc.

Why Dingdingdong?

Dingdingdong is, literally, a call, a bell-sound that is rang by our group to report the moments when we have to slow down, and when we believe that what is maintained doesn't correspond to what the affected persons are truly experiencing.

Dingdingdong is supported by Kadist Foundation.
Poster presented at EHDN/EHA Plenary Meeting, Stockholm, September 2012.

contact@dingdingdong.org