

Patient education in the context of Parkinson disease cared for with deep brain stimulation (DBS): teaching models, goals and actual implications.

Marie GAILLE, philosopher, Senior Researcher SPHERE (UMR 7219) CNRS Université de Paris
 Mathilde LANCELOT, philosopher, PhD, Research Assistant - SPHERE (UMR 7219) CNRS Université de Paris

« Patient Education » : What is it in a nutshell ?

- ➔ **Starting observations:**
- From the 1960 on, Western societies have developed patient education, a flourishing and diverse practice in several countries since then. OMS recommendations since the 1990.
 - In France, patient education as an informal practice and as a practice regulated by Law since 2009.
 - A lack of reflexivity both in epistemological and ethical terms on this practice.
- ❓ **Questions to be investigated:**
 Which knowledge? Which educational relationship? Which goals?
- 🔍 **Analysis:**
Several words and meanings: « éducation thérapeutique », « patient education », patient-manager, health manager, health education, etc.
Several actors & disciplines.
Several aims: knowledge, know-how, being and behavior / « Savoirs-savoir faire et savoir être ».
Several key factors and motivations with important national variations: health education tradition and policies, chronic disease care, patients' participation and patient's movements, patient empowerment, institutionalization both at a national and an international, health budget costs.
A history in the making (Bartlett, 1986).
- Tensions and semantic disputes:** to distinguish between three main visions of patient education:
- To transmit an information/knowledge to the patient in order to help her/him to better deal with her/his condition (vertical or patient centered educational model)
 - A knowledge co-elaborated with the patient in order to help her/him to live better with her/his condition.
 - Patient education as a space of co-elaboration/negotiation of a shared knowledge.

⌘ The educational model recommended by the HAS not only reproduces the traditional medical approach, but also refers in its implementation to school-based or management strategies. (...) However, both the arrival and the duration of the chronic disease have a critical impact not only on the physiological level but also on the psychological balance. (Lacroix 2009) ➤➤

Patient Education for Parkinson disease cared with DBS: What is at stake?

- ➔ **Starting points:**
- A recent history of **patient education in the context of Parkinson' disease** in France (2007) and a history in making for **patient education for Parkinson' patient cared with DBS** in France (2013).
 - From an international perspective, patient education models in the context of Parkinson's disease could be traced back to 1994 (Montgomery et al.)
 - Several development of patient education for Parkinson' disease cared with or without DBS are **in progress** in France and elsewhere. Practices differ in terms of contents, places (clinical centers, hospitals, education center, associations) and funding (National and public health funds and/or pharmaceutical industries).
- ❓ **Questions:**
 What do these education programs bring to patients? Which goal ? What meaning do they bring to the management of chronic diseases and technological care? Do they meet the needs of ageing people, the need to support longer and more technological lives?
- 🔍 **Analysis:**
Several aims and motivations and tensions between different aims: Patient autonomy; "Managing" and better understanding of the disease and treatments; lessen consult's number and frequency; reduction of public health costs in the context of chronic and long-term disease; sharing medical knowledge and disease' experiences; transform the patient-physician relationship, etc.
A patient education "in the making" with new issues concerning the patients' use of and learn from a technological care both from short- and long-term perspectives: How far can/will learning go?



Methodology: review of international literature, conceptual and historical analysis, fieldwork : observation of patient education in the context of Parkinson' disease and interviews with clinicians and patients.

- Results:**
- ❖ A clarification of the multiplicity goals and teaching models of patient education is needed.
 - ❖ A specific attention must be paid to patient education in the context of technological care.
 - ❖ An attention must be paid to the long-term patient education effectiveness.