

Mathilde Lancelot, Agathe Camus, SPHERE UMR 7219 Université Paris 7- Diderot

Title : « Neurodegenerative diseases and global and/or specialized care : practices and discourses »

Section : « Justice and Vulnerability » : « Care for people with disability / Elderly care »

Abstract

We propose to examine and to question some ambiguous discourses¹ about “global patient care” and/or “specialized patient care” in the context of neurodegenerative diseases (ND). Indeed, guidelines² about ND (type Parkinson and Alzheimer diseases) promote the notion of *global care* understood as a somatic, psychic and environmental multidisciplinary evaluation and follow up for patients. However, the notion seems to be used in a decontextualized and unquestioned way. Practices show that these pathologies require specialized and hyperspecialized care. But is this type of care concretely compatible with a global follow up? This reflection inscribes itself into a largest thinking about how to medically and non-medically support persons with neurodegenerative diseases in hospital care context.

First of all, it seems necessary to question the historical meaning of the notions of « global care » and « specialized care »; what it implies and what it highlights in practices. How the notion of « global care » can be distinguished of the notion of « patient-centered-care » ? In addition, it is important to see how global and specialized or hyperspecialized care³ are articulated in practice. Second of all, fieldworks and observations permit us to highlight a patient claim about « a lack of accompagnement. » But what are we talking about when we talk about « accompagnement »⁴? Does that notion, emerging from the patient’s discourses, correspond to the idea of « global care » ?

Thus, we propose to construct an epistemological and philosophical reflection about medical specialization, global care and « accompagnement » on the basis of our field observations focused on two specific care situations : Parkinson’s patient and Alzheimer’s patient, both confronted to non curative care and treatments. Indeed, these two kinds of neurodegenerative diseases require simultaneously non and hyper specialized care. In order to illustrate this point, we will consider two specific situations : deep brain stimulation on Parkinson’s patient (hyper specialized care) and care for Alzheimer’s patient in internal medicine hospital services (patients with Alzheimer disease are cared in such services for intercurrent disease and comorbidity and non specifically for Alzheimer disease). These two cases both illustrate the complex articulation between hyper specialized, non specialized and global care. Therefore, we have chosen to present them as complementary reflexions and work on it as a pair.

¹ Guidelines, medical literature, physicians speeches etc.

² HAS Recommandations « Maladie d’Alzheimer et maladies apparentées : prise en charge des troubles du comportement perturbateurs », Mai 2009 & HAS Guide du parcours de soin « maladie de Parkinson », Septembre 2016. <http://www.has-sante.fr>

³ By exemple : deep brain stimulation in Parkinson’s disease.

⁴ See Gaille M., Horn R., The role of “accompagnement” in the end-of-life debate in France : from solidarity to autonomy, 2016.