

*Ce que soigner une maladie chronique
veut dire.*

*Quelle alliance entre médecine et
« humanités » ?*

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**"L'expérience vécue du patient"
sens et implications pratiques**

projet ANR NormaStim : « Les neurosciences de l'expérimentation à la clinique »
Enjeux juridiques, philosophiques et sociologiques de la stimulation cérébrale profonde »

6/12/2016
UNIVERSITÉ PARIS DIDEROT

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« To humanize medicine »

Introductory remarks

Axe 2 of the project: care concepts and practices
(including normal/pathological/enhancement
distinctions)

A still pending issue to me: what is the specificity of the case we work on in NormaStim ?

- My aim: to contextualize our topic in order to answer this question.
- A secondary aim : to reflect on our own positioning and involvement (is it only about gathering knowledge ?)

« To humanize medicine »

First Medical School in the world to have a humanistic approach to medicine

« To humanize medicine »

A. Mol : to share the issue rather than to incriminate medicine.

The « humanizing » discourse's interest : it calls attention on the lived experience of illness.

What is the lived experience of persons with chronic condition ?

General characteristics of CC :

- Duration & endlessness
- Uncertainty
- Personal and social implications – biographical disruption?

« The crisis becomes routine » (I. Baszanger)

Mapping the philosophy of chronic disease

- L. Nordenfelt, « Chronic Illness and Quality of Life : A Conceptual Framework », *Health Care Analysis*, 1995 > to create a medical art that helps the patient with chronic condition to live with it.
- *Philosophie du soin* : « Prendre soin de quelqu'un, ce serait le traiter non comme objet, mais comme sujet, et non pas comme simple sujet de droits ou de raison, mais aussi comme sujet d'émotions, de besoins vitaux et de vulnérabilités »
- A subjective and individual approach of medical care: an interpretation of G. Canguilhem's work by C. Lefève (a key reference for the previous trend of thought)

Mapping the philosophy of chronic disease

- Hermeneutics
- Phenomenology

The question they raise: what is the issue at stake?

Their answers:

> to measure the distance between the « medical » approach of chronic disease and the experience made by the person with chronic condition.

> to examine if, how, and up to which extent it is possible to overcome this distance.

To listen to the patient

- ... is not to pay attention to her experience of illness

Why would a physician listen to the patient?

- To understand her behaviour ex. G. Reach, why do we cure ourselves? »
- To improve the medical capacity to make a diagnostic and determine a therapy ex. G. Canguilhem's notion of « subjective body » and conception of the interpretative support the patient offers to the physician about her disease.

An especially relevant frame in the case of chronic disease because of its often uncertain, creeping and invisible symptoms

- To take into account the active part played by the patient coping with her chronic condition and benefit from her experience.

The lived experience of the patient

○ Hermeneutics and phenomenology

Common points :

- the importance given to the distinction between the ill person and the patient (Our title maintains the ambiguity !)
- The meaning of chronic condition is examined without distinguishing the impact on the person's identity and the impact of the person's daily life. Both are conceived as connected to each other (M. Bury).

The lived experience of the patient

○ Gadamer's hermeneutic path

- What is a human being ?
- How are we to understand ourselves ?
- What orientation is to be given to our lives?

The physician should take into account these issues when taking care of a patient.

Implications:

- From the « patient » to the « sick person »
- Illness as the experience of a deficiency
- To acknowledge the distance between the physician's approach and the person's experience.

The lived experience of the patient

Example: The use of Gadamer to reflect on psychiatric care
(J. Quintin)

- To prevent the physician from being a mere witness of the patient's condition,
- To involve the physician into it,
- To propose dialogue as a common and endless interpretative activity of the disease
- To include the patient in a shared world

The lived experience of the patient

- The key work by S. K. Toombs to promote phenomenology as a tool of analysis and to give an orientation to medical practice

Background : psychology, philosophy

1973 : diagnosis of multiple sclerosis

Gadamer, a proclaimed disciple of Heidegger and Husserl, declared he could not find conceptual resources to think of the lived experience of the person.

Why could she ?

- A tradition anchored in American philosophy since the interwar period
- Free and creative philosophical style

The lived experience of the patient

- **Starting point** : the distance between the physician and the ill person's points of view has not its source in indifference.

Two realities, rather than one : disease and illness

- **Phenomenology: a tool box**

- Reflexive activity (the stream of our consciousness, our inner experience, the meaning we give to it) **Husserl**
- A socialized individual and the lack of a common world **Schutz**.
- Two distinct experiences: lived and internal/abstract and external **Sartre**
- Embodied being/the body as an object (naturalistic, scientific vision) **Merleau-Ponty**

The lived experience of the patient

- The experience of : I can ... I cannot
- *uncanny, unheimliche*
- Lack of control
- Loss of confidence and easiness in relationship to the world and the other.

Merleau-Ponty: the body as my point of view on the world

The experience of illness as an issue for the physician

Is it possible, and if so how, to get the physician and the medical team to consider the experience of illness as their problem?

The proposal of L. Binswanger in the field of psychiatry

« To overcome the cancer » e.g. the « divide between object/subject »

Dasein analysis

- To find an access to the « world » of sick persons in order to understand them and become able to include them in a common world
- A very involving and demanding professional practice

The experience of illness as an issue for the physician

Gadamer about chronic disease:

- Patients have to learn to live with their pathology, without the hope of being cured;
- Psychological care is required to help them to live with this fact;

See Nordenfelt (promotion of the ability to communicate, and of practical ethics)

The experience of illness as an issue for the physician

- Toombs about chronic disease: Medicine must integrate this action as part of its own activity.

The physician as a healer and a colleague of the patient

- She must deal with the organic problem and the anxiety as the basic element of the experience of illness (*when my body is broken, my life falls apart*)
- She must consider pain as both physiological and existential (E. Cassell)
- She must aim at strengthening the capacities of the patient to cope with her condition (which is not the same thing as reassuring her)

Conclusion

What does the experience of chronic condition bring to the forefront ?

- An involving and demanding conception of medical practice.
- An incentive to conceptualize health and its restoration as focused not only on the elimination of organic problems but also, if not primarily, on freeing the ill person from her state of disorientation, confusion and bewilderment.
- Do we elaborate a « neutral » knowledge when we tackle the issue of the lived experience of the patient ? What does it mean to be normative on this matter?