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Marie Gaille, Agathe Camus

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An ordinary life with chronic condition as a goal for medicine ?

Marie Gaille, philosopher, senior researcher, SPHERE UMR 7219, CNRS Université de Paris
Agathe Camus, philosopher, post-doc, Triangle UMR 5206, CNRS ENS de Lyon

Context assessment

- Demographic and pathogenic context: a massive increase in chronic conditions, disability situations, long-term ageing with various forms of loss of autonomy
- Emergence of *specific forms of life*, marked by lifelong illnesses, different forms of medicalisation, frequent comings and goings between home and care institutions, but also possibilities for action and margins of capacity that are limited, but real

Innovation is needed, in technological and scientific terms, but also in terms of health policies, care and care pathways ➔ to enable people with chronic conditions, a situation of disability or a long old age, to lead as « normal » and « ordinary » a life as possible

« Mrs. D., 86 years old, explains her wish to return home, "if she is in good condition", or to be cared for not far from home. She fears being socially isolated, whereas she is used to receiving visits from her son but also from her friends (...) it is no longer medical knowledge that is in question**, but the concrete consequences of this or that option on the patient's daily life**. »

« The discussion will take place between Mr. G. and the mobile palliative care team and will provide an opportunity to try to determine "what can" the palliative care service do with respect to a set of things that are important to him: relieve pain, maintain his freedom of movement, but also be able to smoke or « to stay alone"... »

(Camus, 2019)

« a woman with multiple sclerosis who is being cared for in an internal medicine unit for a febrile episode, scheduled for discharge the next day, is worried that she will not be able to manage on her own, when she has no help at home and her husband is on a business trip »

Social sciences input: a thick description of chronic condition and a criticism of the « normalcy »

1929 : - chronic condition as an global issue (the individual, the family, the health organisation system) (Boas et Michelson)

1982 : chronic condition as a « biographical disruption » (Bury) - sociology

1986 : chronic condition as a continuous state of crisis (Baszanger) – sociology

2007 : focus on coping capacities (Taylor and Stanton) – health psychology

A chronic condition as a « separate world » ?

What could be an « ordinary » chronic condition? Can we imagine a « normal life » with a chronic condition?

- An issue raised in other fields : disability studies, trauma, state of major social distress or even catastrophies and their aftermaths
- An issue still to be described and conceptualised:
- From the criticism of the « normalcy » to an increased attention to the wish for a « normal life » in ethnographic works:
  - ex.: « home » as the place for a normal life for old persons up to a certain level of dependency (Balard 2011);
  - ex.: to live an « almost normal life »/to live « everybody's life » with and despite a difference/ deficiency (Winance 2019)

@ For further information & bibliographical references :
mariegaille@yahoo.fr / agathe.camus@ens-lyon.fr

Philosophical resources: Kurt Goldstein and Georges Canguilhem

Main ideas :

- What is « normal » is grasped and understood on the basis of what is « pathological » and not the reverse
- Primacy of the individual normativity both in existential and biological terms

« It is, in the end, the patients who most often judge, and from very different points of view, whether they are no longer normal or whether they have become normal again »
(Canguilhem 1966)

- Medecine as a healing practice, working with the remaining capacities of a wounded or chronically ill person to allow for a life worth living despite the restrictions.
- The living environment plays a central role in this medicine : it alleviates or aggravates the implication o the pathological state (Gaille 2019)
- « A reinvented normality » (Mouillie 2018)
- A different life than before, a new kind of normal life, somehow unstable (Meyer 2017)

The wish for a *normal life*, a life *like everyone's life* expressed by persons with chronic condition should be taken into account by the health care system

Philosophy can offers some conceptual and normative tools to medical care to answer such a wish

Next step: from the Normavi project funded by IReSP to a philosophical/ epidemiological collaboration project (ComPaRe Cohort - Community of Patients for Research, www.compare.aphp.fr)