




The Importance of Therapeutic Education in the context of Rare Disease Care

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The Therapeutic Education according to the WHO aims to help the patients to acquire or to maintain the skills and abilities they need to *manage their lives with their disease and* improve their quality of life !

The general concept: patients will improve their skills so their compliance and thus their autonomy and therefore their quality of life

The french definition is **more restrictive** than the World Health Organization definition



*“TE should enable patients to acquire and maintain abilities that allow them to optimally manage their lives with their disease. It is therefore a continuous process, integrated in health care. It is patient-centred; it includes organized awareness, information, self-care learning and psychosocial support regarding the disease, prescribed treatment, care, hospital and other health care settings, organizational information, and behaviour related to health and illness. **It is designed to help patients and their families to understand the disease and the treatment, cooperate with health care providers, live healthily, and maintain or improve their quality of life.**”*

WHO: TE consist in a set of actions performing an individualized program linked to a global approach of the patient.

Vs

French system consist in 3 different frames **regulated by guidelines** + TE programs are linked to an administrative authorization +TPE programs apply only to certain diseases and have to **be accredited by a regional body**

- 30 ALD (serious or chronic illness. This concerns 400 diseases)
- And **rare diseases** (expressly mentioned in the law!)

HPST law 2009

3 forms of Therapeutic Education

- The law of 2009 provides three forms of Therapeutic Education

1. THERAPEUTIC EDUCATION PROGRAMS (TEP)

- TE programs aims to facilitate patients **to acquire skills** in order to understand better their conditions and treatments.

2. SUPPORT ACTIONS

- Provide **assistance and support to the patient and his family**: home, information, discussion groups and self-help meetings, hotline, shares of individual or collective training ...

3. LEARNING PROGRAMS

- Acquisition of technical skills to a better use of drugs and medical devices.
- Reserved to **health professionals** and drug companies.

HPST law

- Why this attention to TE in 2009?
15 million people with chronic disease in France: many of them are struggling to follow the instructions and advice of their doctor
 - patients health deteriorates
 - the caregivers feeling of failure appears
 - the deficit of social security increases
- Through patient education
Patients will improve their skills so their compliance thus their autonomy so their health so their quality of life
The health system will be more efficient

HPST Law and TE Programs framework



An implementation in 4 steps

- Develop an educational diagnosis
- Define an individualized TE program with learning priorities
- Plan and implement individual sessions of TE and / or collective
- Conduct an assessment of the skills








TE programs

- according to national specifications and guidelines
- implemented locally after authorization of the healthcare regional body
- proposed to the patient by his medical doctor and establish a personalized program
- assessed by the High Authority of Health. (HTA agency) "

TE Programs regulation in France

The main principles

-  TEP can be initiated by PO or healthcare professionals.
-  At least two different types of professionals have to be member of the multidisciplinary team in charge of implementing the TEP
-  The TEP has to be implemented by people of which at least one is holder of a TEP abilities certificate. (40 hours training)
-  TEP is not binding. The participation to TEP can't condition the drug reimbursement rate.
-  Principle of prohibition
 - ✓ Programs or actions can not be developed or implemented by the pharma companies
 - ✓ However, these companies may finance these activities or programs.

Therapeutic Education

key issues



Issues for patients :

- ✓ Benefit from a comprehensive / global approach of the disease
- ✓ Take into account the expectations and needs
- ✓ Enhance the experience by becoming an “**expert patient**”
- ✓ Improve the quality of life






Issues for patient organisations :

- ✓ Strengthen their role as a partner of medical doctors, nurses and health system stakeholders
- ✓ TE is a lever to change the patient / caregiver relationship



Therapeutic Education

What opportunities?

-  TE **responds to the specific and varied needs** of any person facing a rare and chronic disease
-  TE enables to **support family care givers**
-  This is a new way of thinking about care, because TE seeks mobilizing the **own personal resources**.

Fundamentally

TE means a new and balanced approach of the **caregiver / patient relationships**, a **new paradigm** based on a partnership process

-  this partnership process is based on the **recognition of the expertise** of the patient
-  This is a great opportunity for associations and the medical profession **to work better together**.

What this new paradigm means for the healthcare professionals ?

Substitute an open educational approach of the care to a restrictive medical approach of the cure, with a global understanding of the patient condition.

An educational approach means for MD:

- Adopt an educational posture
 - "Being able, as a person but also as a professional and scientific, to identify the limits of its own system of representation about health and disease"
 - Trust the patient
 - Recognize and apply as often as possible expertise
 - Move from transmission to mediation
- Create shared moments of educational assessment "to assess and agree together"
 - Perform a non-selective listening
 - Listening the patient's emotions while recognizing one's own emotions

Therapeutic Education Plan of l'Alliance Maladies rares

TE Plan of l'Alliance maladies rares
2013 - 2015

- **Strengthen the capacity** of patient organizations
- **Increase their interest**, inspire them and gives tools to be active stakeholders
- **Ensure** that rare diseases are not forgotten in the development of TE programs
- **Become** the national **referent of TE** for rare diseases
- **Being a key player in research** and make proposals on TE

L'Alliance Maladies Rares

Our actions

- Development of a **practical guide on TE** for rare disease organizations
- Organizing interactive and participatory **workshops**



- **Information campaign** within the associations members (factsheet, information meetings...)



L'Alliance Maladies Rares

TEP team!





Je vous remercie de votre attention !