



# Fundamentals of patient as partner approach in long term healthcare: The patient's perspective

Angela ODERO – Doctoral Researcher

#### INSTITUTE FOR RESEARCH ON SOCIO-ECONOMIC INEQUALITY (IRSEI)



UNIVERSITY OF LUXEMBOURG Integrative Research Unit on Social and Individual Development (INSIDE)

### Context

#### Socio-demographic context

Increased in life expectancy, and the prevalence of chronic diseases' (CD), call for long term management

Technological innovations like the internet have led to an empowered patient, increasingly informed thanks to easy access of information and choice in healthcare providers

#### Cultural context in chronic healthcare

Patients are more involved in:

- Taking responsibility for their health
- Participating in the therapeutic process
- Self-surveillance, self-education, self-treatment and risk prevention

Patients develop an experiential role in coping with their disease Health professionals organize and adapt their practices to the needs of the active patient.

### Research question & aims of the study

Promote and strengthen the \*-*Patient as Partner Approach in healthcare*, inform changes at the micro, meso and macro levels of the public health system

**Research question:** What conditions need to be met in the patient-healthcare practitioner interaction, in order for a partnership to prevail?

#### **Objectives:**

- Identify components underlying the patient-healthcare practitioner relationship, that are essential to a partnership. The patient's perspective
- Determine what patients with chronic diseases require and expect of themselves and from healthcare practitioners

\*Pomey, M. P., Flora, L., Karazivan, P., Dumez, V., Lebel, P., Vanier, M. C., ... Jouet, É. (2015). Le «Montreal model»: Enjeux du partenariat relationnel entre patients et professionnels de la santé. Sante Publique, 27, S41–S50. https://doi.org/10.3917/spub.150.0041

### Methodology

Sample: Patients with chronic diseases

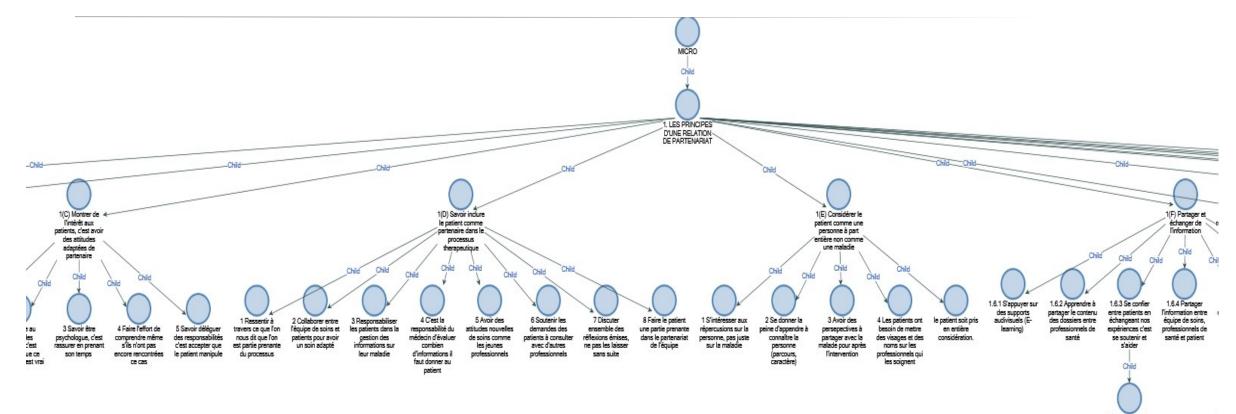
**Criteria of inclusion:** patients with chronic diseases who are members of an association (Cancer, cardiovascular diseases, stroke, rare diseases)

**Data collection:** Semi-structured interviews: 14 questions in 3 categories (clarification; practice & expectations; partnership promoting activities & actions); participants signed a consent form and a socio-demographic form

**Qualitative Analysis:** Thematic categorical content analysis conducted with N'Vivo 12. Selection of verbatim, formulation of items and categorization of items into dimensions. Consensus by 2 researchers and content validation by 3 experts (researchers)



### **Results** Dimensions: Created from regrouping items of same topic together



1.4.5 regrouper les verbatim qui correspondent

Grande Région | Großregion

### Dimensions

A partnership between patients and healthcare practitioners requires

- 1. Recognition of knowledge and health aptitude acquired from living with the disease
- 2. Accepting the limits imposed by the disease in order to learn how to overcome them
- 3. Showing interest in patients through an attitude that supports of a partnership
- 4. Sharing and exchanging information
- 5. Quality communication (that is reassuring, open, pertinent)
- 6. Considering the patient as a person in their own right not as a disease
- 7. Being responsible for ones own health



## 1. Recognition of knowledge and health aptitude acquired from living with the disease

### Patients with chronic diseases declared that:

- A certain level of technical knowledge enables them to participate in decision-making
- Being cautious of medical directives by asking questions, can mean survival
- Their experience enabled them to precisely define their illness
- They have learned to understand when they are well or when something is wrong, by listening to their bodies
- Learn how to look for information across the borders



### 2. Accepting the limits imposed by the disease in order to learn how to overcome them

### Patients declared that:

- Accepting the diagnosis gives them the power to act (and react)
- Learning to test ones capabilities helps in regulating (adjusting) ones actions
- Investing a step further and managing the unknown is to value one's own life
- Learning to deal with the unknown



## 3. Showing interest in patients through an attitude in support of a partnership

### Patients declared that healthcare professionals need to

- Accept that the patient does not want to undergo treatment
- Take them seriously by accepting their word as true
- Discuss issues and concerns as they arise, as opposed to leaving them unaddressed
- Take the time to reassure them (posses some psychologist traits)
- Help them verbalize their requests (cure, psychological support)



### 4. Sharing and exchanging information

### Patients declared that

- Healthcare practitioners should share patient medical records (at their discretion)
- Sharing of information and personal experience with other patients is helpful
- Healthcare practitioners should share information with them (e.g. treatment and therapy options, new developments)
- Health institutions should diffuse information via E-learning and TV hospitals



## 5. Quality communication (conduct, content, reassurance, openness)

### Patients declared that quality communication is based on:

- Health practitioners giving clear and complete explanations about treatment & care
- Health practitioners being honest with them
- Healthcare practitioners being open to their proposals
- Healthcare practitioners paying attention during consultations (not act in hurriedly)
- Learning to brainstorm together, when issues arise, as opposed to leaving them unaddressed
- An environment that allow them to talk to healthcare professionals



## 6. Considering the patient as a person in their own right not as a disease

### Patients affirmed that healthcare professionals should

- Be interested in the impact of the disease on the them, not just in the disease
- Have post-intervention foresight to share with them
- Make a point of meeting them face to face (so they can put names and faces together)
- Treat them as human beings, not as a number
- Take the time to get to know them (path, character)



### 7. Being responsible for ones health

### Patients affirmed that taking responsibility means

- Having the opportunity to choose their treatment
- Getting educated about their disease
- Making the decision to invest in alternative care (even when expensive)
- Gaining autonomy to self-administer their treatment
- Making themselves heard, means relentlessly intervening through own efforts
- Actively monitoring their own habits (diet, drug side effects, alternative treatments, adherence)



### Discussion

Our findings have identified and categorized requirements underlying a potential partnership, and characterized **cultural health capital** and **health literacy** necessary for its practical application.

\*Cultural health capital: A repertoire of cultural skills, attitudes, behaviors and interactional styles that are valued, leveraged, and exchanged by both patients and healthcare providers during their interactions, for optimal healthcare relationships

\*Health literacy: The ability to communicate, obtain and understand health information related to one's specific disease, health, medical care and overall wellness, as well as make appropriate health decisions.

\*J. K. Shim, "Cultural health capital: A theoretical approach to understanding health care interactions and the dynamics of unequal treatment," J. Health Soc. Behav., vol. 51, no. 1, pp. 1–15, 2010.

\*D. W. Baker, "The {Meaning} and the {Measure} of {Health} {Literacy}," J Gen Intern Med, vol. 21, no. 8, pp. 878–883, 2006.



### Acknowledgments









## Thank you for your attention

