

NOMADe

From vulnerability to agency : the contingent path of patients with chronic low back pain

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 MÉDECINE PHYSIQUE
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Research project

WORK PACKAGE 4 : BIOPSYCHOSOCIAL EXPERTISE AND E-LEARNING

Activity 1: Biopsychosocial analysis of the beneficiary population

- Explanatory paradigm: identification of independent variables impacting TNMS in the FWI area
- Comprehensive paradigm : approach to the subjective experience of patients and relatives

Purpose of the presentation

- Restitution of the first results of the study
- Comprehensive paradigm
- Midway through the data collection :
15/30 interviews



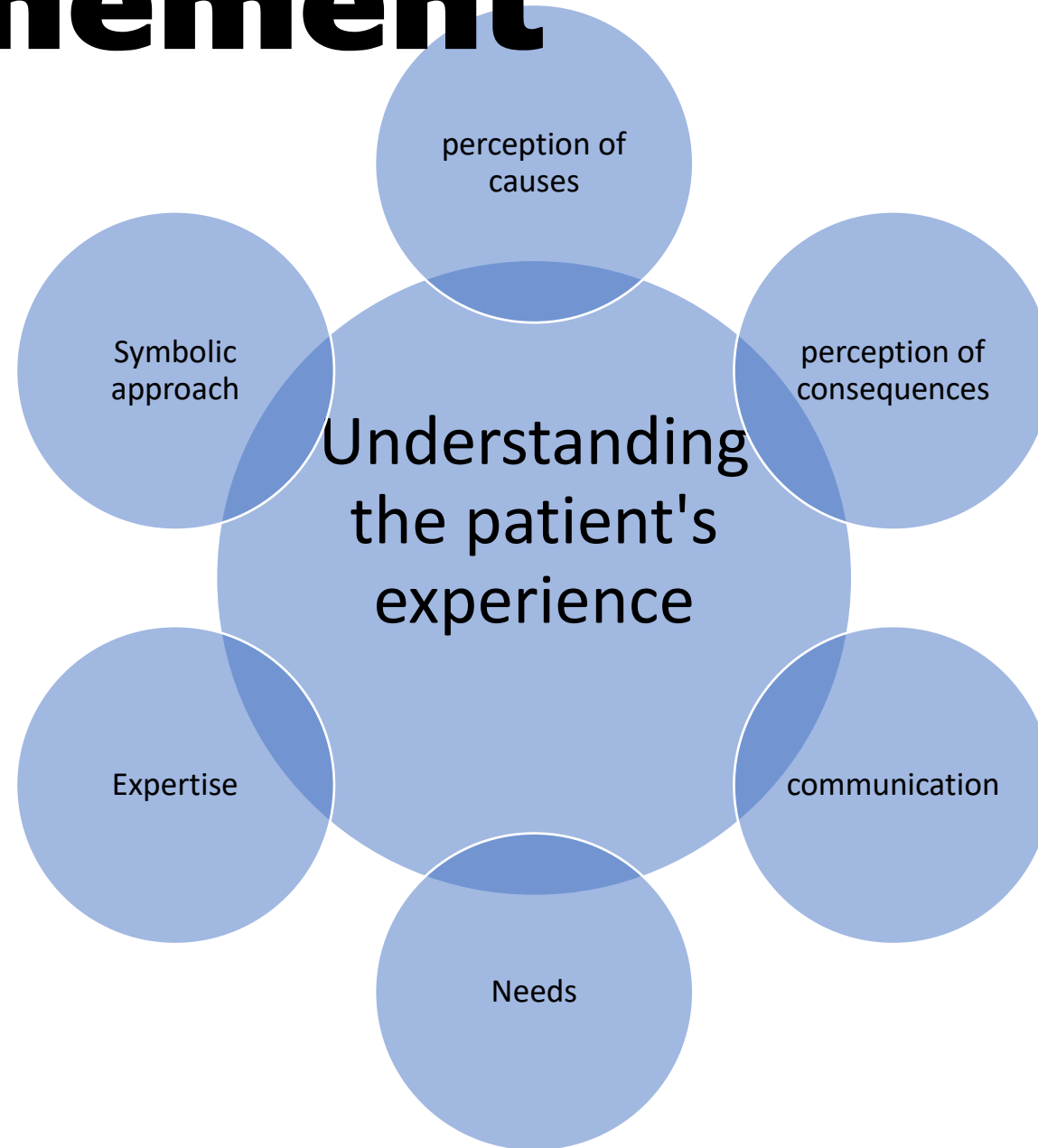
Theoretical approach pragmatism

- Refining the understanding of chronic illness and intervention by opening up :
 - to the "private sensation" (« sensation privée ») of pain and the patient's experience of the illness (Baszanger, 1991);
 - to the patient's **physical and psychic relationship** with his or her work history and experience at work (Davezies, 2013).

Comprehensive paradigm
Inductive approach
Qualitative method

- Data collection method :
 - 30 semi-structured interviews (7-12/21)
 - Sample :
 - France - Wallonia - Flanders
 - Recruitment in the patient and entourage of practitioners and researchers
 - Acute and/or chronic low back pain
 - Ages and duration of various disorders
 - Conditions: Face to face / Videoconference
- Data analysis :
 - thematic

Questionnement



From vulnerability to agency :
the contingent path of **patients**
with chronic low back pain

PREMIERS RÉSULTATS

Contingent path

Contingency and iteration

- Search for solutions,
- "Back and forth" between general practitioners - examinations - specialists - physiotherapists - osteopaths
- « itinéraires thérapeutiques » Janzen (1995) trajectory and therapeutic choice followed by patients and their entourage.
 - "I was very lucky"
 - "A path of struggle"
 - Case of Odette, who stayed in bed for three weeks without daring to complain to her doctor

Contingency and iteration

- Contingency: decisive encounter based on the contingency of links or encounters
 - Importance of meeting a therapist (general practitioner - specialist - physiotherapist - osteopath) who explains, listens and advises.
 - "I was very lucky. I fell into the hands of a professional who explained everything to me in a very educational way. Odile

Contingency and iteration

- **Social inequality - social capital (Bourdieu, 1979)“**
 - I had a friend who... That's because I knew... My brother-in-law...
 - Evelyne makes it clear that if she had not had an acquaintance in the medical field, she would not have followed this route and would not have understood. Her GP prescribed anti-inflammatory and X-rays. According to her, it is very difficult to find the right person and without acquaintances, the delays are sometimes long.
- **Sampling bias**

Initial state :
Vulnerability

Vulnerability and disarray

- Initial state described by the patients:
 - pain,
 - misunderstandings,
 - situation beyond their control,
 - Anxiety about the lack of control over acute pain and its recurrence:
 - " I didn't know who to turn to" Evelyne
 - "When a doctor told me I had to stop sport, it was like being told I had cancer" Margot
 - Before meeting the therapists who helped him understand, Jean-Christophe felt he was: " in a frenzy of looking for a solution. I see some people going to marabouts, it's the market of pain.

Vulnerability

- The potential for a being to be degraded (Soulet, 2005).
 - Aspects
 - Dependent on contingency, not ability to control or act
 - Situational (not people)
 - physical and normative vulnerability

current state described by many
interviewees
Agency

Agency = capacity to act

- "To take ownership" [s'approprier] – "To be an actor" – "To find a way to manage it"
- Underlined elements by interviewees :
 - Understanding
 - Normative aspects
 - Be reassured!
 - « Cheminement thérapeutique » (Massé, 1997)
Therapeutic pathway

Understanding

- Very regularly highlighted by patients.
 - Laura says she needed to understand in order to act.
 - "I like to be explained! I need to put space between the vertebrae." says Madeleine.
 - "Understanding is the beginning of healing and acceptance. Understanding has helped me." says Evelyne.
 - When Margot talks about the importance of the time spent by her osteopath, whom she describes as "gentle" and "psychologist", to explain her pain: *"Before I was told, you have low back pain but I didn't know what was going on. she showed me on myself. And I managed to map out in my head what was happening in my body. This was very important for me. When I understood, it changed my life."*

Normativity: dynamism and management of TNMS

- Description of a self-sacrificing state (initial)
 - "taking it upon oneself « prendre sur soi »,
 - "Don't talk about it",
 - "Don't complain",
 - "don't listen to yourself", not listening to your body or your pain
- continuing an inappropriate lifestyle
 - Odile says she feels "diminished" and "devalued". "I care about the image I give myself [l'image que je me donne]. It's a real job to try to be dynamic. When the pain comes, she says she sometimes treats it with "contempt", so she can go on a ride.
 - "Seeing these images has helped me. There is something there. I'm not complaining for nothing. It's about me [...] I'm the kind of person who bites the bullet [mordre sur ma chique] and goes to work. Now I'm not! I'm going to take care of myself; stay in bed."
Evelyne.

NORMATIVITY ! Normal attitude to pain and suffering

Normativity: dynamism and management of TNMS

- Renouncing social normativity: dynamism – commitment – responsibility – an active life
- Repeated expression of a past negation of the signs that the body was sending them.
- Recurrence of the verb "to accept"
 - Accepting a limitation of one's physical capacities = obligatory passage for ...
- More frequent success in acute and chronic low back pain:
 - injunction of pain
 - Sword of Damocles of their TNMS. Evelyne says that her acute episode is far away but that she feels a "sword above the head" [une épée au-dessus de la tête].
 - Indeed, if they do not preserve themselves, they feel they are at greater risk of limitation.

To be reassured : to be listened to in order to accept - to listen to oneself ?

- "My physio told me it was normal !", says Madeleine, explaining her route. This reassuring attitude was a very important step for her.
- What helped Margot to relieve her acute and chronic pain was "to be reassured", "to have the right advice" to find her lifestyle. One of the doctors she consulted advised her to stop doing sport. For her, "It was like being told I had cancer". Margot says that her doctor helped her to "demystify".

After understanding and appeasement, acceptance and listening : an "active" attitude Agency...

- "You have to accept that you are the actor of your own well-being.
Evelyne
- According to many patients, you have to find your own balance.
The sports practice that suits our habits and interests and our
difficulties.
- "I said to myself: I'm going to be my own reference, the initiator,
the investigator, to get the advice and information that enabled
me to look after myself. Before, I used to follow advice. I was a
magic bullet that went towards everything ... When I chose to start
from myself... Also I got a bit lucky..." Margot

Cheminement thérapeutique (Massé, 1997)

Therapeutic pathway

- Some patients :
 - a strictly biological and chemical view of treatment in a causal scheme
 - treatment: anti-inflammatory drugs, infiltrations, physical aspects of life hygiene
- The majority of patients interviewed :
 - questioning the perceptions of the body and trouble and the western way of life
- « *cheminements thérapeutiques* » : *Use of a variety of knowledge, logics and rationalities of the disease*

Therapeutic pathway

Cheminement thérapeutique (Massé, 1997)

- Odile was very happy to meet her physiotherapist. According to her, her approach and explanations helped her to manage her illness.
- “Alternative rationality”:
 - more "open than the classical approach of medicine". Odile
 - **Broader** "view of things than what is considered to be conventional medicine. Odile
 - "Gentler practices" Evelyne
 - **Global:** " There is a link with the psychological too. Your body is whole. It took me a long time to see things like that. I do what I like and do myself good. It's a whole. [...] My body spoke to me. There are people of my age who have this vision and a post-natal physiotherapist. In my generation, some people understand." Margot
 - « **Humble** » Jean-Christophe

NOMADe

AVEC LE SOUTIEN DU FONDS EUROPÉEN DE DÉVELOPPEMENT RÉGIONAL
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