

Workshop

Experiential Knowledge

Chair: Femke Boelsma

Programme:

1. Nancy Lievyns (Grip): “Nothing about us without us - How to fulfill participation”
2. *Poem* by Ymke Kelders
3. Jacqueline Kool (DSiN): “Lived Understanding: Experiential knowledge with disability (studies) research
4. *Poem* by Ymke Kelders
5. Exchange of ideas

- **Nancy Lievyns
(Grip)**
- **“Nothing about us without us -
How to fulfill participation”**

Ymke Kelders: The dance of day

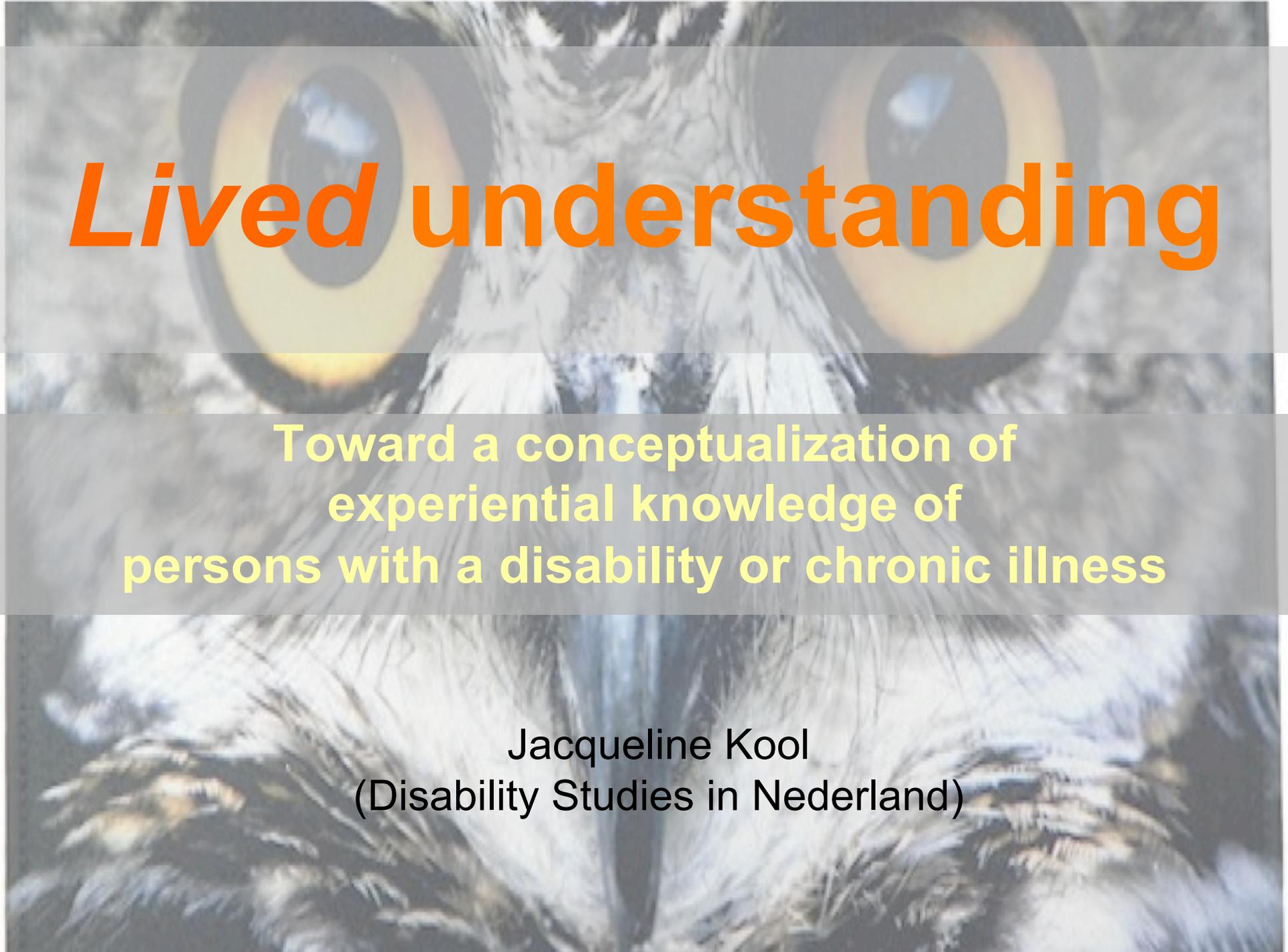
As you turn the lights on in the morning
and whisper gently in my ear
While removing the blankets with a warning
I can smell you're near

You touch my legs that spent the night in stiff position
And I feel your fingers on my knee
Every muscle changes in transition
It's this move that sets them free

When you hold my glass and fill the dryness of my mouth
Wipe the water drops that go down my neck
You wait patiently as I swallow loud
My body doesn't feel like such a wreck

You put me down on the toilet and give me time to pee
You wash my hands, my face, my shoulder
And gently kneel beside me
I know you are the beholder

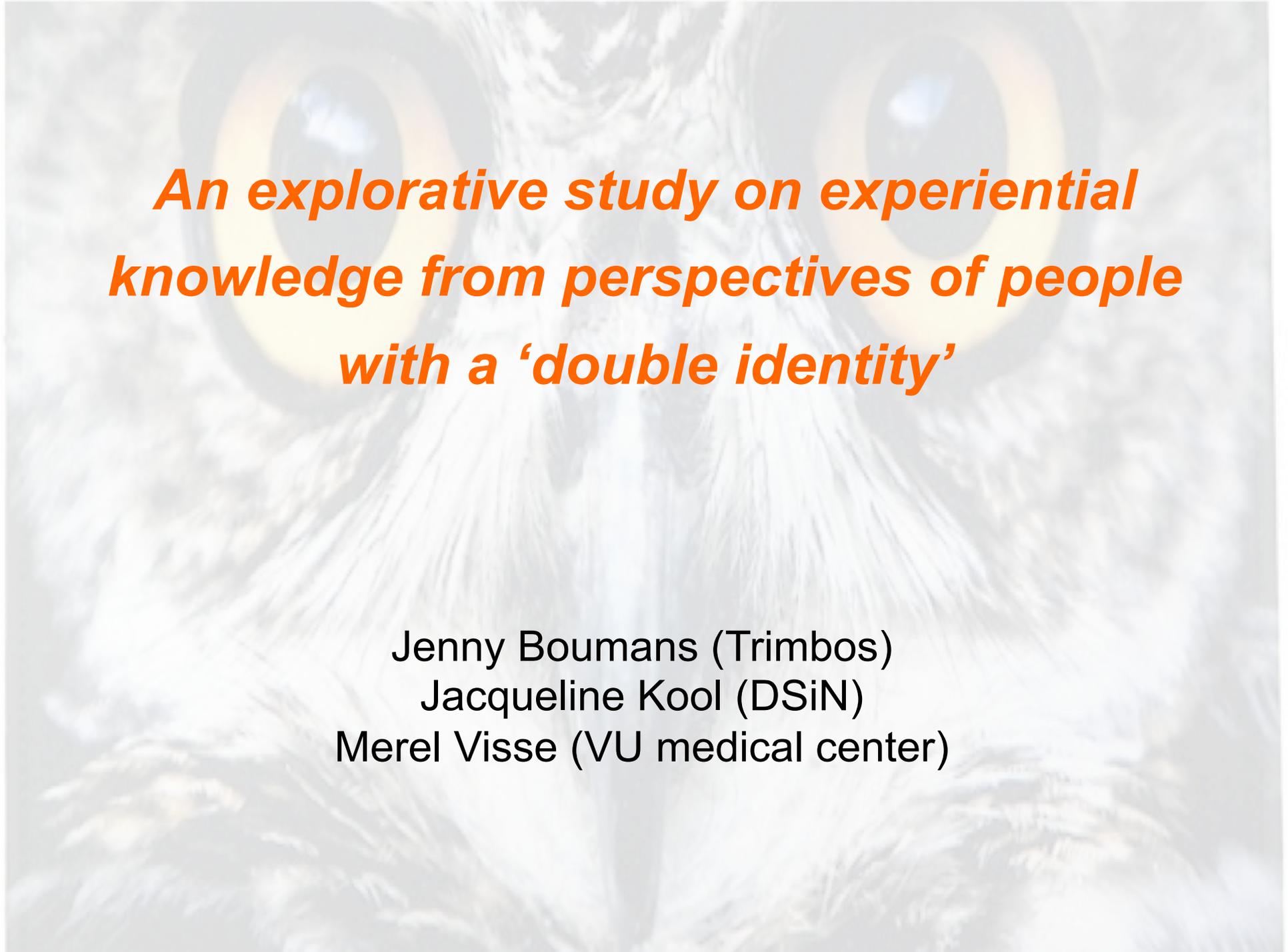
Through you
I still belong to me

A close-up photograph of an owl's face, focusing on its large, yellow, circular eyes. The owl's feathers are a mix of grey, white, and brown, creating a textured background. The image is slightly blurred, giving it a soft, ethereal quality. The text is overlaid on this image.

Lived understanding

**Toward a conceptualization of
experiential knowledge of
persons with a disability or chronic illness**

Jacqueline Kool
(Disability Studies in Nederland)



***An explorative study on experiential
knowledge from perspectives of people
with a 'double identity'***

Jenny Boumans (Trimbos)
Jacqueline Kool (DSiN)
Merel Visse (VU medical center)

Purpose

To contribute to theoretical framework on the nature, meaning and relevance of experiential knowledge of persons with a disability

Background



Four main questions

- What is experiential knowledge? How does it originate?
- What is the role and meaning of experiential knowledge?
- How can we benefit from experiential knowledge in scientific research? What are prerequisites for the use of experiential knowledge?
- What is the relationship between experiential knowledge and scientific and professional knowledge?

Images and metaphors of experiential knowledge



a funnel

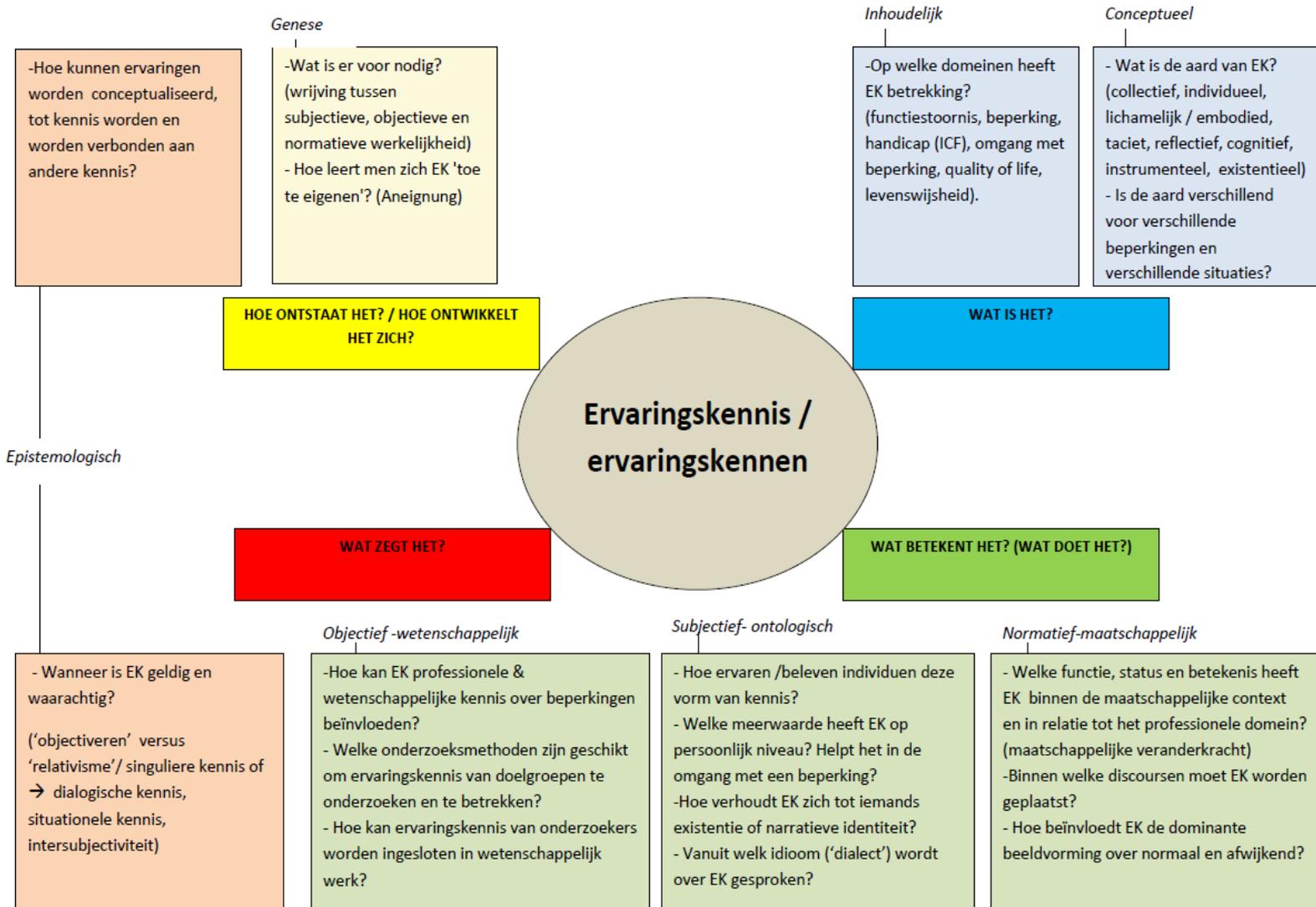
Method

- Responsive approach
- Persons with 'double identity'
- Expertmeetings
- Questionnaire
- Email-questionnaire
- Member check, analysis and interpretation
- Conceptmapping

Images and metaphors



A map of experiential knowledge



What is experiential knowledge?

- existential & societal
 - lifeworld
 - *lived* knowledge
 - multiple meanings
 - practical wisdom
- performative knowledge
- collection of subjective, objective and normative knowledge
 - identity
 - socially situated
 - embodied
- process of understanding
- complex, plural, holistic
 - disruptive

What is it?

- ‘Knowledge that has been acquired by (conscious or non-conscious) reflection on experiences that (mostly) are related to a chronic illness or disability’. (respondent questionnaire)
- ‘To me, experiential knowledge is a form of ‘unique wisdom’: a form of *lived* knowledge’ (expertmeeting)
- ‘You could say that experiential knowledge is something that exists ‘between’ people, instead of within people themselves’. (respondent questionnaire)

Images and metaphors

Being on a
Flyingcarpet



How does experiential knowledge originate?

- ‘Everybody has experiential knowledge and it is knowledge you gain by what you experience and knowledge you gain by thinking about what you experience.’ (expert)
- ‘In a way it is hidden because of certain circumstances. Experiential knowledge is made latent, people have the knowledge, but it is not addressed to it that way, that it is knowledge. (...) It concerns the activation of knowledge that is already present, and its further development (expert)
- ‘It originates from a feeling of alienation, how people view you, how they categorize you. (expert)

Images and metaphors



What is the content of experiential knowledge? (1)

- From practical tips to wisdom
- All-embracing – covers all areas of life
- Four domains:
 - 1. Handicap/ disability; symptoms, course, barriers, coherence
 - 2. How to deal with handicap/disability; effects/ response person and environment
 - 3. Impact on QoL; barriers and facilitators (individual, societal) (NB vgl ICF)
 - 4. Life experiences/wisdom; non-disability related

What is the content of experiential knowledge? (2)

- “Learning how to cope and accept, more than healthy people.” (questionnaire)
- ”To me, experiential knowledge entails more than just the practical issues of living with a disability. From my own viewpoint, what matters is especially the emotional/psychological development and your position within society.” (expert)
- “Knowing that life is not always fun. But despite that: create meaning. That is a part of experiential knowledge that provides self-confidence.” (expert)
- “Layered: you go into depth, more and more existential”;
“Experiential knowledge is being aware of the vulnerability of existence and knowing that life continues.” (questionnaire)

Putting things into perspective & humor

- *“We may question whether wisdom increases.”*

Images and metaphors



inhalor

What is the role (and value) of experiential knowledge?

- ▶ Value of experiential knowledge in our society:
 - Change of perspectives / alternative logic
 - Impetus for societal change
 - Imaging of normal and different
 - Sensitive for ‘stories behind stories’
 - Dialogue <> Tensions
- *‘My own experiential knowledge (and education, experiential knowledge is not positioned in a vacuum) makes that I might better understand that normal is just an agreement/convention.’ (questionnaire)*

What is the role (and value) of experiential knowledge?

▶ Personal meanings

- Practical & existential
- Capacity to...
- Sensemaking & coping with setbacks
- Part of identity and lifestory

‘Experiential knowledge is not a goal, but a means to live your life within physical boundaries, to your own choice’ (questionnaire)

What is the role (and value) of experiential knowledge?

- ▶ Normative role
 - Beyond alienation
 - Understanding and support of the collective
 - Drive: contributing to change!

‘Experiential knowledge is knowledge that emerges from perceiving and acting from the features of my own body and brain. And from a certain moment I notice that this is not the average knowledge. (...) Knowledge by which I notice I deviate from the norm’ (emailquestions)

Images and metaphors

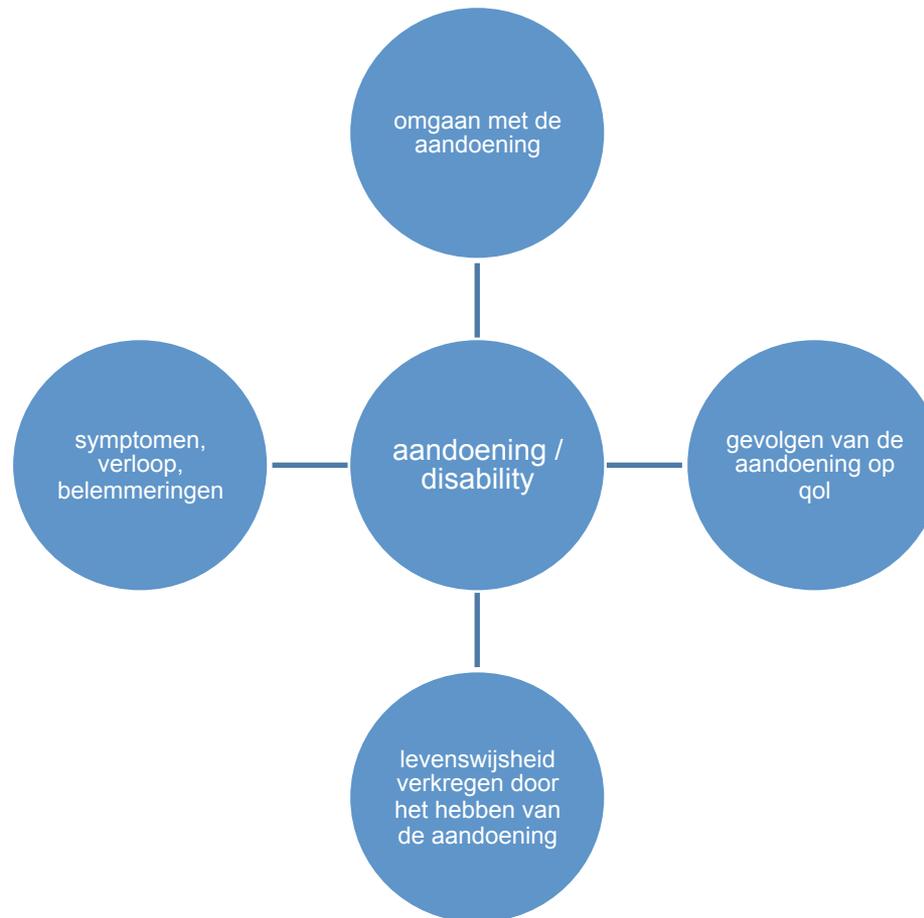


A ducttape mug

Reflection

- Complex
- Layered
- Sometimes a confusion of tongues:
- three positions of the object of experiential knowledge

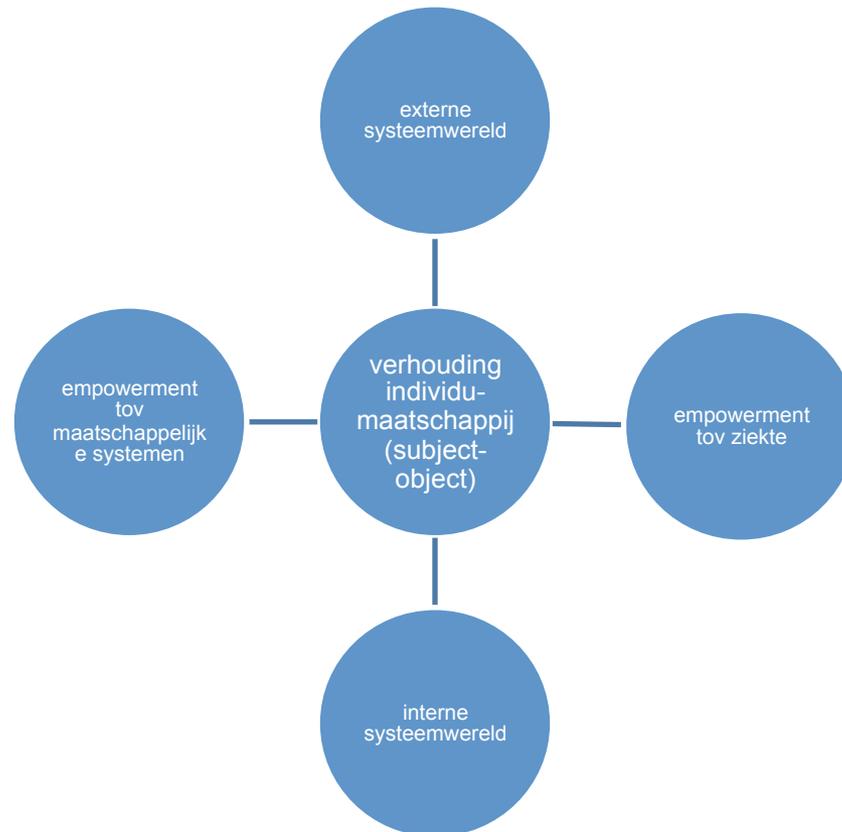
A. The object is the disease or disability



B. *The object is biographical individuality*



C. Het object is the relationship between individuality, disease and society



Conclusion: Seeding document...



Ymke Kelders: Uncontrollable movements

As I lie awake in bed
I open and I close my eyes
Press my leg to the mattress and as it rise
I get up and feel my head

Through the hallway there I move
Controlling every step, hoping you won't be there
Wishing that without informing you went everywhere
It's that image I want to prove

But when I come closer I already hear
Your stuffy breath and silent bones
Prostheses that are attached as clones
I hope these uncontrollable movements will never disappear

As I walk back my whole body feels heavy and strong
I know that you long, for that feeling of total control
Once again I wish I was wrong

**Discussion
&
Exchange of Ideas**