Crossing that line! Recognition of Experiential knowledge of health care professionals *and* client is the key link in transforming health care and social care.

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Crossing that line…

How can we solve the We and Them

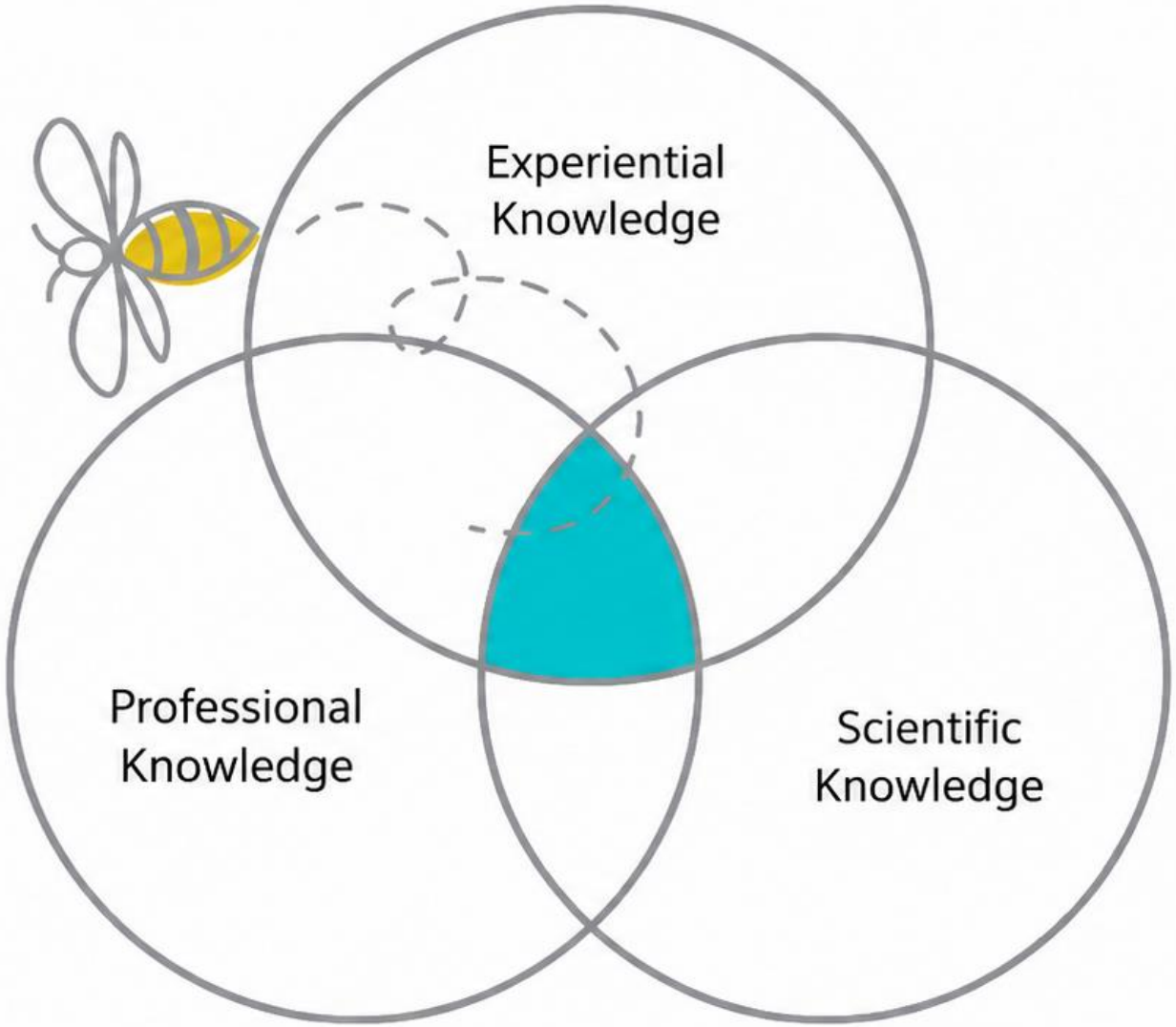
We know that an equal and reciprocal relationship is powerful

Blurring the position of health care professional and patiënt

Crossing the lines of several types of knowledge

The standard: evidence-based medicine

Separate types of knowledge
in separate roles?
Experiential knowledge has the lowest status



Scientific knowledge
Is general and abstract, and deals with averages when it concerns effectiveness research.

Practical professional knowledge (can also be scientific)
Is the "tailoring" of standardized procedures and general knowledge to practical situations. It involves knowing from professional experience how to approach something in changing contexts. *"Knowledge in action."*

Experiential knowledge (can also be scientific)
Is the lived experience of disruptive and disempowering situations of suffering. It is knowing "what it is like to…" and having learned how to cope with it. It involves an insider's understanding of the complexity of the lifeworld and subjective experience. Knowledge that you can feel.

We stand for.....

- Experiential knowledge is crucial for good quality care.
- Experiential knowledge should be available at all levels and in all functions in the organization.
- Experiential knowledge is as important as scientific knowledge.
- Only focusing on peer support workers is counterproductive.

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Experiential knowledge is paradoxical

You would rather not have this – shameful - knowledge about failing, powerlessness and exclusion.

That is why professionals and researchers make their own personal experiences invisible.

At the same time, they want to collaborate with people (clients) who are invited to use their experiential knowledge.

The experiences on which experiential knowledge is based are often difficult to put into words.

- Having experienced the limits of existence;
- Experiences of exclusion and disruption;
- A position often burdened by stigma, judgement, and shame;
- Experiences for which words are often lacking;
- It may be dangerous to talk about it;
- Or because they fall outside the ordinary order and have often been rendered invisible;
- Or because they evoke pain within oneself, and discomfort and helplessness in others.

The contribution of experiential expertise in contact with individuals

- Connecting on a different level, building trust & empowering Interpreter/translator of emotions
- Equal and reciprocal contact
- Breaking through shame and reducing stigma; normalising, feeling “less strange” (“I’m not the only one”)
- Generating hope and offering future perspective: focusing on what *is* possible!
- Addressing injustice and exclusion
- Giving practical tips and explaining (“what helped me”)

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What are the organizational and societal benefits of strengthening experiential knowledge?

- Improvement in the quality of care
- It reduces the burden on healthcare through greater shared responsibility
- It acknowledges the knowledge and expertise of clients and their loved ones (and of professionals who have themselves been clients).
- It connects healthcare with the everyday lived experience
- It contributes to the vitality and wellbeing of employees
- Reduction of stigma
- Sustainable solutions require recognition and ownership

Experiential Knowledge framed as PEPPER

- **Practical:** it is about how to survive on the streets or in the aftermath of abuse or trauma;
- **Existential:** you *know* what it is like to be at the boundaries between life and death; to experience existential loneliness; to be trapped and no longer feel free; to feel desperate; to want to erase yourself because of shame and guilt;
- **Politically critical:** it exposes injustice, neglect, and exclusion; it raises questions of human rights (e.g. the legal case brought against the Dutch state by Manon Kleijweg);
- **Personal:** your motivation and knowledge are grounded in personal experience;
- **Ethical:** it is based on equality, reciprocity, humanity, and freedom of space;
- **Relational:** it develops through exchange and interaction.

Recognizing and using experiential knowledge

- Connecting
- Understanding
- Ensuring
- Strengthening

Arts Based methods

- We use it when collecting, processing, interpreting, and implementing data.
- It gives expression to embodied experiences and experiences that are difficult to put into words or painful.
- It continues where language ends.
- It does justice to the complexity, ambiguity, and ambivalence of data.
- It gives expression to pathic knowledge.
- It combats epistemic injustice.
- Strives for catalytic validity: is capable of transformation

Co-creating a Musical about Suicidality and Other Forms of ‘Misunderstood Behaviour’

“Experts by experience are often passionate and deeply committed.

They do not work by the clock.
This can also lead to burnout.
The butterfly symbolizes the
freedom and space that
are needed, but its wings
can also be burned.”

We stand for…..

- Experiential knowledge should be available **at all levels** and **in all functions** in the organization (also social workers, nurses, psychiatrists and psychologists should be encouraged for a ‘coming out’ with their experiences with mental health problems).
- Experiential knowledge is as important as scientific knowledge.
- Only focusing on peer support workers is counterproductive: professionals, managers, directors should develop their experiential knowledge so a cultural change can happen “So that a culture emerges in which there is space for everyone to share experiences of disruption and recovery. Breaking down the ‘us’ (the professionals) and ‘them’ divide.”

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Some resources

- *Beroepscompetentieprofiel Ervaringsdeskundigheid* (2022). Utrecht: Movisie.
- Kwaliteitssysteem Ervaringsdeskundigheid. KvE - Vereniging van Ervaringsdeskundigen (vved.org)
- Boevink. W. (2017). *Over herstel, empowerment en ervaringsdeskundigheid in de psychiatrie*. Utrecht: Trimbosinstituut.
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- Karbouniaris, S. (2023). *Let's tango! Integrating professionals' lived experience in the transformation of mental health services*. PhD dissertation. Leiden: Leiden University Medical Center.
- Karbouniaris, S., Wilken, J. P., Weerman, A., & Abma, T. (2022). Experiential knowledge of mental health professionals. Service users' perceptions. *European Journal of Mental Health,* 17(3), 23–37. https://doi.org/10.5708/EJMH/17.2022.3.2
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- Slooten, M. van, Sprinkhuizen, A. & Weerman, A. (2023). Inzet van ervaringsdeskundigen in de ggz en aanpalende sectoren. Een inventarisatie. *Participatie en Herstel*, 2, 5-17.
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