Let's tango! Integrating professionals' lived experience in the tranformation of mental health services

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Summary

Introduction

Modern mental healthcare is confronted with challenges on its path of transformance towards recovery-oriented practice, which includes the professional use of experiential knowledge. The integration of lived experiences with mental health problems poses a problem in particular, due to the undervaluation of experiential knowledge in the professional domain and the ongoing presence of strong hierarchical medical-oriented institutional structures. This hinders the further transformation of modern mental health care.

In light of this, this research was aimed at the positioning of experiential knowledge in modern mental healthcare, to value, develop and harness experiential knowledge as a (re) source for organisational transformation.
The main question of this research was: what is the value and perceived impact of professionals' lived experience with mental distress, and how can mental health services integrate experiential knowledge?

The following sub-questions were answered:
1. What can we learn from studies worldwide about professionals harnessing experiential knowledge?
2. What is the value of professionals' experiential knowledge for service users?
3. What dilemmas and challenges do mental health professionals (nurses, social workers, humanistic counsellors, psychiatrists) face when transforming lived experiences into experiential knowledge (including the implications for professional identity)?
4. How can experiential knowledge be (further) developed and integrated into mental health organisations?

Methods

This research took place at three mental health organisations and one addiction care centre in the Netherlands. The collaboration as part of the PEPPER consortium[iv] and the ability to work with multiple stakeholders, including the first person's perspective of the researcher, thereby engendering multi-perspectives, were unique aspects to this research.

We conducted both a literature study and an empirical study, consisting of case studies involving participatory action research, including communities of practices, in-depth interviews, participatory observations, responsive evaluations, and auto-ethnography.

Findings

The theoretical part of this research underlined that the mental health system worldwide is still undergoing transformation in order to meaningfully incorporate lived experience of traditional professionals. This research uncovered numerous conceptualisations of experiential knowledge. Moreover, to date mainly nurses and social workers are speaking out about their own experiences with mental health distress. Only a few former studies researched service users' recovery.

iv The PEPPER consortium aims to stimulate and professionalize the use of experiential knowledge and -expertise of professionals.

These studies yielded positive outcomes, such as: feeling recognised and heard, increased trust and motivation, attaining new understandings of recovery, and increased hope.

The empirical study of this research project suggested that the use of experiential knowledge is transformative. Experiential knowledge manifests in a compassionate user-professional relationship. Service users valued and emphasised the relevance of a relationship based on common ground, in which personal disclosures of distress and resilience of the professional are embedded. As a result, users were often encouraged in their recovery process to an existential degree, and by finding renewed hope. Unsurprisingly, the degree of proximity in the relationship is also a matter to be balanced and attuned to both the user's needs and the professional's personal-professional working style. Purposeless disclosures and over-involvement of professionals were described as a red flag in user-professional relationships.

Different mental health professionals in the consortium were in the process of integrating their lived experiences into their professional roles. For nurses, humanistic counsellors and social workers, this affected both their personal-professional development and how they related to service users and colleagues, as well as their position in the organisation. Specifically, it affected them in terms of perception, which is why these professionals often felt proud but sometimes also ashamed.
While the use of experiential knowledge brought up complex trauma and negative childhood experiences for some professionals, other professionals were less affected by these experiences and integrated their distress seemingly effortlessly into their professional identity.

Contrary to the aforementioned professions, the use of experiential knowledge by psychiatrists was in a premature stage. In addition to the considerations of all mental health professionals when harnessing lived experiences, they were also curious about the clinical relevance of such experiences. They feared sharing experiences would compromise their professionalism and lead to judgement by their peers. By exploring these reservations in a peer supervision setting, they discovered that sharing experiences with open-minded colleagues is different from what they had learned about disclosure in clinical training. This demonstrated the demystifying, destigmatising and humanising potential of experiential knowledge to this group.

A further implementation of experiential knowledge in existing services required investments in the positioning of lived experiences, human resource management and professionalisation. According to this research, social change starts from a bottom-up movement and should be simultaneously facilitated by the top-down policy. It required dialogical and action-oriented strategies to motivate and engage all stakeholders in this mutual learning process.

Discussion

At a micro-level, we discussed that relational ethics seem part of the ingredients of working with experiential knowledge, alongside working in a trauma-sensitive and a positive risk-taking stance.

Some of the service users stated they profited from the reparative and reconnecting elements in the relationship with their professional, and the resulting earned attachment.

Professionals (nurses, social workers and humanistic counsellors) who decided to transform their lived experiences to experiential expertise, were faced with a balancing act in terms of having to cope with instability and re-stigmatisation due to the wounding that (re)surfaced. The majority however went through post-traumatic growth.

For clinicians (psychiatrists), the use of experiential knowledge was in an earlier stage. They used peer supervision to explore the barriers and facilitating factors of sharing experiential knowledge. They had to contest with peers in the field who strived to depersonalise and standardise the rendering of care services.

At a meso-level, we discussed the need for critical political activism and change management in organisations more broadly. The claim of formalisation and the existing threat of encapsulation are valid; however, by providing (discretionary and reflexive) space, experiential knowledge can be legitimised rather than standardised. While it is difficult to introduce life-world logic into predominantly hierarchic discourses like mental health care settings, effort should be undertaken so that different forms of logic can co-exist and lead to mutual learning.

At a macro-level, we discussed that in addition to market, bureaucracy and professionalism, a fourth force has been identified: collaboration. This fourth form of logic represents important social moral values, such as justice and self-development. Professional use of experiential knowledge can form part of it and can lead to rehumanising of services and make visible the (oft-subtle) systemic inequalities that recur in recovery-oriented practices.

The implementation of experiential knowledge in existing service systems requires further investment and attention, as it is both complicated and context-dependent. It will be difficult to reconstruct current systems, as the current field is more and more divided into recovery initiatives on the one hand and hyper-specialist services on the other hand. However, both are in dire need of (professional) experiential knowledge and expertise.

Conclusion

This research uncovered the relevance of experiential knowledge used by established mental health professionals. While its use is still sparse and organisations are struggling to meaningfully incorporate the lived experience perspective in practice, the available qualitative data indicate positive outcomes for those that succeed in this integration. Based on our research, the value of experiential knowledge is captured in relational ethics, practical and emotional insights, existential transformation, and emancipatory politics. In conclusion, the experiential knowledge of professionals has an empathising, normalising, humanising, demystifying, destigmatising and empowering impact on mental health services.

Implications for practice and research

Implications for practice concern the opening up of space for harnessing experiential knowledge by multiple stakeholders. More specifically, there is a need to include experiential knowledge in education and training. In practice, the use of experiential expertise as part of evidence-based practice is needed. Investments in trauma informed recovery oriented care are similarly important. Recruiting and training professionals with lived experiences is vital. Organisations should invest in specific actions and open dialogues with multiple stakeholders, to produce a change in the systems that created the problem, i.e. the splitting of knowledge.

In future research, we recommend incorporating experiential knowledge in all stages of the research and innovation process, including the approach and analysis. Future research should more specifically focus on groups that hold reservations about the topic, e.g. psychologists and psychiatrists. More insights on the requirements for further acknowledgement of this type of knowledge are desirable as well. Collaboration between different types of professionals in teams could advance the use of experiential knowledge. This means that joint research and training are needed. Lastly, more research on the impact of trauma and attachment in professionals with lived experiences is relevant as well as research on how they relate to clients. Such research should also explore the contributions of non-verbal and body language-based approaches to those impacted by all forms of trauma in order to make use of embodied knowledge.