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

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Chapter 7

General discussion

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In this research, we have explored the use of experiential knowledge derived from the lived experiences with mental health challenges of professionals and its possible contribution to mental health services. A significant oversight within the recovery movement is the fact that a substantial number of mental health professionals also have personal lived experiences as service users.

In light of this, we asked ourselves: what is the value and perceived impact of professionals' lived experience with mental distress, and how can mental health services integrate experiential knowledge?

We studied the use of experiential knowledge from a theoretical and an empirical viewpoint, navigating the different contexts in which lived experiences from professionals emerge in mental health and addiction care. At the outset of this research, we aimed to expand the space for experiential knowledge in mental health care as part of the mission of the PEPPER Consortium[iii] .

This led us to conduct both a literature study and an empirical study, consisting of practice-based participatory action research including communities of practice, in-depth interviews, participatory observations, responsive evaluations and auto-ethnography.

First, we return to the findings from our studies, followed by additional micro-, meso- and macro-level reflections. We then conclude with an answer to the main question regarding the value, perceived impact and integration of the experiential knowledge of professionals for mental health services. In the subsequent sections, we clarify the methodological considerations and hint at future directions. We then conclude this chapter with a summary, both in English and Dutch.

Main findings

Chapter 2

In the first study, we reviewed the use of experiential knowledge by traditional mental health professionals and its possible contribution to the recovery of service users. By means of a systematic scoping review, 15 articles (reporting mostly Western research) were selected for further analysis.

The mental health system is in the process of transforming itself, to meaningfully incorporate the lived experience perspective from traditional professionals. The conceptualisation of experiential knowledge was found to be varied, differing from therapeutic self-disclosure embedded in psychotherapeutic contexts to relational and destigmatising use in recovery-oriented practices. Nurses and social workers in particular are speaking out about their own experiences with mental health distress.

iii The PEPPER consortium aims to stimulate and professionalise the use of experiential knowledge and expertise of professionals.

Experiential knowledge stemming from lived experience affects the professional's identity and the system as a whole.

Only a few studies explored the outcomes of service users' recovery. Despite the body of knowledge from the practice of experts by experience and peer support workers increasing, only a small subset of literature reports on the use of experiential knowledge by traditional mental health professionals. Nevertheless, the available data indicates positive outcomes for service users, such as feeling recognised and heard, trust and motivation, and attaining new understandings of recovery and increased hope.

Chapter 3

In the second study, we explored the perspectives of service users (n=22) regarding their healthcare professionals' use of experiential knowledge and the meaning of this use on their recovery.

Their healthcare professionals, mainly social workers, nurses and humanistic counsellors, were trained to harness lived experiences as a complementary resource. In addition to the matters uncovered in the literature review, we learned that the use of experiential knowledge manifests in a qualitative compassionate user-professional relationship. Service users emphasised the relevance of horizontality in the relationship, created by personal disclosures of distress and resilience of the professional. This often stimulated the users' recovery processes in the existential sphere, i.e. in terms of feeling empowered and finding new hopes and perspectives in life.

However, this degree of proximity had also to be balanced and attuned to the user's needs as well as the professional's working style. Purposeless disclosures and over-involvement were mentioned as important red flags. Service users stated to profit conditionally from a mutually shaped relationship, having access to the professional as a type of peer. Some also pointed out the relevance of a professional as in a parental role, referring to the positive transferences they experienced. This seemed particularly relevant to service users who had been in care for an extended period, and it may be related to attachment styles in both users and professionals. Overall, the use of experiential knowledge by mental health professionals was valued as an additional (re)source.

Chapter 4

Subsequently, in the third study, we explored the perspectives of mental health professionals (n=15) who were in a process of integrating their own experiential knowledge in their professional roles as nurses, social workers or humanistic counsellors.

We looked at the dilemmas and challenges faced when transforming lived experiences into experiential knowledge and the implications this has for their (professional) identity. The actual use of experiential knowledge by mental health care professionals in their work affected four levels: their personal–professional development (i), their relationship with service users (ii), their relationship with colleagues (iii), and their position in the organisation (iiii). Professionals with lived experiences took on their new role with grace, demonstrating bravery and resilience.

Having dealt with mental health distress themselves, they risked rejection by colleagues, their position, and sometimes even their personal well-being. Professionals underwent personal-professional development as part of their training, in some cases leading to relapses. While working with experiential knowledge in some cases interfered with complex trauma and adverse childhood experiences, which became reactivated, other professionals seemingly naturally integrated their distress into their professional identity.

Professionals with lived experiences can in fact contribute to the expansion of experiential knowledge in the broader organisation by seeking collaboration with peer support workers, but also with supervisors, managers and policymakers. According to this study, social change starts from a bottom-up movement and synchronously should be facilitated by the top-down policy. Investments in the entire organisation seemed necessary to transform governance, policy and ethics in the working environment. This is elaborated in Chapter 6.

Chapter 5

In our fourth study, we explored the perspectives of psychiatrists (n=8) with lived experiences and their considerations when integrating personal experiences into the professional realm. Although the decision to become a psychiatrist was often related to personal experiences with mental distress and though some feel the need to integrate the personal into the professional, the actual use of lived experiences in this profession is still in its early stages of development. A group of eight Dutch psychiatrists explored the possible value of their lived experiences with stress, trauma, complex family histories etc. in a peer supervision setting. The related findings reveal three main aspects to be considered as regards harnessing experiential knowledge: the personal (i), professionality (ii) and clinical relevance (iii). The psychiatrists looked for opportunities to process, reframe and meaningfully put their experiences to use in the patients' recovery process. At the same time, the fear that those insights are not perceived as 'professional' and are considered a devaluation of the profession sometimes held them back from openly sharing their considerations. The peer supervision setting in this study encouraged sharing personal experiences in a manner other than disclosing them in purely technical terms. This led to mutual recognition, led participants to re-associate their personal background with their clinical practice, and stimulated a learning process on how to incorporate lived experiences in a constructive manner contributing to the demystifying, destigmatising and humanising potential this holds.

Chapter 6

Mental health organisations are struggling to more widely implement experiential knowledge. In light of this, we conducted a multiple case study in 3 mental health organisations and one addiction care facility. These organisations were part of the consortium (PEPPER) and committed to learning from and advancing the use of lived experiences. All aimed to (further) develop and integrate experiential knowledge. For the implementation of experiential knowledge throughout the organisations, three areas appeared important: positioning of lived experiences (i), human resource management (ii) and professionalisation (iii).

The implementation of experiential knowledge within mental healthcare organisations requires a dialogical and action-oriented strategy to motivate and engage all stakeholders in a mutual learning process concerning issues related to the positioning of lived experiences, the development of resources, and the facilitation of professional development while viewing formalisation an opportunity to claim space to work with lived experience.

Reflections

Micro-level: the perspective of professionals and service users

Professionals who harness experiential knowledge were valued for their relational ethics, i.e. mutuality, engagement, recognition and a compassionate working alliance. Service users indicated that the relationship significantly promoted a sense of connectedness and empowerment, thereby preventing re-traumatisation (Carson & Hurst, 2021). Service users in our research also valued the way professionals countered shame, (self-)stigma and, consequentially, feelings of loneliness. In line with the literature (Blank *et al.,* 2016; Byrne *et al.*, 2019), professionals with lived experiences can help in overcoming barriers of shame and stigma and evoke a sense of belonging. This sensitivity to stigma encouraged users 'to stand up and be out and proud in the open', and some of the service users considered themselves or were already on the path of becoming an expert by experience. The personal stories were shared by their professionals not in the name of self-centeredness or to elicit sympathy but simply to acknowledge common ground. They acted as a living example, offering hope and inspiration for recovery. Altogether, if managed and balanced well in the relationship, the use of experiential knowledge by mental health professionals offered a complementary resource for service users' healing and recovery.

Trauma sensitivity

Interestingly, service users were on average very positive about professionals putting their lived experiences to use. They not only referred to their warm, compassionate and authentic attitude, they also implicitly and explicitly referred to a trauma sensitivity. Apparently, professionals were appreciated for listening to the story of 'what happened', making investments to build trust, promoting agency and asking for feedback; this all resembling the concept of recovery-oriented trauma-informed practice (Institute on Trauma and Trauma-Informed Care, 2015). Such professionals focus on the healing and transformation processes rather than on 'fixing' people (Twombly & Schwarz, 2008).

Evidently, not all of the professionals in our studies mentioned having experienced trauma, and this was also not the main focus of our research. However, a growing group of lived experience professionals in the Netherlands has spoken up about their adverse (childhood) experiences.

While not all life events lead to actual distress or illness, a broad cluster of negative events can be considered traumatic, e.g. sexual & physical abuse, emotional & physical neglect, being exposed to mental illness or inconsistency of parents, growing up in poverty, being a refugee, being exposed to war/criminality, being discriminated against, being exposed to bullying, or being exposed to human trafficking (Herman, 1997; Van der Kolk, 2014).

In this regard, trauma is seen as a transdiagnostic vulnerability and a mediating and moderating factor (Marsman, 2021; Vinkers *et al.,* 2021).

Positive risk taking

In close relationships, the negative phenomena of psychological enactments and collusions are reasonably likely to occur due to the level of proximity and identification. Relationships may easily transgress professional boundaries. Paradoxically, the interviewed dyads in this research did rarely find themselves at odds, even while sometimes being subject to difficult and complex situations.

Arguably the strong rapport, identification and sometimes feelings of (counter-) transference between service user and professional might have blurred boundaries. However, service users emphasised the importance of a positive risk-taking stance. We theorise that both professionals and service users recognised possible obstacles at an early stage and turned them into opportunities for healing. The transparency and openness of professionals contributed to this. This means that professional disclosure with user-focused intent, paired with reflexivity, seems paramount. On the other hand, the negative side effects of non-disclosure and withholding lived experiences by professionals are hardly questioned. Also, the perception of what constitutes a risk is highly related to context, culture and ideology.

Contemporary mental health care is characterised by a fixation on risk management and thinking in terms of risks, which is often about controlling threats (Rose, 1998). Survivor movements plea for the dignity of risk and the nature of trust, as it promotes self-determination, autonomy and freedom (Martinelli, 2023). The right to take risks trumps the overprotective and paternalistic attitudes often seen in mental health care.

Earned attachment

Service users are also likely to have profited from the reparative and reconnecting effects of professionals' modelling and reparenting capacities. The appearance of earned attachment later in life seems of reasonable relevance to this particular group. While for years, many scholars assumed that once a primary style of attachment is established in childhood, it will not alter much as the child grows, recent studies demonstrate that the opposite is true (Dansby Olufowote *et al.,* 2020). Earned secure attachment is most often built through healthy, meaningful relationships in adulthood, with a spouse or professional, or through the vicarious experience of secure attachment through parenting your own children (Fisher, 2017). Safe attachment relationships are considered to be the setting in which early emotional injuries are most likely to be healed (Wallin, 2007). The fact that nurses and social workers in general spend more time in and move closely to the personal sphere of users seemed a natural fit in this regard.
In this sense it's vital to look at the relevance of non specific factors in relationships, especially in the context of staff shortages, personnel change and short-term services. Also, the formerly experienced lack of involvement of service users in the creation of social meaning in mental health care, the so-called 'hermeneutical marginalisation', (Fricker, 2007) may be positively corrected by professionals with lived experiences.

In fact, some of the service users in this research emphasised the relevance of creative, sometimes non-verbal communication and resonating qualities of their professional. The ability to understand the unspeakable refers to intuitive aspects of communication and suggests that professionals with lived experiences use their intuition. In addition to mental health workers' reflexive and methodological frameworks, lived experience professionals manage to embed intuitive aspects in their work. How did professionals with lived experiences develop this creativity?

From lived experience to experiential knowledge

Professionals with lived experience have the expertise required to support people living with mental health conditions in various aspects of daily life. Their first-hand phenomena-based experience of certain conditions complements the standard of care (Castro, 2018). From the literature, we already know that experiential knowledge becomes expertise through reflecting on it and starting to integrate this into the professional practice. Accordingly, harnessing experiential knowledge comprises a three-fold process (Timmer, 2009), starting from the lived experience of suffering and recovering from a mental health condition (1), reflecting and learning from it both personally and collectively (2) and developing skills and attitudes to adequately support others (3). This often implies a process of post-traumatic growth and coming to terms with a difficult situation while finding new meanings. Recovery is a process of overcoming, requiring strength, resilience and social support. It is also connected to other narratives and recovery elements overlap, meaning recovery has a collective value.

Balancing act

Whilst working with experiential knowledge in some cases interfered with complex trauma and adverse childhood experiences, which became reactivated, other professionals seemingly naturally integrated their distress into their professional identity. Even though many lived experience professionals, including traditional professionals, transformed their crises and traumas into something constructive, it would be disingenuous to claim that sharing mental health histories candidly is free of risk. Judgement, intolerance and stigma are still prevalent in contemporary mental health culture. Professionals who make their own experiences known risk alienation, like 'othering'. In some cases, professionals' trauma (re)surfaced and the disclosure led to an entire or temporary breakdown of their job while these professionals also had to deal with re-stigmatisation, secondary traumatisation and compassion fatigue. This delicate balancing act between full, candid disclosure and not disclosing at all, seems to be a point of attention in particular for already established professionals, like nurses and social workers.

Post-traumatic growth

Notably, the majority of the professionals underwent a process of post-traumatic growth. Post-traumatic growth typically refers to the enduring positive transformation experienced as a result of adversity, trauma, or highly-challenging life circumstances (Jayawickreme *et al.,* 2021). Professionals in our research overcame the division of roles and knowledge types. They expressed they could not remove the personal from the professional context anymore. The integration of this (previously double) identity was supported by reflexive and oft-intuitive ways of working.

We wondered how this would apply to the (highly educated) psychiatrists and psychologists, working in key positions in mental health care. Interestingly, the literature review already showed that in general, the clinical professions hold reservations to approach the professional-client relationship on equal footing, while the frameworks of social workers and nurses show more openness towards incorporating experiential knowledge (Leemeijer & Trappenburg, 2016). Given their medical leadership and end responsibilities, psychiatrists generally have a large impact on the culture and organisation of mental health care.

Clinicians' self

Soon after the start of our fourth study, a group of psychologists in the PEPPER consortium united to work on the involvement of experiential knowledge in new training curricula. Unfortunately, we did not manage to involve this emerging group in our research. The study with psychiatrists with lived experiences however showed that the integration of a (double) identity was considered to be very exceptional and sometimes even troublesome. Consistent with the literature, clinicians rarely disclose personal information in service of their patients. They strongly identify with their profession; in their eyes, 'the job determines their identity' (Stuyver, 2022). As a result, the 'social self' may become suppressed and psychiatrists develop a deep-rooted sense of professional identity over time ('the medical self') which allows them to do the work as demanded, but which identity becomes dominant (Gerada, 2022). This raised the question of if and how self-perceptions are to be altered in this specific group of psychiatrists with lived experiences.

The peer supervision setting set up as part of our study was an attempt to explore the self as a whole. Participants experienced this as a safe space to share personal experiences with vulnerability and suffering rather than disclose these in purely technical terms. It encouraged participants to break the unspoken medical code of silence, as also mentioned by a few others (Martin, Chilton, Gothelf, *et al.,* 2020). In this group, there was space for participants to relativise self-concepts and sometimes be freed from their often-dominant professional identity. Some experienced relief in self-diagnosing and speaking about mental ill-health openly. Unravelling the essence of personal motives for choosing this profession was paramount, to then reconstruct a personal-professional identity. Alike nurses, social workers and humanistic counsellors, the psychiatrists in our research worked on attaining convenience in sharing personal vulnerabilities and processing them into experiential knowledge. This was perhaps most transformative and precarious to psychiatrists, as the profession itself is associated with mastery and invulnerability. In addition to the aforementioned benefits of the use of experiential knowledge by nurses and social workers, the empirical data of our study with psychiatrists point to a strong demystifying impact when using your own personal lived experiences.

Concerning the latter Martin *et al.* (2020) argue that sharing stories of personal vulnerabilities can lessen stigmatised views of mental health, especially in a medical culture where there is neither room for mistakes, nor space for personal shortcomings. Feeling endorsed to use personal lived experience and to look for framings that affirm a social and hermeneutic dialogue, was completely new to the group of psychiatrists in our study. Experimenting with disclosing personal stories to service users and colleagues led to the realisation that withholding personal experiences has its own set of consequences,

as also argued by others (Wallin, 2007). Qualitative studies show that seasoned therapists tend to be more broad-minded towards self-disclosure (Psychopathology Committee of the Group for the Advanced of Psychiatry, 2001). However, they do have to relate to a large population of colleagues and sometimes service users who were socialised in a certain way and sometimes even internalised negative connotations towards such disclosures. They have been 'raised', so to speak, in a system where personal experiences were excluded for a long time.

Meso-level: experiential knowledge in mental health organisations

At present, the wider implementation of experiential knowledge in Dutch mental health organisations still poses its challenges. Even though a substantive part of the workforce in mental health and addiction care is familiar with recovery from mental distress and trauma, it is uncertain whether the related principles are being deployed in mental health organisations, and to what degree the organisations in this research were working in a recovery-oriented manner. However, the organisations all had active ambassadors who pleaded for the use of experiential knowledge. The distinction of knowledge types previously mentioned was here to stay, notwithstanding concrete investments from these ambassadors.

Political-critical activism

Our research builds on the available body of knowledge on recovery, such as the CHIME-model, a widely-endorsed conceptual framework for personal recovery in mental health, being an acronym of Connectedness, Hope and optimism, Identity, Meaning in life and Empowerment (Leamy, *et al.,* 2011). The model argues that mental health professionals and recovery workers in particular can promote recovery in those they work with, by focusing on these five areas. Additionally, the PEPPER consortium had a wider scope throughout the organisations, through political-critical activism. It targeted the dominant logic by claiming space for a life-world perspective (Habermas, 1982).

Critics of experiential knowledge argue for a depersonalised and detached standard of care, for instance by rotating therapists in order not to become attached and stay distanced (Van Minnen *et al.,* 2018). Other sceptical voices of a group staying reserved on this topic, refer to the dark sides of altruism and possible negative aspects of disclosure, which is how the disqualification and devaluation of lived experiences, even unintendedly, swiftly keep occurring. These opinions are pertinent in understanding the ongoing resistance towards experiential knowledge in mental health care. As it happens, Van Minnen and Korrelboom represent a larger workforce of Dutch clinicians who prevail method and protocol over the relationship (Logt, 2019).

At the onset of activities in our consortium, we observed a polarisation between peer workers and established professionals with lived experiences. In search of a broader and joint implementation of experiential knowledge, we navigated both bottom-up and top-down processes and tried to involve actors from all layers of the organisations. It appeared that the positioning of lived experiences, human resource management and professionalisation in the organisations concerned were paramount, yet not naturally established.

In this sense, it is imperative to acknowledge the longstanding de-emphasis of the role of personal lived experiences with disruptive life experiences, adversities, and trauma in mental health practice. A shared mission to make use of experiential knowledge, regardless of roles or functions, would eventually support collaboration between professionals.

Change management

We discovered that the implementation of experiential knowledge within mental healthcare organisations mostly requires a dialogical and action-oriented strategy to motivate and engage all stakeholders in a mutual learning process while viewing formalisation as an opportunity to create space to work with lived experience. Although the employment of experts by experience at the beginning of the 21st century already paved the way for the substantive use of experiential knowledge, different systemic factors such as co-optation hindered its further growth. From our understanding, the expansion of traditional professionals with lived experiences as a group contributed to a stronger workforce, targeting the existing and sometimes subtle stigma and duality, catalysing recovery-oriented care and paving the way for the normalisation of disclosure. In this way, experts by experience and peer workers set the scene for other professionals to speak up about their lived experiences.

Our research showed that investments are needed on different levels, in decision-making and change-making roles, to further the use of experiential knowledge in and outside mental health organisations. This means that we need ambassadors who take the lead in recognising and supporting experiential knowledge, like executives and managers. Some were bold and courageous in sharing and revealing insights from their personal recovery stories, as demonstrated in our last study.
Given that working with experiential knowledge in fact impacts all organisational layers, it could be considered a form of change management which involves strategy, ethics, governance, policy, planning, monitoring, legitimisation, improvement and innovation. As a consequence, this requires a different type of governance: one that facilitates emergence and embraces uncertainty, risks and disruption.

Formalisation or legitimation?

The Netherlands is one of the first countries that developed a novel quality system for the implementation of experiential knowledge in mental health organisations, initiated by the professional body of lived experience professionals (VvEd) and the Dutch Ministry of Health, Welfare and Sport (VWS). This newly-implemented quality system consists of a quality standard, national register, code of conduct, and national learning plans differentiated on six education levels (VvED *et al.,* 2022).

While some oppose such formalisation and consider it as a threat, the current quality system actually claims space to work with lived experiences and aims to specifically legitimise working with experiential expertise in different roles. It aims to create space in the system to enable the use of experiential expertise.

This means that the work of current experts by experience, peer support workers and traditional professionals as well (e.g. nurses or social workers with experiential knowledge)

will be further supported and facilitated. Experts by experience and peer support workers gain a stronger occupational body. For all other mental health professionals with lived experiences (such as nurses), this quality system may counterbalance any processes of devaluation occurring when they disclose their lived experiences. In line with our findings, the standard promotes the general awareness of recovery-oriented care and stimulates working with lived experience perspectives in organisations (VvEd *et al.,* 2022). In this regard, consortia like PEPPER may profit from the quality system, as it involves all actors using experiential knowledge. It mediates strong preferences and opinions in the debate concerning ownership and the paradox of formalisation of a type of knowledge that is – and should remain- inherently subjective in nature.

Conflicting logic

The quality standard underlines two interesting key points: 1) that those who use experiential knowledge should be trained and have access to peer supervision settings and 2) that discretionary space is of great importance when using experiential knowledge (VvEd *et al.*, 2022).

These requirements seem reasonable if not crucial, given the challenging task to reconstruct systems from the inside out, and dealing with conflicting and oft-competing logic: that of the institution and that of life and the world at large. Additionally and even more fundamentally this concerns the ongoing existing knowledge hierarchy: the traditional vertical epistemology. This hierarchy in knowledge types and underlying perceptions on science (positivism) leads to the ranking of knowledge. It hinders a collaborative process of co-creation of knowledge (Abma, 2022).

To advance the use of experiential knowledge, questioning these traditional hierarchies and power dynamics of established professionals and those of the system as a whole seems crucial. While the dominant discourse of traditional hierarchies will be difficult to challenge, these different forms of logic co-exist and confrontation (in the form of unsettling encounters) can result in mutual learning processes.

Macro-level: experiential knowledge at system level

Experiential knowledge forms the bedrock of survivor research and is rooted in plural user movements, such as the recovery- , mad-, neurodiversity- , survivor- , and disability movements (Faulkner, 2017). Experiential knowledge is a type of knowledge emerging from lived experiences and is considered a new (re)source, complementing professional and scientific knowledge (Borkman, 1976). The starting point for researching experiential knowledge in mental health contexts is understanding that knowledge and power are inseparable. French philosopher and political activist Foucault already reflected that ‘knowledge is always an exercise of power and power always a function of knowledge’ (Foucault, 1980).

Collaboration logic

Our research showed the use of lived experiences in recovery-based mental health services and, consequentially, the estimation of their value, is still in its early stages of development, not only in the Netherlands but internationally as well.

In the past three decades, changes in the healthcare systems of industrialised countries threatened important values of professionalism (Ralston, 2019). This concerns matters including market forces, bureaucracy and outcomes of focused work.

While Freidson (2001) already differentiated between these three forms of logic, i.e. market, bureaucracy and professionalism, the first of these has increasingly influenced mental health services. This interplay between these forms as forces also led to cost control and management strategies (Saks, 2020).

In addition to these forces, Huber & Bouwes (2011) and Tonkens (2021) have identified a fourth form of logic: collaboration, which starts with the active involvement of those whom the services provided concern. This fourth 'logic' represents important social moral values such as justice and self-development, which evidently entered at times when professionalism in psychiatry underwent a loss of social status (Cohen *et al,* 2007). This return and renewed commitment of professionals and investment in education are changing the psychiatric system.

It should be considered a normative practice, in which professional values are to be enacted in dynamic engagement with relevant moral communities (Glas, 2019; Ralston, 2019). In this novel moral era of medicine, professionals are required to focus on services that 'make a difference' – meaning they add value to the lives of those suffering (Van Os & Gülöksuz, 2022). The acknowledgement of experiential expertise requires collaborative ways of working with multiple actors surpassing domains.

Rehumanising services

Will the aforementioned logic contribute to a new discourse? As mental health services form part of a larger political arena, legislation and policy impacting service users' experiences are being developed continuously. In the U.S.A., Canada, New Zealand, Australia, the U.K., and the Netherlands, peer support work is professionalising fast, this in terms of education, certification, function descriptions, and professional bodies (Stratford *et al.,* 2019). Specifically in the Netherlands, traditional professionals' lived experience has been endorsed by way of acknowledgement. The increasing influence of first-person knowledge may serve to enhance value awareness and sensitivity, possibly serving a fourth logic (Ralston, 2019). In line with Brugman's (2020) research, disclosing vulnerabilities seems to help rehumanise mental health services.

In this sense, our PEPPER consortium could be considered a force exercising power in this arena: it practices striving towards shared values and normative professionalisation, in doing so it contributes to the fourth logic. We became aware of the different systemic powers and the prominent position of evidence-based care. PEPPER spearheaded the mission to incorporate experiential knowledge into existing practices and was granted discretionary space to develop new perceptions of professionalisation. The challenges faced were in part challenges related to the (traditional) system: how to reach those who have been trained in traditional frameworks with a typical knowledge distinction, how to re-define 'evidence-based practice' as regards in particular a personalised approach, and to what extent this 'new' knowledge type can or must be standardised.

However, the innovation sought will only take root if there is sufficient commitment from different actors in the system. Our research shows that this implementation entails more than just a technical operation; it requires the emotional labour of highly motivated executives to promote a culture of openness to overcome stigmatisation amongst colleagues, invest in volume, resources, dialogues and training without losing the initial intention to work with experiential knowledge. If done properly, the system will be able to respond to the emerging complexity and bridge the gap between different perspectives and generations.

Systemic inequality

In the Netherlands, neoliberal policy and marketisation have led to cherry-picking and other improper dynamics, e.g. by limiting the service intake to 'light' (less complex) cases (Boumans *et al.,* 2023). Problematically, recovery-oriented and other social practices within neoliberal frameworks are known to target individual changes and not the underlying structures (Paxton, 2020). In particular, psychiatry is known for its sanism and the setting apart (othering) of those diagnosed or labelled 'mentally ill' as inferior or abnormal (Procknow, 2017). Sanism is a devastating form of oppression, often leading to negative stereotyping and the stigmatisation of people with mental health histories (Poole, *et al.,* 2012). It leads to a categorical division, resulting in an empowered group assumed to be normal and healthy versus a powerless group assumed to be crazy and ill. This systemic inequality is often subtle and expressed in implicit judgements, disapproval or microaggressions, referring to the incompetency of the other. It is part of a belief system and culture that unconsciously and consciously sustains it and thereby inhibits (social) inclusion. Experiential knowledge has the potential to tackle this inequality.

Our studies have shown that actors in the system have varying perceptions of the way forward and the position of experiential knowledge. Whereas some (experts by experience) considered it an upgrade, others (traditional professionals) thought of it as a downgrade. Since experiential knowledge has only recently been designated as 'knowledge', it is prone to rejection and co-optation (Van Os, van Delden, & Boevink, 2021). It can politically be presented as an overarching attitude and unjustly described as a thinly veiled effort to cut back on services and expenses, especially in neo-liberal policy (Beresford & Brosnan, 2021; Davidson, O'Connel, Tondora, Styron & Kangas, 2006).

This may be one of the reasons why a wider implementation of experiential knowledge in the system is a slow and difficult process. As a consequence, the implementation of this type of knowledge in existing service systems requires further investment and attention, as it is complicated and context-dependent. This means that the full acknowledgement of experiential knowledge both in the system and as part of the standards of care remains imperative.

System reconstruction

Is it possible to change the mental health system by using lived experiences? Some are opposed to the reconstruction of current services, as intention and identity of experiential expertise may be wasted in the system. Perhaps conservative mental health thinking cannot completely be dismantled or reinvented.

It might be the case that the breaking down of the established order is just an illusion, or that the system as a whole needs to be newly constructed, from scratch. That might result in the disappearance of psychiatry. Instead, there will be human diversity and mental variation, a focus on well-being, healing and recovery practices. From Scandinavian practices, we have learned that this process of de-constructing and redesigning takes time, effort and bravery, not to mention means (Stockmann *et al.,* 2019).
In 2022 the Dutch Ministry of Health, Welfare and Sport underlined in its new healthcare agreement the relevance of collaboration between the social and medical domain, discouraging marketisation and competition (IZA, 2022). In addition, the Trimbos institute, which is the national research centre for mental health in the Netherlands, has recently explored the benefits and pitfalls of the current reforming narrative (Boumans *et al.,* 2023). It advocates for a positive health paradigm, integration and collaboration of services, de-medicalisation, and prevention, and it underlines the relevance of experiential knowledge both inside and outside of systems. The current field is shaped by reform and recovery initiatives (such as recovery colleges) on the one hand, and by hyper-specialisation of mental health services on the other hand. The integration of experiential expertise throughout the whole field will pose a challenge, as will the allocation of sufficient finances for these investments.

Methodological considerations

This research took place in three organisations that provide mental health services and one organisation for addiction care in the Netherlands. The collaboration as part of the PEPPER consortium, which already formerly acknowledged experiential expertise as an equal source of knowledge, was a unique aspect to this research. It also provided the ability to work with multiple stakeholders as well as incorporating the first-person perspective of the researcher, thereby engendering multi-perspective reflexivity.

In the first study, we sought an international overview of mental health practices that include experiential knowledge, which is why a literature study was conducted. One limitation in this respect was that we did not follow a more extensive protocol for conducting a systematic review; however, the scoping review conducted already showed that the use of experiential knowledge by established professionals is a rather unique phenomenon.

The subsequent studies involved qualitative case studies with participatory action research (Abma *et al.,* 2019). The main strength of these studies was their scope of engaging (educated) professionals with lived experience in addition to peer workers or experts by experience. Moreover, the first researcher's personal lived experiences and reflections added insights to this research and underlined the significance of relational ethics and the dominant discourse as regards the non-disclosure of personal information, partially out of protection, partially as a result of socialisation and traditional training. Furthermore, the use of non-verbal, art-based methods demonstrated value as a means of articulating silenced knowledge, both in my personal journey and in the organisations participating in this research.

My personal stance and experiences were used to identify and explain blind spots. The advantage of embodying both a professional and client perspective and explicitly reflecting on the tensions occurring led to more congruence and visibility in my role as a researcher. As mentioned before, no researcher (nor practitioner) is neutral. By reflecting on my frame of reference and intersectionality, I practised 'identity politics' (Voronka, 2015). By using critical research approaches, the current still-unequal position of experiential knowledge in mental health becomes visible. Changing this requires larger systemic and structural investments.

While this research adds to a growing body of research on the value of experiential knowledge in the rendering of mental health services broadly, we recognise several limitations:

Firstly, all of our qualitative studies are all highly context-related, to a typical western country such as the Netherlands. It is not clear whether these results could be equated to or translated for use in other countries. Secondly, all studies concerned small sample sizes with homogeneous groups and thus limited generalisability. Convenience sampling was undertaken, since the number of professionals who use experiential knowledge openly is still limited. Further exploring the perceptions of those professionals remaining reserved in the development of using experiential knowledge seems a worthwhile endeavour.

Although the perspective of service users has been incorporated in the research and the main researcher being a service user as well, this was not our first entrance. It could be of value to further broader explore service users' opinions, specifically concerning the use of experiential knowledge by psychologists and psychiatrists.

Furthermore, exploring the value of experiential knowledge in other organisations and settings may prove enlightening, as well as further researching the role of trauma and trauma awareness. In addition to the current body of research, both quantitative and qualitative international research is needed to understand the value of experiential knowledge in a broader context.

Conclusion

At the onset of this research, we asked the following research question:

'What is the value and perceived impact of professionals' lived experience with mental distress, and how can mental health services integrate experiential knowledge?'

Although both in the Netherlands and elsewhere, the use of experiential knowledge by professionals is sparse and the transformation to meaningfully incorporate the lived experience perspective of traditional professionals is still in process, the available qualitative data from this research indicate positive outcomes.

Following the PEPPER principles and based on our research, the experiential knowledge of established professionals can be distilled into four essential aspects:

1) Relational ethics
Lived experience from a relational point of view becomes meaningful in interpersonal contact. Its narrative, interpretation and mentalisation can be constructed intersubjectively and non-verbally. Relational ethics practices by lived experience professionals are often comprised of mutuality, validation, engagement, recognition, radical acceptance and a compassionate working alliance. This is in line with previous research that demonstrates the importance of these elements for personal recovery (Wilken, 2010).

2) Practical and emotional knowledge
Coping with the challenges of mental illness or addiction in everyday life generates a form of practical as well as emotional knowledge. This concerns knowing how matters manifest and are experienced (or 'innerstanding'), not only related to the condition but also related to the (cultural) context the client is situated in. It consequently leads to skills and capacities often associated with peer support (Caron-Flinterman *et al.,* 2005).

3) Existential transformation
Philosophers like Heidegger, Merleau-Ponty and Levinas have found that human existence consists of paradoxes. Those who capture experiential knowledge have experienced these contradictions, of having dealt with helplessness, powerlessness or desperateness and yet drawn inspiration from it, such as hope, perspective and pride. Considering these experiences as transformative is a way to hold up to the world (Rouse, 1986, p. 260). Existential transformation overcomes object-subject dualism, mind-body dualism but also healthy-ill dualism. Incidentally, existentialism is linked to experiential knowledge; people assign meaning to their being in the world (Weerman, 2016). It also has its roots in existential psychology traditions (Yalom, 2002).

4) Emancipatory politics
The lived experiences and experiential knowledge of professionals are a source of power and may empower those marginalised. This entails resilience and the ability to (re)discover new meanings, a search for positive identities and regaining agency over one's life (Boumans, 2016). By voicing and addressing social and moral injustice, a lived experience perspective can be part of emancipatory politics to counter different forms of discrimination and exclusion. This is an effort inside health care but also in/of the society at large. This means that this can only be achieved in collaboration with other fields and domains and by complementing the existing logic with experiential knowledge.

Altogether, experiential knowledge affects different levels (the individual, the organisation and the system). Professionals who harness experiential knowledge, have integrated the personal into the professional practice in such a way that it is congruent and comprehensible and service users may profit from. Experiential knowledge as a complementary (re)source can stimulate users' recovery processes and serve the organisation as a whole. It may also conflict with other types of knowledge leading to the question: which kind of knowledge is decisive?
The transformation of services includes a (re)sensitisation towards interpersonal and humanising approaches. In this regard, the formalisation of the positioning of experiential expertise can be part of a system change, as long as it is part of a larger emancipatory movement that takes into account trauma, diversity and social justice. This means that

awareness of the strong power dynamics that easily withhold the use of experiential knowledge is a vital aspect as well.

The experiential knowledge professionals can bring to the table has an empathising, normalising, humanising, demystifying, destigmatising and empowering impact, which can be beneficial to people in need of care and supports their recovery and healing processes.

Future directions and pathways

In contextualising this corpus of work, we will move on to some closing reflections for future practice and research. The current dissertation is ultimately practical and action-oriented and generated many questions and directions for future research and practice.

Future practice

There are several practical implications following this research. Firstly, this research supports the opening up of space to harness experiential knowledge by multiple actors and in different contexts, including traditionally educated professionals. Even though conducted in small case studies, the value of lived experience has been underlined by both service users, professionals and executives.

Practice starts with education: in all primary curricula, the inclusion of experiential knowledge as a form of knowledge complementary to scientific and practice-based knowledge, is paramount. In this way, professionals will more naturally acknowledge and include insights from lived experiences and overcome the current division between the private and the professional spheres. In addition, professionals will be supported in developing a congruent and integrated personal-professional identity. Secondly, we recommend developing post-graduate training for professionals in line with these findings. In future mental health practice, elaborating on the use of experiential knowledge could be of interest, as part of trauma-informed recovery-oriented systems of care. Furthermore, experiential knowledge is a clear contribution to evidence-based care and supports the inclusion of service users' preferences. By mediating and combining all knowledge types, the first-person perspective is fostered and complements current standards of care.

Existing mental health organisations need to invest in the recruitment and training of professionals with lived experience, considering the strength and additional value in care this knowledge provides. Embracing mental health practice in all its complexity, including the impact of relational, (non-specific factors) is paramount. Specific actions and open dialogues with multiple stakeholders in organisations (service users, all types of professionals, managers, policymakers) are necessary to change the stigmatised and undermining viewpoints (like the view of 'if everything fails, you can always become an expert by experience') and turn them into opportunities. While alternatives to regular mental health settings are essential, such as the upcoming recovery colleges, we believe it is important to produce changes in the system that created the problem of devaluing lived experience. This will provide the needed acknowledgement for formerly silenced voices and helps to reconstruct mental health practice from the inside out. However, this is also one of the most challenging tasks to undertake.

Future practice should reflect on the dominating forms of logic and open up the dialogue, by jointly reflecting on the established (power) structures between staff and users.

Future research

As a consequence of this qualitative research, many themes could be further studied in different contexts and ways in the near future.

For future research purposes, we recommend incorporating experiential knowledge as part of the research set-up, approach and analysis, while working with lived experience researchers. Even though we believe researching the body of evidence of lived experience and experiential knowledge is difficult to realise from a positivist paradigm, we encourage all research activities that could improve services. We think that reflection sessions with those involved are essential to such an improvement process, even when working with quantitative methods.

Future research could more specifically focus on the (sub)groups who to date remain reserved on the topic of working with experiential knowledge, like psychologists and psychiatrists. We also recommend researching the elements necessary for further acknowledging this type of knowledge and claiming space in education and training for these professionals.

Furthermore, we think that collaboration between different types of professionals could advance the use of experiential knowledge, and we suggest setting up joint research and training teams who look for innovation. Research processes can stimulate readiness in teams, especially when these are action and change-oriented.

Lastly, we recommend further research on the impact of trauma and attachment in professionals with lived experiences and how they relate to clients. Additionally, investigating the contribution of non-verbal methods and bottom-up (body based) approaches currently developed for those impacted by disruptive and traumatic life experiences is relevant.

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