Universiteit Leiden
The Netherlands

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

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Citation

Karbouniaris, S. (2023, September 13). *Let's tango!: Integrating professionals' lived experience in the tranformation of mental health services*. Retrieved from https://hdl.handle.net/1887/3640655

Version:	Publisher's Version
License:	Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden
Downloaded from:	https://hdl.handle.net/1887/3640655

Note: To cite this publication please use the final published version (if applicable).

Chapter 1

General introduction

Introduction

The interest in experiential knowledge grew vividly over the past 25 years (Boevink, 2017). Research done so far indicates the value of lived experiences as a relevant source of knowledge in The Netherlands (Wilken, 2010; Van Erp *et al*., 2011; van Haaster *et al*., 2013; Weerman, 2016; Boevink, 2017). Lived experience with mental health challenges provides insights from the first-person perspective. Some argue to rather speak of 'living experiences', as some experiences still shape current lives, and having them lived refers to a safely relegated circumscribed past (Martin, 2022).

Experiential knowledge is a type of knowledge emerging from lived experiences and is considered a new (re)source, alongside professional and scientific knowledge (Borkman, 1976; Weerman, 2016; Dings & Tekin, 2022). It is grounded in life's disruptive and traumatic experiences. It is also called embodied or pathic knowledge from the 'inside out', sometimes intuitive and challenging to verbalize. Experiential knowledge requires emotional labour and especially time to reflect on the personal and related experiences of peers. It obtains meaning in its context and (inter)subjectivity.

After the introduction of experts by experience in the mental health field, professionals also stepped forward with their lived experiences in mental health and addiction. Some turn their own journey of recovery into a profession, while others have already established a professional career when deciding to draw from personal lived experiences. Either way, they choose to harness experiential knowledge in service of others, thereby contributing to mental health services. This research focuses on professionals who were originally trained to distance themselves from their personal experiences, and act neutrally, but feel a need and desire to explore how to make use of personal experiences with mental health issues or addiction in their work with service users.

Moreover, research demonstrates that an impressive number of professionals have been exposed to traumatic and disruptive experiences in their lives. Estimations of the number of professionals with lived experiences fluctuate between 45% and 75% of the practitioners in mental health care (Zerubavel & Wright, 2012; Weerman, 2016).

Traditionally the personal has been divided from the professional into many mental health disciplines. Implicit and explicit norms are to keep personal information and moreover, vulnerabilities out of clinical practice (Psychopathology Committee of the Group for the Advanced of Psychiatry, 2001). Professionals are trained to be reserved and self-effacing (Von Peter & Schulz, 2018). Whilst the concepts of 'professional self-disclosure and 'wounded healer' are familiar to (existential, humanistic, person-centred) psychotherapists and may host meaningful principles for the therapeutic alliance, there is a threat that the focus of the interaction will shift from user to professional. This is not only considered problematic to users: revealing the personal violates the self-protection function of the professional. Powerful underlying processes such as 'identification' and 'transference' are generally psychologised and negatively framed in modern mental health culture (Brugmans, 2020). Hence, the norm is to 'hide' the personal rather than to 'expose', leaving professionals who'd like to process and harness their lived experiences, at risk (Byrne, Happell & Reid-Searl, 2017).

However, professionals with lived experiences are presumed to better connect with clients and value their strengths. They often capture a great sense of moral and ethical sensitivity. They also address the stigma that hinders individuals from social participation in society (Goldberg, Hadas-Lidor & Karnieli-Miller, 2015; Weerman, 2016) as well as address complex issues of coercion in the mental health field (Abma, Voskes & Widdershoven, 2017). A recent study in the Lancet highlighted that people with lived experiences are key agents for change in stigma reduction and therefore need to be strongly supported to (co)lead social interventions (Thornicroft e*t al.,* 2022). However, more research is needed to generate knowledge about its meaning and how to include lived experiences in the professional domain, to contribute to service users' healing. Until now, there is little empirical evidence about the nature and value of experiential knowledge applied by professionals in mental health care services. The current research contributes to filling this gap.

Recovery-oriented care

Experiential knowledge stems from recovery, a learning process enabling someone to live with the overwhelming impact of an illness (Anthony, 1993; Deegan, 1993). Essentially, recovery overcomes the traditional thinking of 'having to cure', thereby also mediating the perspective of temporary loss and the long-term impact of life events. Recovery is sometimes reframed as 'discovery', the journey through which someone discovers new meanings and purposes. Thomas Martinelli's (2023) research into recovery from drug addiction has demonstrated how our understanding of the concept of recovery continues to evolve. Recovery can refer to the process of recovering from an illness or addiction (including related outcomes), as well as a paradigm to approach, organise and deliver treatment, support services, and research (Martinelli, 2023). Recovering is often described as a long-term process aimed at positive change that takes place in an interwoven personal, social and societal context, which may include improvements or growth in different life domains (Martinelli, 2023). In this way, recovery is also connected to sources of experiential oft-tacit knowledge on how to live with distress and stigma from a survivor's perspective. It embraces insights based on co-creation and intersubjectivity. Conceptionally, recovery is also closely related to 'healing'. Deegan (2002) refers to recovery as a self-directed process of healing and transformation. Healing is often a prolonged process of becoming healthy again. It emphasises the agency of the self in the healing process as opposed to crediting professionals with curative powers (Deegan, 2002). In this light, the task of mental health professionals becomes one of empowering people to help them build skills and a sense of agency. The recovery process has the aim of helping people learn to become self-directing as opposed to compliant (Deegan 2002).

In the Netherlands, Wilma Boevink introduced the three related emancipating concepts of recovery, empowerment and experiential expertise (Boevink, 2017) aiming to contribute to the recovery of people with severe and long-term mental distress and to incorporate them in evidence-based practices. She was one of the first to research the recovery movement as part of a large mental health transformation, adding to the overseas work of Patricia Deegan and William Anthony.

The recovery movement argued that people's dignity and self-determination are at stake, and strived for full rights and participation of the marginalised. Furthermore, Boevink and many others stress the need for an exploration of the relationship between trauma and mental distress (Boevink, 2009; Marsman, 2021). Following this, experts-by-experience and peer support workers have been widely introduced in Dutch mental health and addiction care, and paid employment opportunities increased over the past 25 years. The development of a recovery-oriented culture that incorporates the lived experiences of people dealing with mental distress and addiction in the Netherlands was largely twofold:

1. It led to *new forms* outside of traditional care institutions, such as types of supported living within a community. From there, several forms of peer support in the community were set up, sometimes with the help of governmental funding, such as recovery colleges.
2. It led to *reform attempts* to change established services from within, countering the existing routines and hierarchy. As part of this reform, traditional professionals spoke up about their lived experiences as well, claiming discretionary space for those experiences previously hidden and forbidden.

In this way, experiential knowledge aims to contribute to fundamental changes in mental health care and social justice, and to promote sensitivity and diversity of services and communities.

Experiential knowledge

Experiential knowledge is derived from lived experiences with disruptive and oftentimes traumatising life events. Its primacy lies in the 'life-world' as a starting point of consciousness and knowledge and an original definition by Borkman dates back to 1976:

'Experiential knowledge is the truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others' (Borkman, 1976, p.446).

Since the word 'experiential' refers quite literally to the subjective experience, the above also captures the bodily and sensory or intuitive aspects of an embodied experience. The embodied experience can be difficult to articulate and may partially remain tacit or implicit. It is based on the concept that people attach a knowing from the inside out to their experiences, which is not necessarily on a cognitive level. Its meaning is constructed by an individual or co-constructed through dialogue between persons. Although it is sometimes considered contradictory to professional knowledge, it can actually be seen as a first source of knowledge, as professional knowledge could not exist without its tacit background (Polanyi, 1966).

Experiential knowledge goes beyond the illness itself, and typically involves the following domains (Haaster *et al.*, 2013; Castro *et al.*, 2019):

1. knowledge about your own body, mind, behaviour, acts and personal recovery;
2. knowledge about the availability and operation of service providers, professionals and service systems, about therapies and side effects, and what would be helpful to the

individual;
3. knowledge about responses in the community, both positive and negative, inclusion, exclusion, stigma and community recovery/participation;
4. knowledge about how people with similar experiences or situations can be supported in their recovery.

First, the insights provided can be practical in terms of coping with certain struggles related to illness, but also in terms of having knowledge of systems and the broader community. Secondly, experiential knowledge captures the integration of dualities, such as pride versus shame and life versus death, and overall imbues the knower with the ability to translate problems into meaningful existential insights. Thirdly, it voices silenced knowledge and critically challenges existing power dynamics and processes of exclusion. Fourthly, it highlights the personal in the professional arena. Fifthly, it is sensitive to ethics and gives space to moral questions. Lastly, it takes relational aspects into account, such as the theme of balancing proximity and distance.

Transformation of mental health care

As modern mental health care is transforming to recovery-oriented practices, including professional use of experiential knowledge, challenges arise. Sceptics point out that these new practices may become encapsulated and undermined when there is a lack of organisational coherence and a tendency to resort to more conservative practices (Holley, Gillard & Gibson, 2015).

The assimilation of care as usual and professionalisation of experts-by-experience and professionals with lived experience is reasonable to occur (Roennfeldt & Byrne, 2020). On the other hand, the creation of undesirable norms as an outcome of professionalisation and thereby exclusion of certain phenomenology may also occur (Dings & Tekin, 2022). Altogether, this may risk the further dividing, polarisation and segregation of client or survivor movements due to ideology and diversity conflicts (Beresford & Russo, 2016).

Especially in cases where lived experience practitioners are exposed to unrealistic challenges and excessive expectations, and do not succeed in using experiential knowledge appropriately, this may result in added harm for clients or other undesirable effects, including the loss of position or status and disillusionment about the professionals or (former) service users concerned (Corrigan, 2016; Byrne, Happell & Reid-Searl, 2017). The listed challenges seem realistic; however, this has also kept the potential of experiential knowledge hidden. The chances and opportunities experiential knowledge brings to the table in particular were kept at bay in traditional mental health care contexts.

Despite critiques, the contribution of experiential knowledge is increasingly acknowledged and formalised in participatory policy in varying countries such as the Netherlands, the United Kingdom, the United States of America, Canada and Australia. The Dutch Ministry of Health stressed that improved arrangements are needed for quality purposes and invested in a national quality system in collaboration with the Dutch professional body of lived experience professionals (‘VvEd’, the *‘Vereniging van Ervaringsdeskundigen’*) (Van Erp *et al.,* 2022).

Internationally, regulations and guidelines to acknowledge lived experience are also on the rise and recurring in statements by nationwide professional bodies such as psychiatrists (Royal Australian and New Zealand College of Psychiatrists, 2016), psychologists (British Psychological Society, 2020) and social workers (Vereniging Hogescholen, 2022). Additionally, the World Health Organisation has stated that peer expertise should be regarded as a third domain of expertise in mental health care (WMHR, 2022).
While this transformation in mental health care services is still ongoing in the Netherlands, by times it seems to have plateaued (Van Os *et al*., 2021). The extent to which co-creation with service users takes place is limited or sometimes co-opted (Van Os *et al.*, 2021). Despite evident efforts, the expected effects are not always visible to service users. The contribution of experiential knowledge might compete with a mental health orientation that is governed by evidence-based outcomes, hyper-professionalisation, bureaucracy, 'best practices' and neoliberal commodification, being highly valued by the mainstream health sector and leading to a standardisation of care and treatments (Aadam & Petrakis, 2020). This results in recurring discussions about evidence-based practice including its technical approaches, and also generated criticism about the positioning of lived experiences and experiential knowledge in recovery-oriented mental health practices, despite patients' values and preferences being one of the three original pillars of evidence-based medicine (EBM).

As a follow-up to Weerman's studies on experiential knowledge in higher education, and the contribution this made to social work in particular (Weerman, 2016; Weerman & Abma, 2018), this research has been based on the onset of the RAAK[i] research project framework: 'The contribution of experiential expertise of professionals in care and welfare practices' that commenced in 2017 and thereafter further evolved as the PEPPER Consortium. In line with the research consortium's definition, the body of knowledge of experiential knowledge is related to Practical, Existential, Political-critical, Personal, Ethical and Relational aspects, captured in the acronym 'PEPPER' (Weerman *et al.*, 2019). The PEPPER consortium consists of a number of mental health agencies and two universities. It aims to stimulate and professionalise the use of experiential knowledge of professionals. Three of the participating mental health organisations were selected for this PhD research and additionally, in the last study, one addiction care organisation participated.

Aim of this research

The aforementioned developments have greatly impacted professionals currently working in the field in the Netherlands. Although many professionals would like to integrate their lived experience as an essential source in their work, they don't seem to have the proper resources nor support from their organisation to effectuate this. Subsequently, insights stemming from a first-person perspective might sometimes be contractionary to professional codes of conduct or institutional standards, leading to potential (disciplinary) conflicts. In light of this, a reflection on readiness, professionalism and organisational culture involving all stakeholders seems desirable.

i RAAK stands for: *Regional Action and Attention for Knowledge dissemination*, as part of the Dutch organisation for Scientific knowledge (NOW) providing national grants for innovative applied research in the Netherlands.

The integration of lived experiences in professional practices is especially problematic due to the splitting of different types of knowledge from the professional domain and the ongoing existence of a strong hierarchic and medical-oriented institutional structure. This hinders a further transformation of modern mental health. Therefore, this research aims to research the positioning of experiential knowledge, to value, develop and harness it as a (re)source for organisational transformation.

A broader aim is to create space for the use of experiential knowledge derived from professionals' lived experiences and its possible contribution to mental health services. This includes a joint inquiry and evaluation of (the use of) lived experience and its possible contribution to a) the professional and service user, b) the organisation and transformation and c) professionalisation in terms of quality of care. In addition to knowledge transfer to the mental health field, this research also aims to contribute to bachelor, master and post-graduate training of mental health care workers.

The main question of this research is:

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

Sub-questions are:

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?

Research methodology

Case studies with participatory action research

This research took place in three providers of mental health care and one provider of addiction care in The Netherlands. As part of the broader aim to create space for experiential knowledge in modern mental health care, participatory health research and responsive evaluation methods were used to contribute to the learning and implementation processes in practice.
The research was characterised by its compassionate and reflexive approach, involving multi-perspective reflexivity on the research questions and any other themes that arose within the field of study. Different layers (micro-, meso-, macro-) were targeted in the participating organisations to stir up social-organisational change. A multiple-stakeholders perspective was taken into account by engaging with service users, different types of professionals, policymakers and executives.

A qualitative framework was used, as ‘qualitative researchers study things in their natural settings, attempting to make sense of or to interpret phenomena in terms of the meanings people assign to them’ (Denzin & Lincoln, 2011), in this case specifically the lived experience of professionals and the perspectives of relevant stakeholders (service users, professionals and their colleagues, and executives).

Auto-ethnography

Employing reflexivity includes connecting the personal to the cultural by using auto-ethnography as an important voice-over (Ellis, Adams & Bochner, 2011). Auto-ethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters or assuming they do not exist (Ellis, Adams & Bochner, 2015). Auto-ethnography aims to attend to the complexity of the first-person narrative, and it is a relational practice, within which meaning is influenced by the interpersonal. In applying this practice, the research becomes relatable in a personal and professional sense, which can then be used to explore and understand identity and power in relation to those being researched (Beresford, 2005).

Thanks to the involvement of researchers with lived experiences, the research also included auto-ethnographic perspectives. The involvement of the insider’s perspective and the so-called ‘double identity’ of the researcher was expected to provide an enriched perception of the obtained findings (Kool, Visse & Boumans, 2013). Next to the PhD researcher, several lived experience co-researchers have made contributions to this research. An advantage of working with lived experience researchers is that they identify themselves with part of the subject and understand the insider’s perspective.
A disadvantage could be the close involvement with the subject. However, in line with social constructionism, it would similarly be ignorant to believe in researchers’ neutrality in any case. In that regard, this research adheres to a participative-inclusive tradition (Groot *et al.*, 2019). This research approach attempts to encounter and challenge the prevailing structures and hierarchy of mental health services, e.g. the process of silencing lived experiences.

The research consists of both a literature review (A) and an empirical study (B). The literature review focuses on the state-of-the-art of experiential knowledge and recovery-oriented care. The empirical part of the research consists of practice-based studies, including communities of practices, in-depth interviews, participatory observations and responsive evaluations with the professionals concerned and service users in the participating organisations. The process of integrating professional acts and research is described as participatory action research (Reason & Bradbury, 2008).

Researcher positionality

My research topic and I hold an extensive and intense relationship, as I was faced with existential matters at quite an early age. At the age of eighteen months, I moved from Greece to the Netherlands, because my Dutch mother could not accommodate well enough to Greece, where she met my father, and the Greek culture. After moving a fair amount, from my grandparents’ house to several small rental apartments in the southern part of the Netherlands, I started questioning my roots. I was very eager to attend Greek

school at the age of four, although I had no contact at all with my family in Greece. At the age of six, I stopped speaking entirely for a significant period and my mother consulted a psychologist. No reason or cause was found, although I remember my mother was socially very isolated.

When I first started 'messing around with food' at the age of nine, I assumed it was an attempt to express myself in a way I couldn't do differently. In the meantime, I distanced myself from my mother and was desperately seeking other parental figures. I was always longing for substitute moms and dads, so to speak, and held warm transference feelings in secrecy for many of my teachers in primary and secondary school. There was a little girl inside me who kept striving for perfection and had a huge hunger for warmth and love while, at the same time, she wanted to fade away. Lack of roots and trust, negative self-esteem, anxiety and early youth trauma formed the ideal substances of an almost poisoning cocktail resulting in an eating disorder and eventually also a dissociative disorder.

It wasn't until the age of eleven that I revisited my father in Greece and started travelling back and forth during (almost) every holiday, while also falling victim to abuse. At age seventeen, severe pneumonia caused me to drop in weight, and I was admitted to the hospital for several days. After that period I was advised to turn to the mental health care sector and I got diagnosed with anorexia, bulimia, eating disorder not otherwise specified, dissociative and compulsive symptoms, identity problems and mild depression (dysthymia). Finding proper help was difficult, and I always felt fearful and avoidant when starting (another) treatment plan for my eating disorder. I repeatedly dropped out of care after a few days. The search for my core self remained unprecedented in many treatment attempts. From my seventeenth to my twenty-third birthday, I entered eight treatments (both in- and outpatient) at five different treatment centres in the Netherlands. I felt very lost when I – in 2004- contacted a nearby hospital where I met my current psychiatrist.
I realised that I had been surviving to avoid being exposed to 'added harm' in my journey through mental health. From the very first moment, the psychiatrist acknowledged he couldn't help me properly and sent me to a psychotherapist with whom I proceeded onwards the following six years, not only resulting in a breakthrough but also leading to the success of achieving a long-desired mother role.
In 2017, I returned to the psychiatrist for trauma therapy. Just like the body keeps the score (Van der Kolk, 2014), the body also stores memories tacitly which has made me often dissociate and refrain from a long-awaited personal transformation.

I discovered that exposure to unbearable pain, combined with ambivalent attachment in my younger years, led to the development of separate parts of myself. Parts that were not even aware of other parts in my system. Some parts were structurally dissociated and carried traumatic memories, while other parts continued to live daily life normally and can function very well. This post-traumatic phenomenon is also understood and referred to as 'a structural dissociation of the personality' (Steele, Boon & Van der Hart, 2016; Fisher, 2017). A rocky road lasting eight years in which we tried to establish a therapeutic relationship paired with different (spiritually and bodily) resources of the Comprehensive Resource Model, helped me to overcome my self-phobia.

The somatic work in particular was essential in reconnecting with myself. Cognitive therapies did not resonate with me as much as the body-based work. While traditional psychotherapy is largely underpinned by psychoanalysis and psychodynamics, looking for new frameworks that affirm a social and hermeneutic dialogue was helpful. This journey has been captured in a first-person account paper (Karbouniaris, 2021) and in published poetry (Karbouniaris, 2023).

Despite, but also thanks to my struggles, I obtained a bachelor's degree in social work but decided not to fragment my identity as either 'ill' or 'professional', which is why I refrained from working as a mental health professional. Alternatively, I had the opportunity to start working as a researcher at the Research Centre for Social Innovation where I felt and still to date feel strongly engaged with the user perspective. By doing research in and with the field, I found my way to open up the dialogue between practice, innovation, and research and provide constructive criticism. I started studying social sciences and attained my master's degree in 2012 after doing research on a grassroots and user-led mental health service called 'Vriend GGZ'. This enriched my view and awareness of the ongoing developments outside the mainstream system and care as usual, especially through engaging in critical discourses.

As a lecturer in social work, I often use my personal story as a relevant source for our students. I am very grateful for the opportunities HU University of Applied Sciences Utrecht and specifically the research group for Participation, Care and Support have given me to conduct this research.

Outline of the dissertation

This dissertation consists of both a literature review (A) and an empirical study (B) with a total of seven chapters, navigating the different contexts in which lived experiences emerge in mental health and addiction care.

To address the question of what the value and perceived impact of lived experiences for mental health services is, we started with a scoping literature review. The results are described in *Chapter 2*. We investigated the use of experiential knowledge by mental health professionals reported in studies in different countries. *Chapter 3* describes the results of the study in terms of the perspectives of service users. The perspective of nurses, social workers and humanistic counsellors who followed training to integrate their own lived experiences into their professional role is captured in *Chapter 4*.
Chapter 5 contains a follow-up study with psychiatrists in a peer supervision setting, exploring their considerations upon integrating the personal into the professional realm. *Chapter 6* describes a case study of four participating organisations that work on the development and integration of experiential knowledge. The dissertation ends with a discussion and summary of findings, as well as implications for practice and future research in *Chapter 7*. To further contribute from an insider's perspective to the central topic of this research, we have added personal auto-ethnographic reflections throughout the dissertation.

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