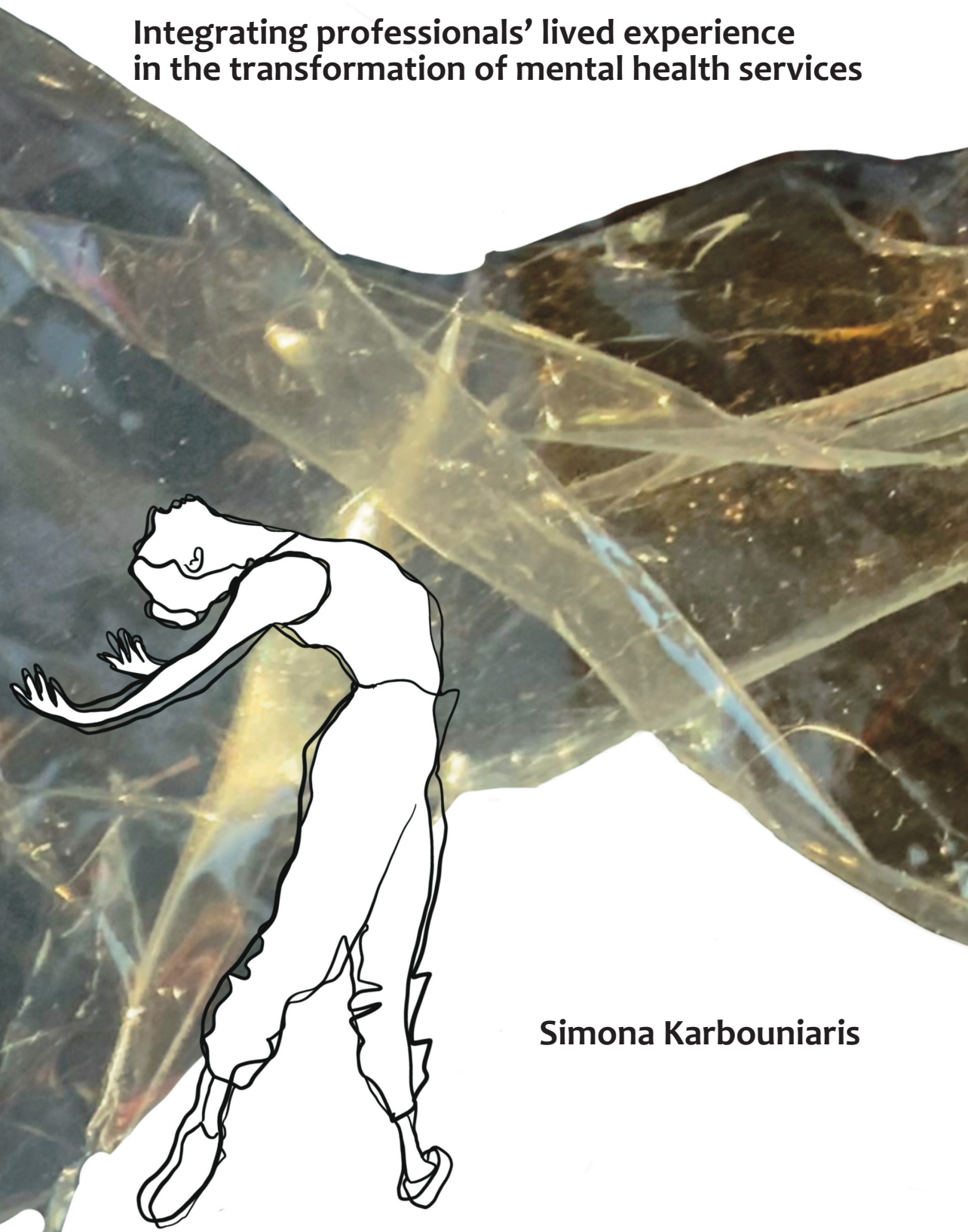
Let's tango! Integrating professionals' lived experience in the tranformation of mental health services

Karbouniaris, S.

Let's tango!

Integrating professionals' lived experience in the transformation of mental health services



Simona Karbouniaris

Let's tango!

Integrating professionals' lived experience in the transformation of mental health services

Simona Karbouniaris

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

Simona Karbouniaris
PhD dissertation, Leiden University Medical Center, the Netherlands
Cover and illustration by Roos Steen
Layout by Mirjam Kruisselbrink
Printing by Gildeprint
ISBN/EAN: 978-90-8928-157-9

The work presented in this dissertation was supported by the University of Applied Sciences Utrecht (HU).

Let's tango!

Integrating professionals' lived experience in the transformation of mental health services

Proefschrift

ter verkrijging van
de graad van doctor aan de Universiteit Leiden,
op gezag van rector magnificus prof. dr. ir. H. Bijl
volgens besluit van het college voor promoties
te verdedigen op woensdag 13 september 2023
klokke 12.30 uur

door
Simona Karbouniaris
geboren te Patras (Griekenland)
in 1980

Promotores:	Prof. dr. T.A. Abma
	Prof. dr. J.P. Wilken
Co-promotor:	Dr. A. Weerman
Promotiecommissie:	Prof. dr. E.F. van Furth
	Prof. dr. R.R.J.M. Vermeiren
	Prof. dr. S. Keuzenkamp (Vrije Universiteit Amsterdam)
	Prof. dr. J.J. van Os (UMCU)

In memory of Wouter and all others who couldn't sufficiently profit from care …

Table of contents

Preface

'*It's all about the truth of things. What is the truth of illness, what is the truth of addiction? What is the truth of mental health or mental illness? And of course, to deal with something and to help people, you have to know what their truth is. But I just find the truth in itself of value and I must say that my personal development has been the search for truth. I am not saying I have got there.*'

'*Only in the presence of compassion will people allow themselves to see the truth*'.
Gabor Maté, 2022

Dr Gabor Maté is a Hungarian-Canadian physician and author who has a background in family practice and a special interest in childhood development and trauma. He is renowned for his compassionate approach towards addiction and mental distress and is one of the few who translated the language of trauma into concepts such as 'truth', 'wounding', and 'healing'.

Although trauma has different faces, Gabor Maté's words legitimise the journey of many who end up in care facilities, either as a professional or on the other side, as a service user. He underlines the essence of subjectivity and at the same time refers to the long-lasting effects of childhood adversity on later health and well-being, and the complex aftermath of trauma manifesting in all sorts of disbalances.

Research in mental health and addiction in the last decades advanced by combining expertise from different scientific fields, including the voice of those with lived experiences with mental illness. It contributes to embracing more diversity and plurality in existing and new facilities. By acknowledging the interplay between biological, psychological, social and spiritual dimensions, the road towards a fully embodied practice is paved.

The collective wisdom of Gabor Maté and many other experts on trauma, therapy, recovery and spirituality have made these pages and my own life and work profoundly richer. Over the years I have written a series of auto-ethnographic reflections, that touched upon my lived experiences with attachment and trauma wounding. These personal insights have been interwoven throughout the entire manuscript as a source of knowledge and hopefully help the reader to consider the different perspectives and layers that I tried to capture in my work. These reflections also reveal my biography, experiences, normative persuasions and frames that inevitably have played a role in the process of sensemaking and interpretation. I want to acknowledge my limitations as a higher educated, European, female, non-clinician, researcher with a strong preference for a non-pathologising framework for all forms of mental disbalances. Researchers are not value-neutral, and these reflections can be read as an attempt to illuminate how all aspects of myself are at play in my research.

My wish is to inspire and invite all wounded healers to step forward and embrace opportunities to engage relationally in encounters with those who are struggling today.

Utrecht, March 2023, Simona Karbouniaris

A note about language

‘Let’s tango’ symbolises the dance of freedom of professionals with lived experiences with mental distress. It also touches upon the ability to use embodied knowledge in existing power dynamics and to be creative and improvise.

Throughout the text, in this dissertation, the terms ‘service user’, ‘user’ and ‘patient’ are used to refer to those making use of (mainly) mental health services. I am aware of certain groups’ preferences for alternative terms such as ‘client’ or ‘survivor’. I have tried to adapt to the perspective of those involved in the different studies and have expressed my personal preference in my reflections. More on this matter follows in the dissertation itself. Additionally, the terms expert-by-experience, peer (support) worker and peer expert are interchangeably used for those who work in mental health services without having obtained their credentials in the traditional manner. Obviously, this does not mean that experts-by-experience, peer (support) workers and peer experts don’t work in a professional way. On the contrary, many of them have received training.

Given that traditional professionals have started harnessing experiential knowledge in addition to their core profession, i.e. professional knowledge acquired as social worker, nurse, humanistic counsellor, psychologist, or psychiatrist, I append ‘lived experience’ as an adjective, e.g. ‘professional with lived experiences’.

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.

References

Aadam, B. & Petrakis, M. (2020). Ethics, Values, and Recovery in Mental Health Social Work Practice. *Mental Health and Social Work*, pp. 23-43.

Abma, T., Voskes, Y. & Widdershoven, G. (2017). Participatory Bioethics Research and its Social Impact: The Case of Coercion Reduction in Psychiatry. *Ssrn*, *31*(2), pp. 144–152.

Anthony, W.A. (1993). Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. *Psychosocial Rehabilitation Journal*, 16, pp. 11–23.

Beresford, P. (2005). Redistributing profit and loss: the new economics of the market and social welfare. *Critical Social Policy*, *25*(4), pp. 464–482.

Beresford, P. & Russo, J. (2016). Supporting the Sustainability of Mad Studies and Preventing its co-option. *Disability & Society*, *31*(2), pp. 270–274.

Boevink, W. (2009). *Lijfsbehoud, levenskunst en lessen om van te leren. HEE-gesch(r)ift*. Utrecht: Trimbos Instituut.

Boevink, W. (2017) *Over herstel, empowerment en ervaringsdeskundigheid in de psychiatrie.* [Doctoral dissertation]. Maastricht University.

Borkman, T. (1976). Experiential Knowledge: A analysis of self-help groups. *Social Service Review*, *50*(3), pp. 445–456.

British Psychological Society (2020). S*tatement on clinical psychologists with lived experience of mental health difficulties*. BPS.

Brugmans, J. (2020). *Revitalising disclosure*. [Doctoral dissertation]. Erasmus University Rotterdam.

Byrne, L., Happell, B. & Reid-Searl, K. (2017). Risky business: Lived experience mental health practice, nurses as potential allies. *International Journal of Mental Health Nursing*, *26*(3), pp. 285–292.

Castro, E. M., Van Regenmortel, T., Sermeus, W. & Vanhaecht, K. (2019). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory & Health*, *17*, pp. 307-330.

Corrigan, P.W. (2016). Lessons learned from unintended consequences about erasing the stigma of mental illness'. *World Psychiatry, 15*(1), pp. 67–73.

Deegan, P.E. (1993). Recovering our sense of value after being labeled mentally ill. *Journal of psychosocial nursing and mental health services, 31*(4), pp. 7—11.

Deegan, P.E. (2002). Recovery as a self-directed process of healing and transformation. *Occupational Therapy in Mental Health*, *17*(3-4), pp. 5-21.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The Sage handbook of qualitative research*. Sage.

Dings, R. & Tekin, Ş. (2022). A philosophical exploration of experience-based expertise in mental health care. *Philosophical Psychology*, pp. 1-20.

Ellis, C., Adams, T.E. & Bochner, A.P. (2011). Autoethnography: an overview. *Historical Social Research*, *36*(4), pp. 273–290.

Fisher, J. (2017). *Healing the fragmented selves of trauma survivors: Overcoming internal self-alienation*. New York: Routledge.

Goldberg, M., Hadas-Lidor, N. & Karnieli-Miller, O. (2015). From Patient to Therapatient: Social Work Students Coping With Mental Illness. *Qualitative Health Research, 25*(7), pp. 887–898.

Groot, B. C., Vink, M., Haveman, A., Huberts, M., Schout, G., & Abma, T. A. (2019). Ethics of care in participatory health research: Mutual responsibility in collaboration with co-researchers. *Educational Action Research*, *27*(2), pp. 286-302.

Holley, J., Gillard, S. & Gibson, S. (2015). Peer worker roles and risk in mental health services: A qualitative comparative case study. *Community Mental Health Journal*, *51*(4), pp. 477–490.

Karbouniaris, S. (2021). Fragmented selves: a first person account on trauma and dissociation. *Archives of Psychiatry & Psychotherapy, 23*(3).

Karbouniaris, S. (2023). Living the madness. *British Journal of Social Work, 53,* pp. 1916-1918.

Kohrt, B. A., Ottman, K., Panter-Brick, C., Konner, M., & Patel, V. (2020). Why we heal: The evolution of psychological healing and implications for global mental health. *Clinical Psychology Review, 82*, 101920.

Kool, J., Visse, M. & Boumans, J. (2013). *Ervaringskennis en wetenschappelijke kennis vanuit het perspectief van mensen met een 'dubbele identiteit': doorleefd verstehen!* Utrecht/Amsterdam: DSiN/Trimbos Instituut.

Marsman, A. (2021). *Beyond dis-ease & dis-order.* [Doctoral dissertation]. Maastricht University.

Martin, A., (2022). Healer, reveal thyself. *Academic Psychiatry*, *46*(2), pp. 269-270.

Martinelli, T. F. (2023). *In search of recovery. Exploring frontiers of drug addiction recovery through people, pathways and policy.* [Doctoral dissertation]. Tilburg University.

Maté, G. (2022). Lecture. Trauma summit 13 & 14 June 2022. Belfast, UK.

Maté, G. & Maté, D. (2022). *The Myth of Normal: Trauma, Illness & Healing in a Toxic Culture.* Random House.

Paxton, R. (2020) *White trauma: tracing trauma informed recovery and white supremacy in social work practice.* [Master thesis]. Ryerson University.

Polanyi, M. (1966). *The Tacit Dimension.* New York: Doubleday & Company.

Poole, J. (2007). *Behind the rhetoric of hope. A critical course analysis of recovery discourses in*

Ontario. University of Toronto.

Psychopathology Committee of the Group for the Advanced of Psychiatry (2001). Reexamination of Therapist Self-Disclosure. *Psychiatric Services, 52*(11), pp. 1489–1493.

Reason, P. & Bradbury, H. (2008). *SAGE Handbook of Action Research.* Los Angeles, London, New Delhi, Singapore.

Roennfeldt, H. & Byrne, L. (2020). How much "lived experience" is enough? Understanding mental health lived experience work from a management perspective. *Australian Health Review, 44*(6), pp. 898–903.

Royal Australian and New Zealand College of Psychiatrists (2016). *The contribution to practice made by psychiatrists who have a personal experience of mental illness.* Available at: https://www.ranzcp.org/news-policy/policy-and-advocacy/position-statements/psychiatrists-with-lived-experience-mental-illness.

Steele, K., Boon, S. & van der Hart, O., (2016). *Treating trauma-related dissociation: A practical, integrative approach.* WW Norton & Company.

Thornicroft, G., Sunkel, C., Aliev, A. A., Baker, S., Brohan, E., El Chammay, R., ... & Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet, 400*(10361), pp. 1438-1480.

Van der Kolk, B. (2014). *The body keeps the score: Mind, brain and body in the transformation of trauma.* Penguin UK.

Van Erp, N., Boertien, D., Scholtens, G. & Van Rooijen, S. (2011). *Ervaringsdeskundigheid en herstelondersteuning. Voorbeelden uit de geestelijke gezondheidszorg.* Utrecht: Trimbos-instituut.

Van Erp, N., Boertien, D., Liefhebber, S. & van den Berg, A. (2022). *Beroepscompetentieprofiel ervaringsdeskundigheid.* Vereniging van Ervaringsdeskundigen (VvEd), Trimbos-instituut, Movisie en Kenniscentrum Phrenos.

Van Haaster, H., Wilken, J. P., Karbouniaris, S., & Hidajattoellah, D. (2009). *Kaderdocument ervaringsdeskundigheid.* Utrecht: Landelijke Denktank Opleidingen Overleg Ervaringsdeskundigheid

Van Os, J., van Delden, J. J. M. & Boevink, W. (2021). De stem van de patiënt in de psychiatrie: niet gehoord, cocreatie, coöptatie of parallelle organisatie?. *Tijdschrift voor Psychiatrie,* (2021/10), pp. 727-730.

Vereniging hogescholen (2022). *Sociaal in beweging, empowerment van de sociaal professional als fundament.* Den Haag.

Von Peter, S. & Schulz, G. (2018). "I-as-We" – Powerful boundaries within the field of mental health coproduction. *International Journal of Mental Health Nursing, 27*(4), pp. 1292–1300.

Weerman, A. (2016). *Ervaringsdeskundige zorg- en dienstverleners. Stigma, verslaving & existentiële transformatie.* [Doctoral dissertation]. Vrije Universiteit Amsterdam.

Weerman, A., de Jong, K., Karbouniaris, S., Overbeek, F., van Loon, E. & van der Lubbe, P. (2019). *Professioneel inzetten van ervaringsdeskundigheid.* Amsterdam: Boom.

Weerman, A. & Abma, T. (2018). Social work students learning to use their experiential knowledge of recovery. An existential and emancipatory perspective. *Social Work Education, 38*(4), pp. 453–469.

Wilken, J.P. (2010). *Recovering care: A contribution to a theory and practice of good care.* [Doctoral dissertation]. Amsterdam: SWP.

World Mental Health Report: transforming mental health for all (2022). *The BMJ*. Geneva Switzerland: World Health Organisation.

Zerubavel, N. & Wright, M.O.D. (2012). The dilemma of the wounded healer. *Psychotherapy, 49*(4), pp. 482–491.

Chapter 2

Use of experiential knowledge by mental health professionals and its contribution to recovery: literature review

Karbouniaris, Simona
Abma, Tineke
Wilken, Jean Pierre
Weerman, Alie

Published in: Journal of Recovery in Mental Health, 2020

Abstract

Objective

This article explores the use of experiential knowledge by traditional mental health professionals and the possible contribution to the recovery of service users.

Design and Methods

The review identified scientific publications from a range of sources and disciplines. Initial searches were undertaken in databases PsycINFO, PubMed, and Cochrane using specific near operator search strategies and inclusion and exclusion criteria.

Results

Fifteen articles were selected. These were published in a broad range of mental health and psychology journals reporting research in western countries. In the selected articles, a varying conceptualization of experiential knowledge was found, differing from therapeutic self-disclosure embedded in psychotherapeutic contexts to a relational and destigmatizing use in recovery-oriented practices. Nurses and social workers especially are speaking out about their own experiences with mental health distress. Experiential knowledge stemming from lived experience affects the professional's identity and the system. Only a few studies explored the outcomes for service users' recovery.

Conclusion

A small body of literature reports about the use of experiential knowledge by mental health professionals. The mental health system is still in transformation to meaningfully incorporate the lived experience perspective from traditional professionals. There is little data available on the value for the recovery of service users. This data indicates positive outcomes, such as new understandings of recovery, feeling recognized and heard, and increased hope, trust, and motivation. More research about the meaning of experiential knowledge for the recovery of service users is desirable.

Introduction

This article explores the use and possible contribution of experiential expertise of mental health professionals to the recovery of users. It will present findings from a literature review on the use of experiential knowledge by mental health professionals.
It is part of a PhD research on the value of experiential knowledge for the recovery of users of mental health services. This review includes qualitative and quantitative studies published between 2015 and 2020.

Since the 90s, peer support workers (also referred to as 'experts by experience' and 'lived experience practitioners') in several western countries around the world started using their lived experiences as part of mental health services changing their focus to recovery-oriented care. This led to the further professionalization of peer support in general. Lived experiences of service users, often connected to stories of personal recovery, illustrated how people cope with severe psychiatric conditions or addiction (Weerman, 2016). Experiential expertise is based on a lived experience with a particular disease, disability, or other disruptive life event (Castro *et al.,* 2019). In 1976, sociologist Borkman became the first to clarify the concepts 'experiential knowledge' and 'experiential expertise. She defined experiential knowledge as "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).

It refers to wisdom and know-how gained from a personal experience with a phenomenon, such as a disease or disability. Experiential expertise, the second concept, was defined as "a competence or skill in handling or resolving a problem through the use of one's own experience" (Borkman, 1976). The most important difference between both concepts is that everyone with the same problem may have experiential knowledge, but the degree to which one has integrated and is competent to share the knowledge with others varies (Castro *et al.,* 2019). Experiential knowledge has been introduced as the 'third' source of knowledge, alongside academic and practice-based knowledge, stemming from intuitive knowledge focusing on the elaboration of existential and moral insights in view of practical questions and dilemmas (Boevink, 2009).

Roots can be found in the users' and survivor movement that arose out of the civil rights movement of the late 1960s and personal histories of psychiatric abuse by well-known activists like Judy Chamberlin in the US, Mary O'Hagan in New Zealand, and Wilma Boevink in the Netherlands. Since then, many former service users have developed into peer support workers, being employed in the field of addiction and mental health care (Doukas and Cullen, 2010). Generally, effect studies have compared the practice of peer support workers to treatment as usual and found no significant difference between peer and non-peer staff (Lloyd-Evans *et al.,* 2014; Chien *et al.,* 2019). Only one randomized control study that researched peer supported self-management for people discharged from a mental health crisis team suggests that peer-delivered self-management reduces readmission to acute care and feelings of loneliness, and enhances social networks (Johnson *et al.,* 2018). Despite these inconclusive results, investments have been done in the promotion and uptake of peer support internationally (Stratford *et al.,* 2019).

In the US, Canada, New Zealand, Australia, UK, and The Netherlands, peer support work is professionalizing fast, in terms of education, certification, function descriptions, and professional associations (Stratford *et al.,* 2019). While peer support workers form a growing part of the work force, there are still issues around the broader implementation and innovation. A number of these issues is related to the status in the organization concerning roles, responsibilities, and payment (Moran *et al.,* 2013). Other issues are related to an institutional culture, which, in most cases, is still dominated by the medical model (Kemp & Henderson, 2012; Faulkner, 2017).

The most recent development is that professionals from the traditional disciplines, like nurses, social workers, psychologists, and psychiatrists, also bring to the surface their personal lived experience, which so far had been hidden, because of professional standards precluding its use (Banks, 2012). However, all helping professions, from psychotherapy to social work, are known to attract individuals with a history of psychological troubles in general (Zerubavel and Wright, 2012; Reid and Poole, 2013). Research reveals that a considerable number of professionals in mental health care has been exposed to traumatic and disruptive experiences in their lives. Estimations fluctuate between 45% and 75% (Zerubavel and Wright, 2012; Weerman, 2016). Being aware of one's vulnerabilities is basic to the training of psychoanalysts, the Rogerian tradition, and other humanistic approaches (Ziv-Beiman and Shahar, 2016). To 'know oneself' was, in fact, crucial in a number of psychotherapeutic traditions (Amundson and Ross, 2016). Although clinicians have been encouraged to process their issues as part of their personal-professional development, the use of personal lived experiences in mental health care practice, so far, has been limited.

Whereas the introduction of peer support workers in mental health services contributed to the transformation in the direction of a recovery-oriented landscape in general, it also consequently led to a division between professionals. Traditional professionals felt unseen and disadvantaged (Weerman *et al.,* 2019). Weerman et al. explain how working alongside a peer support worker eventually facilitated the coming out of mental health professionals in The Netherlands (Weerman *et al.,* 2019). This led to further acknowledgement of the worth of lived experience in mental health settings. Yet, many other professionals felt urged to keep their personal experiences at bay (Weerman and Abma, 2018). To date, there is very little scientific evidence on the professional use of this type of knowledge in mental health care. Therefore, this review explores the international context on the use of experiential knowledge by professionals in mental health settings and searches for possible contributions to the recovery of service users.

Methods

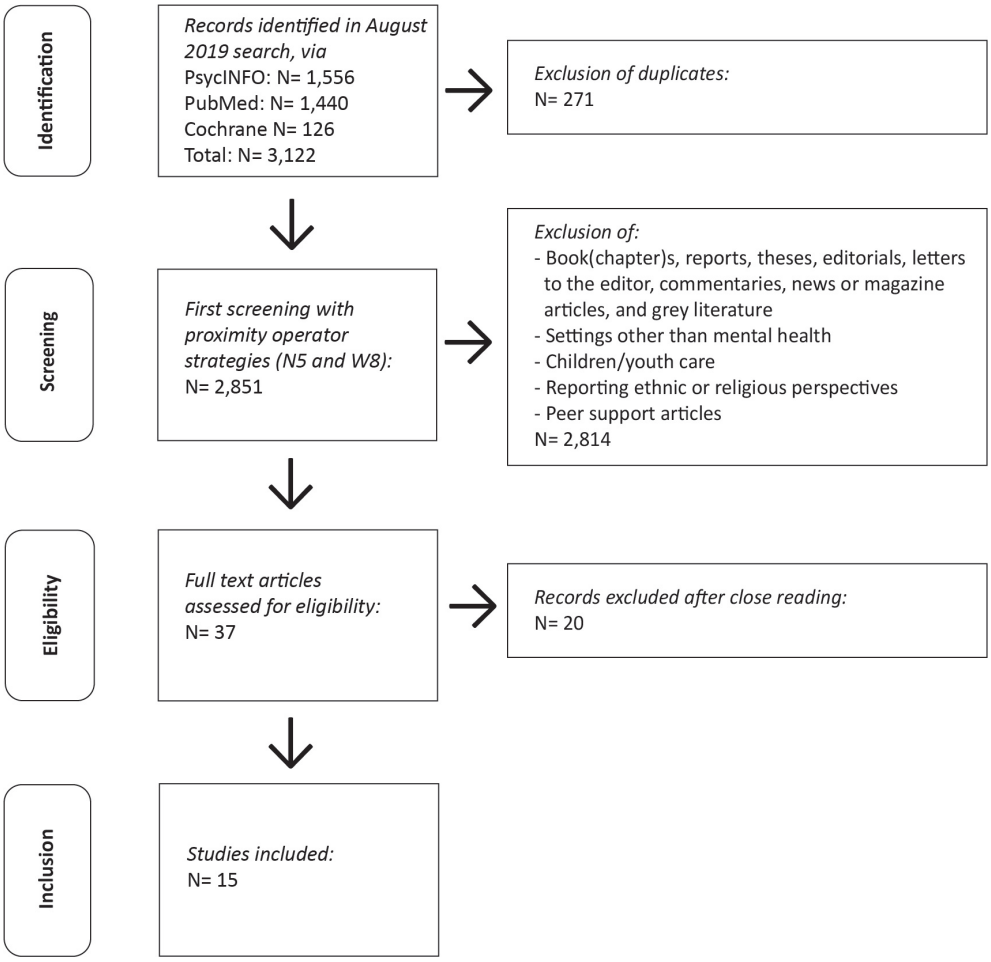
A literature review was conducted including qualitative and quantitative studies from 2015 to 2019, consulting the following databases: PsycINFO, PubMed, and Cochrane Library. The research question highlighted what the value and impact of experiential knowledge of professionals for mental health services is, which led to a further operationalization and a refined search string combining the following terms: mental health personnel, psychiatric nurses, social workers, psychiatrists, (psycho)therapists, counsellors, psychologists, practitioners and self-disclosure, posttraumatic growth and/or lived experiences and/or wounded healer and/or experiential knowledge and/or recovered.

The literature search was conducted by the first author and two information specialists. A preliminary check with three different search strings resulted in more than 3,000 publications. Duplicates were excluded. By using a 'near operators' search strategy[ii]. This number was reduced to 2,851 articles in the aforementioned databases. A set of inclusion and exclusion criteria was used to ensure that the publications selected captured the research question. The focus of the literature study was on journal articles published in English-language, peer-reviewed journals.
The articles had to be available online, identifiable through an electronic database, and published between January 2015 and June 2019, focusing on recent developments. The end date was the time when the search commenced. Books, book chapters, published reports, theses, editorials, letters to the editor, commentaries, news or magazine articles, and grey literature (e.g., unpublished reports) were excluded. The articles included are research and empirical findings, systematic reviews, scoping reviews, critical interpretive reviews, and narrative reviews.

All potentially relevant articles were screened upon title and abstract. The publications varied considerably in size, scope, and profundity. Articles from professional areas other than mental health (e.g., somatic care) were excluded, as well as publications focusing on children/youth care. Furthermore, articles that focused on ethnic and/or religious perspectives were also excluded.
A second screening upon relevance resulted in 37 relevant articles. Articles describing contributions of non-traditional mental health professionals exclusively, such as those of peer support workers, were excluded. Close reading of the 20 remaining articles upon relevance concerning the actual use of experiential knowledge amongst traditional professionals reduced the number of included articles to 15 publications.

ii Proximity operators yield more precise search results.

Figure 1. *Flow chart*



Results

The 15 selected articles were published in a broad range of mental health and psychology journals. Most of the studies involved qualitative research, using different methods like grounded theory, discourse analysis, auto-ethnography, narrative analysis, and a consensual analysis. Five studies were found using a quantitative design. Characteristics of the included publications are listed at the end of the article.

We describe findings related to the use of experiential knowledge by traditional professionals and possible contributions to the recovery of service users. In the selected articles a varying conceptualization of experiential knowledge is identified, differing from use of personal knowledge in traditional psychotherapeutic contexts to recovery-oriented practices. These conceptual differences partly depend on the paradigm, either being medical-clinical or recovery-oriented.

Findings

A scarce body of literature reports about the use of experiential knowledge by mental health professionals. Mainly professionals practising applied professions, e.g., social workers and nurses, are increasingly speaking out about their own experiences of using mental health services (Richards, Holttum and Springham, 2016). Some studies report that traditional professionals became inspired after working alongside peer support workers (Oates, Drey and Jones, 2017; Von Peter & Schulz, 2018). Byrne, Happell & Reid-Searl state that mental health nurses tend to enjoy closer relationships with consumers than other professionals (Byrne, Happell and Reid-Searl, 2017). We differentiate the use of experiential expertise affecting the personal-professional identity, system-related changes, and the recovery of service users.

Personal-professional transformation

Professionals who started using their experiential knowledge believe that their service user experiences enhance their current work, such as an adequate use of self-disclosure, increased emotional empathy and insight, and the ability to hold hope for service users (Richards, Holttum and Springham, 2016). Levitt et al. and De Vos et al. both point out that therapists with lived experiences use disclosures in a more relational and responsive manner by demonstrating humanity and sincere care for service users (Levitt *et al.,* 2016; Vos, Netten and Noordenbos, 2016). Some professionals undergo training to be able to use their lived experiences as actual experiential knowledge. Training and supervision is considered particularly helpful to reflect on the interaction between experiential knowledge and the profession, since conflicts in values, attitudes, and actions pose a challenge at the meeting point between the service user and professional part within one individual (Goldberg, Hadas-Lidor and Karnieli-Miller, 2015). Oates et al. describe how crossing the boundary between the professional and the service user was at first seen as a taboo, and possible reoccurring self-stigma should be addressed (Oates, Drey and Jones, 2017; Peter and Schulz, 2018). Goldberg et al. identified the transformation process ‘from patient to therapatient’ (here, clinical social workers) in Israel (Goldberg, Hadas-Lidor and Karnieli-Miller, 2015).

This process included four stages starting with an initial exploration of themselves as potential help providers and not merely as receivers, questioning the possibility of a service user being a therapist, feeling incompetent to identifying their ability to be professional, and finally integrating service user and therapist parts in one identity. Richards et al. describe how professionals face dilemmas in integrating both identities, depending on the discursive resources most salient in relation to the contexts (Richards, Holttum and Springham, 2016).

Goldberg et al. argue that, by making professionals familiar and comfortable with a hybrid identity, they make extensive use of their lived experience in ways that contribute to service users (Goldberg, Hadas-Lidor and Karnieli-Miller, 2015). New identity constructions incorporate positive identities of "wounded healer," "personhood," and "insider activist," in which mental distress is normalized as human experience, and recovery is "of life" rather than from illness. In this way, professional and service user identities can complement one another and enable empathy with and access by other service users, as well as fulfilling a destigmatizing role within mental health services (Richards, Holttum and Springham, 2016). Levitt et al. also stress that using one's own experiences might also be influenced by personality styles and work preferences (Levitt *et al.,* 2016). Lebel et al. refer to Riessman's introduced Helper Therapy Principle in 1965, which suggests that when an individual (the "helper") provides assistance to another person, the helper may benefit himself (LeBel, Richie and Maruna, 2015). Giving help can be reintegrative for the professional himself.

Contributions to the system

Research illustrates the mental health system in mainly the western countries (Australia, UK, USA, The Netherlands, and Israel) is struggling to meaningfully incorporate the lived experiences of professionals (Richards, Holttum and Springham, 2016; Byrne, Happell and Reid-Searl, 2017).

Even though traditional professionals with lived experiences might want to open up, this is not a common practice. Professionals with lived experiences who work in an environment where the served population has been stigmatized may want to fulfil a role as social change-maker, albeit often without the consent of academic colleagues. Clinicians and therapists seem most reserved in this development since academic socialization holds expectations to keep own needs, aspirations, and weaknesses out of the clinical practice (Peter and Schulz, 2018). They are trained to be self-effacing (Peter and Schulz, 2018). While the concepts of 'professional self-disclosure' and 'wounded healer' are familiar for psychotherapists and host meaningful principles to strengthen the therapeutic alliance, there is a threat that the focus of therapy will shift from user to therapist (Levitt *et al.,* 2016; Berg, Antonsen and Binder, 2017; Simonds and Spokes, 2017; Pinto-Coelho *et al.*, 2018). The risk to be portrayed as an impaired professional and the negative connotation thereof have hindered these practitioners (Tay, Alcock and Scior, 2018). Oates et al. address the taboo of disclosure and debate the extent to which personal and professional boundaries are negotiated during clinical encounters (Oates, Drey and Jones, 2017). It takes effort and self-reflection to critically bring these taboo and power differentials to the foreground (Peter and Schulz, 2018). The introduced new hybrids and ambivalences are considered undesirable or even dangerous because they threaten the status quo and the apparent logic of the system (Peter and Schulz, 2018). This can lead to significant risks to the mental health and well-being of the concerned activists. Byrne et al. state that mental health professionals in general tend to have pessimistic views about the capacity of people

diagnosed with mental illness to recover, so supportive colleagues may not be available (Byrne, Happell and Reid-Searl, 2017). The risk of being encapsulated or being ignored in the system seems realistic, leading to both internal and external conflicts. Others warn for the appearance of a new and separate group, since professionals with lived experiences might present different and superior than peer support workers and other professionals (Richards, Holttum and Springham, 2016). Self-care techniques seem important mediators against these identified risks (Byrne, Happell and Reid-Searl, 2017). Other possible beneficial factors in this regard include therapist self-insight, adequate training and guidance, and a safe work environment (Vos, Netten and Noordenbos, 2016).

Contribution to recovery of users

Few scientific studies report about the actual contribution to the recovery of service users. Whereas therapeutic disclosures are pursued to evoke favourable changes in clinical symptoms, there are few insights on the use of experiential knowledge and outcomes in broader terms of recovery and quality of life (Levitt *et al.,* 2016; Noyce and Simpson, 2018; Pinto-Coelho *et al.,* 2018; McCormic *et al.,* 2019).

Some professionals use their experiential knowledge for specific therapeutic purposes, such as providing new insights into the recovery process, modelling, and enhancing hope (Vos, Netten and Noordenbos, 2016; Berg, Antonsen and Binder, 2017). De Vos et al. argue that users with eating disorders benefit from being treated by a recovered therapist (Vos, Netten and Noordenbos, 2016). The most important changes reported were feeling recognized and heard, diminished levels of shame, increased feelings of hope, increased sense of trust, more openness/honesty, and a stronger motivation to change (Vos, Netten and Noordenbos, 2016). Another study shows how the lived experience instantly increased empathy and deepened the understanding of anxiety, low mood, or suicidal thoughts (Oates, Drey and Jones, 2017). When recovered from certain distress, these experiences enable the professional to see openings of recovery for others (Vos, Netten and Noordenbos, 2016). Identification, as an underlying dynamic, is associated with increased commonality and helps to normalize mental distress (Richards, Holttum and Springham, 2016).

Conclusion

We found a scarce body of literature from research in western countries concerning the use and value of experiential knowledge by traditional mental health professionals. Nurses and social workers especially are speaking out about their own experiences with mental health distress, and some became inspired by working alongside peer support workers or lived experience practitioners, which facilitated coming outs about hidden personal histories with mental health distress (Richards, Holttum and Springham, 2016; Oates, Drey and Jones, 2017; Peter and Schulz, 2018). The use of experiential expertise affects the personal-professional identity, the mental health care system, and the recovery of service users.

Firstly, professionals who use experiential knowledge want to enhance their practice with adequate self-disclosure, more empathy and insight, and the ability to hold hope for service users.

Experiential knowledge is used in a relational and responsive manner, and the decision to use personal experiences might be related to personality styles (Levitt *et al.,* 2016; Vos, Netten and Noordenbos, 2016). Several authors describe the transformative process professionals undergo in order to integrate the professional and personal identity into a new identity construction, in which professional and service user identities can complement one another and mental distress is normalized as human experience (Goldberg, Hadas-Lidor and Karnieli-Miller, 2015; Richards, Holttum and Springham, 2016; Oates, Drey and Jones, 2017). Giving help can also be beneficial for professionals themselves (LeBel, Richie and Maruna, 2015).

Secondly, research illustrates the mental health system is struggling to meaningfully incorporate lived experiences of professionals (Richards, Holttum and Springham, 2016; Byrne, Happell and Reid-Searl, 2017). The use of experiential knowledge by traditional professionals is not a common practice. Clinicians and therapists seem most reserved in this development. Even while historically academic professionals developed interesting concepts such as 'the wounded healer' and 'therapeutic self-disclosure,' using personal experiences for professional purposes remained controversial, putting emphasis on the therapist's possible vulnerability. It takes effort and self-reflection to critically bring these taboo and power differentials to the foreground, affecting the well-being of the concerned activists. Self-care techniques seem important mediators besides self-insight, adequate training and guidance, and a safe work environment (Vos, Netten and Noordenbos, 2016; Byrne, Happell and Reid-Searl, 2017).

Lastly, few scientific studies report how experiential expertise might affect recovery of service users and quality of life in broader terms. Some studies indicate positive findings, such as providing new insights into the recovery process, feeling recognized and heard, diminished levels of shame, increased feelings of hope, increased sense of trust, more openness/honesty, and a stronger motivation to change (Vos, Netten and Noordenbos, 2016). The lived experience may increase empathy and deepen understanding of anxiety, low mood, or suicidal thoughts (Oates, Drey and Jones, 2017).

The limited number of articles found indicates a lack of scientific knowledge about professionals working with their experiential knowledge and its meaning for the recovery of service users. This is not surprising, since the notion of the value of lived experiences and its use in recovery-based mental health services is still in its early stages of development. More research is desirable. Therefore, the empirical part of the first author's PhD research focuses on the lived experiences and experiential knowledge of traditional mental health professionals and its possible meaning for the recovery of service users.

Limitations

Because of the limited number of studies, evidence about possible contributions of the use of experiential knowledge for the recovery of service users is still scarce. Most of the included articles concerned qualitative studies with limited sample sizes. Also, some articles were written from a specific area, like eating disorders or psychotherapy. Furthermore, two articles that were selected for the review came from one PhD study, which may have limited its scope.

Authors	Title	Journal	Year of publication	Sample	
Berg, H., Antonsen, P., & Binder, P.-E.	'Sincerely speaking: Why do psychotherapists self-disclose in therapy? A qualitative hermeneutic phenomenological study'	Nordic psychology	2017	A qualitative hermeneutic phenomeno-logical study (n=10 therapists)	
Byrne, L., Happell, B., & Reid-Searl, K.	'Recovery as a lived experience discipline: A grounded theory study'	Issues in Mental Health Nursing	2015	Grounded theory study amongst 13 lived experience practitioners (LEP) in Australia	
Byrne, L., Happell, B., & Reid-Searl, K.	'Risky business: Lived experience mental health practice, nurses as potential allies'	International Journal of Mental Health Nursing	2017	Grounded theory study amongst 13 LEP in Australia	
De Vos, J. A., Netten, C., & Noordenbos, G.	*'Recovered eating disorder therapists using their experiential knowledge in therapy: A qualitative examination of the therapists' and the patients' view'*	Eating Disorders: The Journal of Treatment & Prevention	2016	Qualitative cross-sectional design incl. questionnaire amongst 205 users and 24 practitioners with lived experience	
Goldberg, M. Hadas-Lidor, N. & Karnieli-Miller, O.	*'From patient to therapatient: Social work students coping with mental illness'*	Qualitative Health Research SAGE	2015	Qualitative narrative analysis (n=12)	

	Site	Objectives	Findings
	Norway	Study on the rationale of self-disclosure of therapists	Therapists understood self-disclosures as a way of normalizing experiences, humanizing the therapeutic interaction and underlining the importance of emotional self-acceptance. However, self-disclosures were considered insignificant or potentially harmful if they resulted in a change of focus from therapist to service user.
	Australia	To explore the existing and potential role for lived experience practitioners in the ongoing implementation of recovery principles within the mental health sector	The findings suggest that lived experience practitioners experienced significant barriers to the implementation of recovery-focused practice with three main issues: 1) Recovery co-opted, 2) Recovery uptake, and 3) Recovery denial. Lived experience practitioners are the logical leaders of recovery implementation due to their own internal experience and understandings of recovery but must be enabled to take on their role as recovery experts and leaders.
	Australia	To generate a theory to explain experiences of LEP in the implementation and development of their roles	Participants described the unique vulnerabilities of their mental health challenges being known, and while there were many positives about disclosing, there was also apprehension about personal information being so publicly known. Self-care techniques were important mediators against these identified risks. The success of lived experience roles requires support and nurses can play an important role, given the size of the nursing workforce in mental health, the close relationships nurses enjoy with consumers, and the contribution they have made to the development of lived experience roles within academia.
	The Netherlands	To examine recovered eating disorder therapists using their experiential knowledge and how this influences therapy and the service users they treat	Results showed that to be effective experiential knowledge and self-disclosure need to be shared thoughtfully and should not include specific details about ED symptoms. Other factors noted that enhanced the benefits of experiential knowledge included therapist self-insight and self-care, adequate training and guidance, and a safe work environment. Service users stated that being treated by a recovered therapist had a positive effect on their recovery process.
	Israel	To explore the experiences of social work students with psychiatric difficulties and their challenges as they went through the different stages of development as health care professionals	Findings reveal the developmental process students underwent from being patients to being ‘therapatients’. This process included four stages: 1) exploration of the health care world, 2) questioning the possibility of a service user being a therapist and feeling incompetent, 3) identifying their ability to be professionals, and 4) integrating between their user and therapist parts.

Authors	Title	Journal	Year of publication	Sample	
LeBel, T. P., Richie, M., & Maruna, S.	'Helping others as a response to reconcile a criminal past: The role of the wounded healer in prisoner reentry programs'	Criminal Justice and Behavior	2015	Quantitative survey (n= 258) formerly incarcerated persons completed a survey; 229 users and 29 staff members)	
Levitt, H. M., Minami, T., Greenspan, S. B., Puckett, J. A., Henretty, J. R., Reich, C. M., & Berman, J. S.	'How therapist self-disclosure relates to alliance and outcomes: A naturalistic study'	Counselling psychology quarterly	2016	Naturalistic study of 52 therapy dyads (n=16 therapists and 52 users) quantitative analysis	
McCormic, R. W., Pomerantz, A. M., Ro, E., & Segrist, D. J.	*'The 'me too' decision: An analog study of therapist self-disclosure of psychological problems'*	Journal of Clinical Psychology	2019	Quantitative Vignette study (n= 104)	
Noyce, R., & Simpson, J.	'The experience of forming a therapeutic relationship from the user's perspective: A metasynthesis'	Psychotherapy research	2018	Review (meta-ethnographic study of 13 studies)	

	Site	Objectives	Findings
	U.K.	This study was designed to assess the professional-ex or wounded healer role of formerly incarcerated persons by examining potential differences between staff members and users in prisoner reentry programs	Findings support the notion that the wounded healer or professional-ex role is related to desistance and can potentially transform formerly incarcerated persons from being part of "the problem" into part of "the solution" to reduce crime and recidivism.
	U.S.A.	To examine types and functions of therapists' self- disclosure in relation to therapy alliance and outcomes	Findings indicated that the number of disclosures not significantly correlated with outcome or alliance scores, but disclosures that acted to humanize the therapist were associated with fewer clinical symptoms post-session than disclosures expressing appreciation or encouragement. Also, disclosures that conveyed similarity between the therapist and service user were associated with fewer post-session clinical symptoms and interpersonal problems when compared to disclosures that conveyed neither similarity nor dissimilarity. As well, neutral therapist self-disclosures were associated with better service user functioning than disclosures that relayed negative or positive information about the therapist.
	U.S.A.	To test the hypothesis that service user perceptions of therapists are most favourable when therapists self-disclose their own personal experience with the same psychological problem to a moderate extent	This study provides empirical data regarding the effect of the extent, rather than the mere presence or absence, of therapist self-disclosure regarding personal psychological experiences. The moderately extensive self-disclosure condition yielded the highest overall therapist perception.
	U.K.	To synthesize qualitative research exploring users' perspectives of forming a therapeutic relationship with their therapist or counsellor	The majority of service users voiced a preference for having similar personal characteristics to their therapist, believing that this would contribute to an implicit understanding of their difficulties and would make the therapist more effective. Additionally, they preferred their therapists to disclose information in order to facilitate the therapeutic relationship.

Authors	Title	Journal	Year of publication	Sample	
Oates, J., Drey, N., & Jones, J.	'Your experiences were your tools'. How personal experience of mental health problems informs mental health nursing practice'	Journal of psychiatric and mental health nursing	2017	Qualitative interviews with nurses with lived experiences (n=27)	
Pinto-Coelho, K., Hill, C. E., Kearney, M. S., Sarno, E. L., Sauber, E. S., Baker, S. M., Thompson, B. J.	'When in doubt, sit quietly: A qualitative investigation of experienced therapists' perceptions of self-disclosure'	Journal of Counseling Psychology	2018	Consensual qualitative research (n=13)	
Richards, J., Holttum, S., & Springham, N.	'How do "mental health professionals" who are also or have been "mental health service users" construct their identities?'	SAGE Open	2016	Discourse analysis (n=10)	
Simonds, L. M., & Spokes, N.	'Therapist self-disclosure and the therapeutic alliance in the treatment of eating problems'	Eating Disorders: The Journal of Treatment & Prevention	2017	Quantitative study (n=120 women with history of eating problems)	

	Site	Objectives	Findings
	U.K.	To explore the extent and influence of mental health professionals' personal experience of mental ill health on clinical practice	The influence of personal experience in nursing work was threefold: 1) through overt disclosure, 2) through the 'use of the self as a tool,' and 3) through the formation of professional nursing identity. Personal experience of mental illness in mental health nurses creates understanding of and empathy for mental health service users, and in certain circumstances, it is seen as giving mental health nurses credibility when talking to those in their care. The notion of mental ill health experience informing therapeutic contacts within mental health nursing practice should be contextualized within the broader picture of nurses using themselves and their experiences in their work.
	U.S.A.	To learn from experienced therapists about the use of successful and unsuccessful therapeutic self-disclosure (TSD) over time	Therapist self-disclosure is a controversial intervention because of the concern about the focus shifting from the service user to the therapist. Experienced therapists suggested disclosure can be very helpful but that therapists should not disclose if it is not in user's best interest, if the therapist feels too vulnerable, and if the therapist's personal issues are strongly involved.
	U.K.	To explore how mental health professionals with mental health service user experience construct their identity	Participants constructed their identity variously, suggesting both "unintegrated" and "integrated" identities in relation to some professional contexts. Integrated identities can potentially be foregrounded to contribute the social value of service user and highlighting positive and hopeful perspectives on mental distress.
	U.K.	To model relationships between different types of therapist self-disclosure, therapeutic alliance, service user self- disclosure, shame, and severity of eating problems	The analyses presented provide support for the contention that therapist self-disclosure, if perceived as helpful, might strengthen the therapeutic alliance. A strong therapeutic alliance, in turn, has the potential to promote patient disclosure and reduce shame and eating problems.

Authors	Title	Journal	Year of publication	Sample	
Tay, S., Alcock, K., & Scior, K.	'Mental health problems among clinical psychologists: Stigma and its impact on disclosure and help-seeking'	Journal of clinical psychology	2018	Quantitative online survey (n= 678 clinical psychologists)	
Von Peter, S., & Schulz, G.	''I-as-We' - Powerful boundaries within the field of mental health coproduction'	International journal of mental health nursing	2018	Auto-ethnography	

	Site	Objectives	Findings
	U.K.	To assess the prevalence of personal experiences of mental health problems among clinical psychologists, external, perceived, and self-stigma among them, and stigma-related concerns relating to disclosure and help-seeking	Personal experiences of mental health problems among clinical psychologists seem fairly common. Stigma, concerns about negative consequences of disclosure, and shame as barriers to disclosure and help-seeking merit further consideration. Within clinical psychology and across mental health professions more generally, there are unspoken beliefs that "experts" should be immune to human distress, which need to be challenged more openly.
	Germany	To explore some of the reasons for why self-disclosure is so difficult and how these difficulties may prevent productive forms of coproduction	Mental health professionals often revert to an "I-as-we", speaking of themselves as a collective and thereby reifying the boundaries between 'vulnerable users' and 'invulnerable professionals.' Ethnographic examples are given of how these boundaries are produced by a continuous, often invisible, and powerful category work. It is discussed how the dichotomous logic of these boundaries can cause people on both sides to feel reduced to a representation of a certain species, which can take on an existential dimension. Ways out are identified for mental health professionals to self-reflexively engage with their own crisis experience in co-productive and other relationships.

References

Amundson, J.K. & Ross, M.W. (2016). The Wounded Healer: From the Other Side of the Couch. *The American journal of clinical hypnosis, 59*(1), pp. 114–121.

Banks, S. (2012). *Ethics and values in social work*. Hampshire: Palgrave Macmillan.

Berg, H., Antonsen, P. & Binder, P.E. (2017). Sincerely speaking: Why do psychotherapists self-disclose in therapy?–A qualitative hermeneutic phenomenological study. *Nordic Psychology, 69*(3), pp. 143–159.

Boevink, W. (2009). *Lijfsbehoud, levenskunst en lessen om van te leren. HEE-gesch(r)ift.* Utrecht: Trimbos Instituut.

Borkman, T. (1976). Experiential Knowledge: A analysis of self-help groups. *Social Service Review*, *50*(3), pp. 445–456.

Byrne, L., Happell, B. & Reid-Searl, K. (2017). Risky business: Lived experience mental health practice, nurses as potential allies. *International Journal of Mental Health Nursing, 26*(3), pp. 285–292.

Byrne, L., Happell, B. & Reid-Searl, K., (2015). Recovery as a lived experience discipline: A grounded theory study. *Issues in mental health nursing, 36*(12), pp. 935-943.

Castro, E.M., Van Regenmortel, T., Sermeus, W. & Vanhaecht, K. (2019). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory and Health, 17,* pp. 307–330.

Chien, W.T., Clifton, A.V., Zhao, S., & Lui, S. (2019). Peer support for people with schizophrenia or other serious mental illness. *Cochrane Database of Systematic Reviews,* (4).

Corrigan, P.W. (2016). Lessons learned from unintended consequences about erasing the stigma of mental illness. *World Psychiatry, 15*(1), pp. 67–73.

Doukas, N. & Cullen, D. (2010). Recovered addicts working in the addiction field: Pitfalls to substance abuse relapse. *Drugs: Education, Prevention and Policy, 17,* pp. 216–231.

Faulkner, A. (2017). Survivor research and Mad Studies: the role and value of experiential knowledge in mental health research. *Disability & Society, 32*(4), pp. 500–520.

Goldberg, M., Hadas-Lidor, N. & Karnieli-Miller, O. (2015). From Patient to Therapatient: Social Work Students Coping With Mental Illness. *Qualitative Health Research, 25*(7), pp. 887–898.

Johnson, S., Lamb, D., Marston, L., Osborn, D., Mason, O., Henderson, C., ... & Lloyd-Evans, B. (2018). Peer-supported self-management for people discharged from a mental health crisis team: a randomised controlled trial. *The Lancet, 392*(10145), pp. 409–418.

Kemp, V. & Henderson, A.R. (2012). Challenges faced by mental health peer support workers: Peer support from the peer supporters point of view. *Psychiatric Rehabilitation Journal, 35*(4), pp. 337–340.

LeBel, T.P., Richie, M. & Maruna, S. (2015). Helping others as a response to reconcile a criminal past:

The role of the wounded healer in prisoner reentry programs. *Criminal Justice and Behavior, 42*(1), pp. 108–120.

Levitt, H.M., Minami, T., Greenspan, S.B., Puckett, J.A., Henretty, J.R., Reich, C.M., & Berman, J.S. (2016). How therapist self-disclosure relates to alliance and outcomes: A naturalistic study. *Counselling Psychology Quarterly, 29*(1), pp. 7–28.

Lloyd-Evans, B., Mayo-Wilson, E., Harrison, B., Istead, H., Brown, E., Pilling, S., ... & Kendall, T. (2014). A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC psychiatry, 14,* pp. 1-12.

McCormic, R.W., Pomerantz, A.M., Ro, E., & Segrist, D.J. (2019). The "me too" decision: An analog study of therapist self-disclosure of psychological problems. *Journal of Clinical Psychology, 75*(4), pp. 794–800.

Moran, GS., Russinova, Z., Gidugu, V., & Gagne, C. (2013). Challenges experienced by paid peer providers in mental health recovery: A qualitative study. *Community Ment Health J, 49,* pp. 281 – 291.

Noyce, R. and Simpson, J. (2018). The experience of forming a therapeutic relationship from the clients perspective: A metasynthesis. *Psychotherapy Research, 28*(2), pp. 281–296.

Oates, J., Drey, N. & Jones, J. (2017). 'Your experiences were your tools'. How personal experience of mental health problems informs mental health nursing practice. *Journal of Psychiatric and Mental Health Nursing, 24*(7), pp. 471–479.

Peter, von S. & Schulz, G. (2018). "I-as-We" – Powerful boundaries within the field of mental health coproduction. *International Journal of Mental Health Nursing, 27*(4), pp. 1292–1300.

Pinto-Coelho, K.G. Hill, C.E., Kearney, M.S., Sarno, E.L., Sauber, E.S., Baker, S.M., ... & Thompson, B.J. (2018). When in doubt, sit quietly: A qualitative investigation of experienced therapists' perceptions of self-disclosure. *Journal of Counseling Psychology, 65*(4), pp. 440–452.

Reid, J. & Poole, J. (2013). Mad Students in the Social Work Classroom? Notes From the Beginnings of an Inquiry. *Journal of Progressive Human Services, 24*(3), pp. 209–222.

Richards, J., Holttum, S. & Springham, N. (2016). How Do "Mental Health Professionals" Who Are Also or Have Been "Mental Health Service Users" Construct Their Identities?. *SAGE Open, 6*(1).

Simonds, L.M. & Spokes, N. (2017). Therapist self-disclosure and the therapeutic alliance in the treatment of eating problems. *Eating Disorders: The Journal of Treatment & Prevention, 25*(2), pp. 151–164.

Stratford, A. C., Halpin, M., Phillips, K., Skerritt, F., Beales, A., Cheng, V., ... & Davidson, L. (2019). The growth of peer support: an international charter. *Journal of Mental Health, 28*(6), pp. 627-632.

Tay, S., Alcock, K. & Scior, K. (2018). Mental health problems among clinical psychologists: Stigma and its impact on disclosure and help seeking. *Journal of clinical psychology, 74*(9), pp. 1545–1555.

Vos, de J.A., Netten, C. and Noordenbos, G. (2016). Recovered eating disorder therapists using their experiential knowledge in therapy: A qualitative examination of the therapists and the patients view. *Eating Disorders: The Journal of Treatment & Prevention, 24*(3), pp. 207–223.

Weerman, A. (2016). *Ervaringsdeskundige zorg- en dienstverleners. Stigma, verslaving & existentiële transformatie.* [Doctoral Dissertation]. Vrije Universiteit Amsterdam.

Weerman, A. & Abma, T. (2018). Social work students learning to use their experiential knowledge of recovery. An existential and emancipatory perspective. *Social Work Education, 38*(4), pp. 453–469.

Zerubavel, N. & Wright, M.O.D. (2012). The dilemma of the wounded healer. *Psychotherapy, 49*(4), pp. 482–491.

Ziv-Beiman, S. & Shahar, G. (2016). Therapeutic self-disclosure in integrative psychotherapy: When is this a clinical error?. *Psychotherapy, 53*(3), pp. 273–277.

Reflection I: "Relational ethics?"

There is a personal angle to the writings of my dissertation, related to my own healing process. Parallel to the studies of this PhD research, I have been visiting a seasoned psychiatrist, who had quite a different take on the therapeutic relationship than my previous therapist. Although he worked trauma-focused and body-oriented, something was lacking. He was part of the dominant field, where the acknowledgement of experiential knowledge has been very scarce, and possibly also limited educated in normative professions.

For instance, even though therapy was already running for about a year, he did not talk about himself, nor share anything personal. This felt very unbalanced and unequal to me. While I was dreading intimacy but doing my best to open up, he'd stay in his 'safe' position and take the lead without really attuning to my needs. I remember he once asked me to stop masking my feelings, referring to my apparently visible defence mechanisms. This felt very uncomfortable and completely unsafe, pushing me towards vulnerability. It also made me mad in a way and perhaps primed me to further investigate his way of working. Obviously, relational ethics was not part of his framework, let alone was he trained in harnessing lived experiences, which is why I could not hold him to account for missing something. But what struck me most was the rationale behind his reservations. I deliberately started opening up discussions around it, in almost every session. Sometimes he'd discriminately say that he does reveal more to other clients depending on their illness and the relationship he had with them. Other times, he'd say that he did not expect any therapeutic profit out of self-disclosing or sharing personal matters and that the therapeutic relationship itself is overrated. I questioned the assumption of having processed all issues in learning therapy, in order to interact as a 'neutral' therapist. And I thought of the self-protective nature of this detached working style as I had experienced in earlier encounters with therapists, but I also decided to continue navigating this topic with him and I kept asking how he was doing and what he was occupied with. I needed more confidence in him as a person for the sake of my own process. Luckily, after a few confrontations new openings appeared.

He realised what was at stake and the next session he came back to me sharing his realisation of 'how uncommon' it actually is to expect openness from clients. They have to grant trustworthiness to a fairly unknown therapist so they are demanded to practice openness all the time. It also made him aware of how fast clients adjust to the situation and their position, as often being dependent on professional help.

After this period, he gradually started sharing more of himself, but this was clearly a search. Maybe I failed to bridge the gap between the differences of the cultural worlds we were part of. His work context could be characterised as a 'cure and short-term treatment setting', as well as his view on knowledge (positivistic) was obviously quite in conflict with the 'care and recovery' principles and the (social) constructivism paradigm highly esteemed in my work setting. This difference was like night and day.

I wondered, how this would work for other clients, would they accept a professional hiding self? Reciprocity can certainly not be enforced, but how do they obtain a sense of safety in the relationship with a relative stranger? I was also curious to find out what lived experiences could mean to those who resort to mental health care. How do clients reflect on professionals who integrate the personal with the

professional and what are their perceptions of helpful professional relationships? How do they reflect on intentional disclosures and sharing of their professional? How does that affect the power balance in the relationship? I wondered whether identification could contribute to the relationship. What could be the benefits and pitfalls of proximity in the relationship? How does that relate to the risk paradigm in mental health care? These were some of the topics that inspired me in my first study.

Chapter 3

Experiential knowledge of mental health professionals: Service users' perceptions

Karbouniaris, Simona
Wilken, Jean Pierre
Weerman, Alie
Abma, Tineke

Published in: European Journal of Mental Health, 2022

Abstract

Introduction

Nowadays the Western mental health system is in transformation to recovery-oriented and trauma informed care in which experiential knowledge becomes incorporated. An important development in this context is that traditional mental health professionals came to the fore with their lived experiences. From 2017 to 2021 a research project was conducted in the Netherlands in three mental health organizations, focusing on how service users perceive the professional use of experiential knowledge.

Aims

This paper aims to explore service users' perspectives regarding their healthcare professionals' use of experiential knowledge and the users' perceptions of how this contributes to their personal recovery.

Methods

As part of qualitative research, 22 service users were interviewed. A thematic analysis was employed to derive themes and patterns from the interview transcripts.

Results

The use of experiential knowledge manifests in the quality of a compassionate user-professional relationship in which personal disclosures of distress and resilience of the professional are embedded. This often stimulates users' recovery process.

Conclusions

Findings suggest that the use of experiential knowledge by mental health professionals like social workers, nurses and humanistic counsellors demonstrates an overall positive value as an additional (re)source.

Introduction

Personal and social recovery from serious mental illness has been subject to study over the past 30 years. A commonly used definition of recovery remains "that it involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (Anthony, 1993, p.527). Recovery-oriented care contributes to the acknowledgement, support and development of identity and autonomy (Wilken, 2010). This affects both an individual level, e.g., gaining control and developing one's identity, and a social level, such as being part of the society. Recovery can be enhanced by learning from personal experiences e.g., on how to cope with stress and stigma.

During the transformation of mental health care in the Western countries towards recovery-oriented care, a group of established professionals came to the fore with their personal experiences involving mental health distress and trauma (Karbouniaris *et al.,* 2020). This concerned especially nurses and social workers who became inspired after having worked alongside peer support workers who became part of the workforce. Many of them actually primarily chose their profession due to their own history of suffering from mental health problems (Straussner *et al.,* 2018). The use of experiential knowledge by professionals seems to fit well into the transformation towards recovery-oriented care, and might be considered as a new (re)source, alongside methodological/clinical and theoretical knowledge (Weerman, 2016).

Nevertheless, a professional use of such experiences often goes beyond the purview of traditional medical professionalism and is therefore contested. Mental health professionals' readiness to disclose lived experiences may in fact be significantly affected by (historical) prohibitions. This stands also influenced by different views on mental health professions and related standards of care. Professional frameworks of social workers and nurses show more openness to incorporate experiential knowledge, than those of psychiatrists and psychologists (Leemeijer & Trappenburg, 2016). The evolvement of lived experiences to experiential knowledge is defined as "the truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others" (Castro e*t al.,* 2019, p. 308). These professionals being "out and proud" might help increase recovery and social inclusion for service users more generally (Holttum, 2017). However, they often have not been trained on how to harness this appropriately or effectively for the benefit of service users (Byrne *et al.,* 2022).

Concurrently, a second large transformation in mental health care has been the awareness of relational trauma (maltreatment, neglect, abuse, inconsistent caregiving, discrimination) as an important, but underestimated cause of mental distress, as well as evidence that the current mental health system can re-traumatize people (Butler *et al.,* 2011). This led to the concepts of "trauma informed care" and "Trauma Informed Recovery Oriented Care" directing specific attention to the relationship, minimizing distress and maximizing autonomy by trusting on healing potential (Marsman, 2021; Reeves, 2015; Sahmsa, 2014). It requires a system to make a paradigm shift from asking, "What is wrong with this person?" to "What has happened to this person?" (Harris & Fallot, 2001).

Accordingly, the intention of trauma informed care is to provide support services in a way that remains accessible and appropriate to those who may have experienced trauma, modifying system procedures (a) and attuning relationally (b) (see Table 1).

Table 1. *Retraumatization (Institute on Trauma and Trauma-Informed Care, 2015)*

What Hurts?
A. System (Policies, procedures, "the way things are done")
- Having to continually retell their story
- Being treated as a number
- Procedures that require disrobing
- Being seen as their label (ie., addict, schizophrenic)
- No choice in service or treatment
- No opportunity to give feedback about their experience with the service delivery
B. Relationship (Power, control, subversiveness)
- Not being seen/heard
- Violating trust
- Failure to ensure emotional safety
- Noncollaborative
- Does things for rather than with
- Use of punitive treatment, coercive practices and oppressive language

Trauma informed recovery is considered to bring together the best of both worlds, by prioritizing self-agency, empowerment, and creating atmospheres for recovery that embody consistency and confidentiality, minimizing the possibilities of triggering past trauma, and integrating users in service evaluation (Huntington *et al.,* 2005). On a par with recovery and the use of experiential knowledge, trauma informed approaches search for sensemaking among service users. All these approaches originate from the notion that self-inquiry and understanding the trauma can help users to come to grips with their situation and history, and to create a meaningful life.

Theoretical Lens and Background

The claim of recovery oriented and trauma-informed models calls into question how users perceive the way professionals use experiential knowledge. Our study stands grounded in a relational perspective on care, signaling the importance of relationships.

Available research involving service users' perceptions raises questions about the nature of power in provider-user encounters and stresses the emphasis on relational work. Experts have emphasized the importance of using the relationship as a vehicle to understand and resolve relational difficulties, often associated with early trauma and attachment wounding (Cronin *et al.,* 2014). Bordin's tripartite conceptualization of the working alliance dates back to 1979, yet it already addressed the agreement on goals, tasks, and developing an affective bond between professional and user (Bordin, 1979). Findings from a narrative study amongst users support the relevance of relational contact with professionals, who

provide hope and also play an important role in social recovery as being the reconnection to the outside world (Wilken, 2010). A meta-ethnography of the perspectives of persons with severe mental illnesses, underlines that a positive relationship between provider and user rests on an interpersonal relationship, allowing a transgression of professional boundaries (Ljungberg *et al.,* 2015). On the contrary, pessimistic and uncaring professionals who acted paternalistic and disrespectful were perceived as non-helpful, especially in a context were discontinuity, insufficient time, and coercion pertained (Ljungberg *et al.,* 2016). These types of relationships leave no space for negotiating the relationship and hinder development, contributing to further suffering and hopelessness (Ljungberg *et al.,* 2016).

Relational and care ethics scholars have emphasized the importance of respect and openness for the world of the person, via practicing good ethics in every encounter. The professional's presence, seeing and listening to the user's needs in a reflective and sensitive way, is a necessity emphasized over and over again in this tradition (Arman *et al.,* 2015; Baart, 2004; Wilken, 2010). The constituents of such relationships lie both in the attitudes and behaviors of the concerned professionals, next to factors related to the organizational context (Ljungberg *et al.,* 2016). In this regard, also lived experiences of professionals are presumed to increase empathy, understanding and the ability to hold hope for users, thereby countering stigma (Richards *et al.,* 2016; Vos *et al.,* 2016).

In order to contribute to the knowledge about the value of professionals' experiential knowledge, we conducted an empirical study investigating both the perspectives of professionals and of service users. This article aims to provide an in-depth understanding of the latter. Another part of our study, focusing on the perspectives of these professionals, already demonstrated that -thanks to professional proximity- a strong working relationship can be established (Karbouniaris *et al.,* 2022).

Methods

Research Setting

This study took place in three mental health organizations in the North-Eastern region of The Netherlands. All three organizations were committed to professionalize the use of experiential knowledge that health care professionals posses. Approximately ten professionals in each organization followed a one-year post-bachelor training in working with the experiential knowledge of health care professionals. This training consisted of 16 training days focusing on narrating health care professionals' recovery stories, collective discussions and reflections on impacting the entire organization (see Appendix C). The participating professionals with lived experiences were invited to share and harness experiential knowledge while working with users and colleagues.

Design

This study was embedded in a larger participatory action research project that started in 2017 as a joint programme of different (mental) health care organizations and three universities. A team of researchers, with two of them having lived experiences (author 1 and 3), initiated it, and patient advocacy services of the involved organizations supported it.

For this part of the study, a qualitative design with reflexive thematic analysis was used to specifically voice the users who were involved in the professionalization process of professionals using experiential knowledge.

Our design was inspired by the tradition of responsive evaluation that favors personal experiences and draws upon the ordinary ways people perceive quality, by listening to their stories and mutual learning through an open dialogue (Abma *et al.,* 2016; Abma *et al.,* 2020). This plurality requires that the "research design" gradually emerges in conversation with as many stakeholders as possible (Abma *et al.,* 2017). Relevant stakeholders who were engaged in the research from the start have been: service users and peer support workers, professionals with and without lived experiences and their supervisors. They were engaged in the training of the professionals using experiential knowledge.

The study's main section consisted of in-depth interviews and a focus group collecting user experiences. For this purpose, two topic lists were designed (see Appendix A and B).

With the actual involvement of service users, the insiders' voice was articulated, even though it remained limited to the aforementioned set-up project design. To stimulate participation, all users also received personal invitations to participate in annual project-conferences and regular project meetings. Some of the users presented the themes discussed in this study from a personal stance, not only to the involved professionals but also to students, researchers, managers, directors and the broader public as the conferences had an open and dialogical character.

Participants and Data Collection

Service users were pre-invited by professionals and ultimately selected by the research team according to the following inclusion criteria:

- Service users had to be in regular contact (at least on a weekly basis) for at least six months with a professional (social worker, nurse or humanistic counsellor) who attended the post-bachelor training "professional use of experiential knowledge". Appendix C includes more information about the training and competences.
- The mental health provision took place in a (recovery oriented) mental health setting.
- Participating service users had to have the ability to reflect and express themselves verbally well in Dutch language.
- To capture a broad range of experiences, we included a variety of participants with regard to gender, age, and mental health care setting.

Between 2018 and 2020, a group of 22 service users, 15 women and seven men with ages varying from 22 to 70 years (M = 45.5), was interviewed by the first author. This group had been receiving care from in total ten different professionals who all had been trained to use their experiential knowledge. The majority of this service user group reported being in care for an extended period of time, often starting from young adulthood. Reported mental health problems differed from trauma, (complex) post-trauma stress disorder,

adverse childhood experiences, depression, bipolar disorder, dysthymia, psychosis, schizophrenia, autism, eating disorder, borderline personality disorder, attention deficit hyperactivity disorder, addictions, obsessive compulsive disorder, anxiety disorder and burn-out (Table 2).

Table 2. *Participant characteristics (N = 22)*

Respondent	Gender	Age category	Mental health setting	Professional
P1	F	36–45	Day care	Professional A
P2	F	46–55	Outpatient	Professional B
P3	F	36–45	Outpatient	Professional C
P4	F	56–65	Supported living	Professional D
P5	F	36–45	Outpatient	Professional C
P6	F	46–55	Supported living	Professional D
P7	M	56–65	FACT team	Professional D
P8	M	26–35	Supported living	Professional E
P9	M	26–35	Supported living	Professional E
P10	F	26–35	Day care	Professional A
P11	M	56–65	Day care	Professional A
P12	F	46–55	Day care	Professional F
P13	F	56–65	Day care	Professional F
P14	F	26–35	Day care	Professional F
P15	M	20–25	Supported living	Professional G
P16	F	36–45	Supported living	Professional H
P17	M	46–55	Supported living	Professional H
P18	F	66–75	Day care	Professional I
P19	F	46–55	FACT team	Professional I
P20	M	46–55	FACT team	Professional J
P21	F	26–35	FACT Team	Professional J
P22	F	36–45	FACT Team	Professional J

All interviewed participants were receiving mental health care either via a day care program, a Flexible Assertive Community Treatment (FACT)-team, an outpatient therapy setting and/or a supported living setting. Next to the professional with lived experiences, the participants remained in contact with one or more other professionals who didn't use such resources, such as a psychiatrist or (psycho)therapist.

Each interview had a duration of 60 to 75 minutes and took place either at the mental health care institute or at the participant's home, depending on individual preference.

The first author disclosed her background as a service user of mental health herself in the interviews, making her personal interest in the subject explicit. Even though some seemed surprised to be interviewed by a researcher with lived experiences, this seemed to instantly deepen the connection between researcher and participant.

All in-depth interviews were first transcribed, then summarized and returned to the individual participant to check the credibility (member check). Relevant information with regard to the research question was captured in the summary. Participants were asked to comment on the summaries, in order to validate and enrich the understanding. Some of them shared that they benefited from the written summary, because it structured (a part of) their narrative in a supporting way. To further trialogue, both participants and related professionals were then also invited to share possible new insights with each other and the researcher.

After the first validation, service users were invited to a focus group meeting in September 2020 for additional sense-making and mutual learning. Five of the interviewed participants joined this focus group, as it took place in between the first and second COVID-19 wave in the Netherlands. A topic list was used to structure the meeting (Appendix B). To introduce themselves, participants were asked to bring an object that symbolizes their relationship with a professional using experiential knowledge. One of them carried a small golden pig representing the transformation supported by his practitioner in saying goodbye to his work as a former farmer. Another participant took a drop spindle to symbolize the fine attuned balance and proximity in the contact with her practitioner. Findings from all the interviews were presented and discussed as part of a member-check.

Analysis

Braun & Clarke's (2006) thematic analysis approach was used in order to identify, analyze and reflect on possible patterns or themes. Braun & Clarke (2006) differentiate between passive and active thematic analysis, with passive analysis being when themes emerge from the data. By using an active analysis, the researcher acknowledges his/her role in identifying patterns, selecting those of interest and choosing how to report them. The analysis started by reading the interview transcripts and summaries thoroughly line by line. Themes recurring from the interview-data were coded and categorized (open coding) with Atlas Ti software, and a cross-case analysis was performed (axial coding). Then the retrieved codes were condensed to themes without losing their intended meaning (condensed meaning units). The analyses were discussed with an advisory board to achieve consensus on emerging themes and to increase the credibility of findings (Barbour, 2001; Meadows & Morse, 2001). Emerging themes were also discussed and refined during a focus group with users. Participants confirmed findings and supplemented them with new examples. In order to establish transparency in the analysis procedure, Table 3 illustrates the analytic process of abstraction from condensed meaning units to themes. Initial findings were compared to the existing literature on recovery, trauma-informed care and experiential knowledge.

Table 3. *Illustration of analyzing scheme*

Condensed meaning units	Codes	Themes
The moment I saw her, was the moment I knew we would fit well together.	First contact	User-professional relationship
I sometimes look at him as a Big Friendly Giant. We laughed a lot together, we ate together, other times we would sit together and say nothing in each other's presence.	Recognition and identification	User-professional relationship
It's a way of levelling and I appreciate this authentic contact.	Reciprocity	User-professional relationship
He immediately knew what I meant when I felt immensely isolated as a human, I have felt left out in this community, totally lost.	Lived experiences as an additional source	Learned lessons with distress and resilience
He resonated with the desperateness and hopelessness of that felt sense.	Well attuned use	Learned lessons with distress and resilience
My professional helped me with my considerations to disclose about my depression upon return to my workplace.	Practical insights	Learned lessons with distress and resilience
She is like a source of inspiration to me, the way she navigates life.	Positive role model	Stimulating users' recovery
He helped me in resolving a part of the shame, because he made clear that it happened to me.	Stigma reduction	Stimulating users' recovery
Once she came to me and told me that I am not my depression, even though I suffer from depression. She just flipped my perspective, it was such an eye-opener to me!	Creative openings	Stimulating users' recovery

Quality Procedures

In line with the qualitative nature of this study, we used credibility criteria (Frambach et. al., 2013; Lincoln & Guba, 1985). The first researcher (author 1) joined three professionals in their daily work-setting, in order to gain an in-depth understanding of the context (prolonged engagement). Users were asked in which context they felt most comfortable being interviewed to build up rapport. Researchers visited some users at home, for example, where the researcher had to adjust to the users' domestic conditions, such as taking a break to smoke or showing pictures and sharing memories of important moments in their recovery process. The data collection procedure stopped when saturation was reached: the point where patterns are repeated. After the interview, users received a summary of the interview-transcript with the question whether they recognized it and have any additional reflections (member check). Most of the users responded positively and stated they felt the researcher had "seen and heard" them. Some of them had additional remarks that they wanted to add. Next to the interviews, participant observations and a focus group were held for triangulation purposes. Findings were discussed and presented during several conferences to a wider public of mental health professionals. This fostered the transferability of findings.

The first researcher kept a journal consisting of raw data and field notes in which important steps and changes were reported with regard to the communication with stakeholders, the interviewing and analyzing process. Reflections were shared with the research-team to sharpen the analysis.

Ethical Considerations

According to the Medical Ethics Review Committee of VU University Medical Center (registered with the US Office for Human Research Protections as IRB00002991; FWA number: FWA00017598) the Medical Research Involving Human Subjects Act did not apply to our research. Approval was also obtained from the ethical commission of the participating organizations for the activities and the publication involving findings. The Dutch code of conduct for research integrity (VSNU, 2018) as well the research code of VUmc, have been taken into account. In conformity to European privacy regulations (General Data Protection Regulation), all data has been stored in a protected environment. Sensitive data (such as the written summaries) amongst participants and researchers has been transferred by email with encryption. In addition to informed consent and confidentiality, various ethical principles were taken into consideration, such as mutual respect, participation, active learning, making a positive change, contributing to collective action, and personal integrity (Abma *et al.,* 2019; Banks & Brydon-Miller, 2018). Ethical guidelines as well as dedicated time within our research team meetings and conversations with critical friends and peers were helpful in discussing issues of power, ethics, and responsibilities.

The research team recognized the needs of individual participants. For example, while all participants were able to read the 1-to-2-page summary, some of them preferred to be guided through the text via a phone call with the researcher. Also, the researchers respected the participants' boundaries. One example: some participants did not want to take part in the focus-group (in 2020) because they already said goodbye to their professional and did not want to be reminded about that specific period of their lives. Another example: a participant asked whether it was okay to bring her buddy for emotional support during the interview. The researchers respected this wish. They also wanted to make sure every participant had the ability to travel to the campus site where the focus-group was organized. Travel expenses were covered. One of the participants asked for personal guidance on her way from the station to the campus, which is why the researcher accompanied her during that part of her journey.

Results

The study's main finding is that the use of experiential knowledge manifests itself in the quality of the user-professional relationship in which personal disclosures of the professional's distress and resilience are embedded, often stimulating users' recovery process.

The value of experiential knowledge can be captured in the following themes: user-professional relationship, learned lessons on distress and resilience, and stimulating users' recovery process.

User-Professional Relationship

Basically all participants attribute the quality of the relationship to their professional's used experiential knowledge. Even though the majority did not ask explicitly for a professional bringing in this type of knowledge, participants vividly recalled the first time they met their professional with lived experiences.

> *I longed for someone who could be like a parent to me, someone who really engages in my life and someone who would not let me down. Definitely not a newbie. The moment I saw her, was the moment I knew we would fit well together. (P21)*

Participants shared how they (to some extent) recognize themselves in their professional, provoking feelings of proximity and reciprocity.

> *I sometimes look at him as a Big Friendly Giant. We laughed a lot together, we ate together, other times we would sit together and say nothing in each other's presence. It's a way of levelling and I appreciate this authentic contact. (P17)*

The key element in this relationship consists of the experienced "togetherness" which for some participants was a clear difference from the power-imbalances they experienced during earlier encounters in mental health care.

> *I also visited a therapist in the past who hardly had any time nor empathy for me. I have felt very small in front of such professionals. Maybe I should not say this, because they were probably just doing their best, but something was lacking. My professional with lived experiences bridged that lack by staying in touch with me and showing some of his struggles of the past, in order to support me. (P14)*

Participants emphasize that they felt supported and resourced by their professional with lived experiences which gave them the felt sense of "acceptance"; they sometimes relate to these professionals as peer or parent.

> *He is very approachable, very open. He accepts me the way I am and actually has a relativizing impact on everyone here. Last week he shared that he had an 'off-day', showing a real human side! (P13)*

However, one participant also expressed concern about the way professionals with lived experiences may become personally involved, while perhaps being unable to assess the situation from a distance.

> *I have been addicted to hard drugs for one year. I totally crashed. I didn't take care of myself, didn't wash myself, wore the same clothes. I was chatting and cheating, because my focus was only on the next shot. I kept my professional out of this reality for a long time and told her I found a job and that I was doing fairly well.*

> *She didn't see it, she was blind, until I got arrested! I don't blame her for anything, she cares about me. (P20)*

Some participants warned about purposelessly disclosing personal information which may result in a user thinking that he/she needs to take the feelings of the professional into account.

> *Professionals should, in no case, just start sharing personal stuff. It has to contribute to a goal. I need to have the feeling that somebody really is there, for me. (P1)*

Additionally, some service users mentioned they'd become wary when knowing that a professional had experienced certain distress. More specifically, an expressed concern was a possible shift of focus from the service user to the professional.

> *I can see the risk of using lived experiences. I could start thinking: 'Oh god, he has experienced this or that so I should not say that I have similar difficulties'. (P21)*

By way of contrast, participants also gave examples of contra-productive concealments, in which professionals who don't work with experiential knowledge, kept relevant personal information hidden. This led to interesting comparisons between professionals using their lived experiences in a professional context versus professionals who do not overtly share personal information.

> *I have seen professionals who leave out their personal background completely when meeting service users and I consider that to be risky because they might unconsciously project things on service users and end up in a role of rescuer or prosecutor. (P1)*

Altogether, the use of experiential knowledge manifests in a compassionate working relationship, colored by recognition, proximity, reciprocity and acceptance. Provided that these are well-balanced and well-timed, users report benefits from these relational elements.

Learned Lessons on Distress and Resilience

The majority of the participants shared that their professional worked with professional disclosures often captured in a recovery-story or metaphor. Participants offered interesting insights into experiential knowledge used by their professionals, especially referring to the lessons learned on distress and resilience. Some participants specifically valued the existential and/or spiritual insights of their professional with lived experience.

> *He immediately knew what I meant when I felt immensely isolated as a human, I have felt left out in this community, totally lost. He resonated with the desperateness and hopelessness of that felt sense. (P5)*

Professional disclosures concerned specific details of coping with mental health issues,

such as depression, psychosis, addiction or trauma, but also concerned emotional and practical insights based on general experiences in the recovery process, e.g., knowing how difficult it can be to return home after having spent months in an inpatient setting.

> *My professional helped me with my considerations to disclose about my depression upon return to my workplace. (P10)*

In the latter case disclosures aimed to provide insights on how to practically adapt one's living and/or aimed to provide emotional support.

> *She once drove me to a doctor's appointment, which was absolutely against policy. She however showed me how much she cares for me, because she knew I was super nervous. (P19)*

To summarize, participants divided the use of experiential knowledge in dosed disclosures into existential, spiritual, emotional and practical insights.

Stimulating Users' Recovery Process

Participants appreciated the way recovery stories of their professional stimulated them to construct their own narrative, find meanings and arrive at deeper insights about themselves. They spoke about their professionals as a positive and hope-providing role-model since he or she had experienced mental distress and yet found a path to personal and social recovery.

> *She sometimes says: 'you may consider me to be your mom', which I really liked because I didn't have a real parent when I was young. She is like a source of inspiration to me, the way she navigates life. (P22)*

The professional's obtained balance appeared as an inspiration to service users. They valued seeing both the strengths and the vulnerable sides of the professional because it then also led to self-acceptance and a decrease in self-stigma and shame.

> *He helped me in resolving a part of the shame, because he made clear that it happened to me. (..) I felt less of a burden, seeing how he also had his struggles. He gave me tips on how to prepare answers that I could use in social encounters. (P6)*

Some participants shared that they believe professionals with lived experiences embrace reality as it is, emerging in a direct, sometimes even humorous communication-style.

> *Whenever I have a shitty day, she comes to me and asks how I am doing. I often used to answer "just kill me!" after which she starts to laugh and says "hey, you don't want others to have to clean all that mess!". (P8)*

In this way, professionals sometimes overtly discussed fixed beliefs that recur in the public about people with a mental ill health history.

> *My practitioner discussed the implications of returning to work with me. What advantages and disadvantages can one think of, when opening up your story towards a supervisor at work? She really contributed to my dilemma and stimulated me to think about my future and how I wanted it to be. (P4)*

Also, participants felt that their professional tried to search for new and creative openings to move forward. Of particular interest was "out of the box thinking" that was said to be particularly helpful in the recovery process of users, facilitating hope and empowerment.

> *Once she came to me and told me that I am not my depression, even though I suffer from depression. She just flipped my perspective, it was such an eye-opener to me! (P9)*

Participants shared how their professionals were keen on promoting users' agency.

> *She continuously left it up to me to direct and guide my own process. Of course she would ask how things are evolving but, she did not predominate in any kind of way. She held a lot of trust in me. Actually she was also calling off her colleagues to not cling to diagnoses and to look beyond those labels. (P11)*

Furthermore, participants appreciated that their professionals regularly postponed judgments and some gave interesting examples of "positive risk taking" in which professionals balanced risk and recovery.

> *Of all therapies and treatments, I mostly benefited from the conversations with my professional having lived experiences because he did not judge me. Not even influenced me when I expressed a wish for euthanasia. (P16)*

Participants also suggested that the use of experiential knowledge always should be accompanied by sufficient professional knowledge and skills, enabling it to be appropriately used. In summary, participants felt stimulated and inspired in their recovery process, by their professionals with lived experiences.

Discussion

This qualitative study describes users' perceptions on the use of experiential knowledge by professionals with lived experiences.
The first theme emphasizes the importance of a warm, compassionate relationship in which disclosures and insights from professionals' with lived experiences are well embedded. From this study, we have seen that users appreciate the personal perspective from their professional, integrated in a core profession as a nurse or social worker. Findings elucidate that employing experiential knowledge seems to enhance the working relationship – as long as the professional does not become too personally involved or imposes on users. Although trauma informed literature does not explicitly plead for the use of experiential knowledge by professionals, a more equal relationship can be considered beneficial for service users (MacNeil & Mead, 2005). Professionals who are

impacted by trauma themselves could reasonably be more profoundly attuned and relatable, thereby engendering a sense of "connectedness" (Leamy *et al.,* 2011). This can help service users feel more comfortable and empowered to discuss and prevent new traumatic experiences (Reeves, 2015; Stanford *et al.,* 2017). While both recovery oriented and trauma-informed approaches aim to strengthen users' independence, the strong rapport and sometimes (counter)transference feelings between professional and user also may possibly lead to blurring the relationship's boundaries. A positive risk-taking stance in this dilemma is becoming more prominent in novel trauma concepts, whereas traditional clinical practice used to focus on the risks, such as re-enactments (West, 2017). Therefore, a user-focused intention on professional disclosure, paired with a reflexive dialogue to evaluate interactions between user and professional, seem paramount.

The second theme indicated that professionals' insights were rooted in both the experience of distress and the resilience in dealing with such. For some, this did not necessarily concern an explicit verbal encounter. Interestingly, an embodied consciousness, also considered as "tacit or implicit experiential knowledge" of the professional seemed to resonate with users' suffering. Participants in this study often felt themselves seen and understood on a deeper level. They felt heard by their professional, whose aim it was to stay present and endure, rather than offer, a cure. Even while in many cases the lived experiences of the professional differed significantly, there was a resemblance of its felt sense; e.g., the hurt or the (self) rejection. Realizing that professionals who have "established lives", may yet also be affected by grief, loss and social exclusion, remains crucial. Yalom supports this, stating that should there be therapist's growth and healing, the user's healing and effective therapy is likely to happen (Yalom, 2002).

The third theme clarified that users felt inspired by their professional contributing to a reconstruction of life and self. Consistent with the literature, mental health issues often lead to a fragmentation of the identity and loss of relationships with others (Fisher, 2017). Recent attachment theories show that earned-secure attachment can be cultivated through healthy meaningful relationships later in adolescence and adulthood; e.g., through the vicarious experience of parenting one's own children or through an attuned friendship (Feinberg, 2015; Fisher, 2017). Participants in our study referred to their professional as "peer" or "parent", which may indicate they attained such a reparative relationship. Professionals also served as a positive and hope-providing role model in having found ways to move forward. According to the study's participants, this also contributed to self-acceptance, self-agency, and a decrease in shame and self-stigma. Findings from trauma-literature show that impactful experiences can be surrounded by silence and conspiracy that communities and the immediate social context often maintain (Cavanagh *et al.,* 2015). This study shows that participants felt stimulated to break the silence and construct new recovery narratives.

Strengths and limitations

This study is based on a qualitative analysis and describes the perspectives of service users in three Dutch mental health care organizations, individuals who had been in regular contact with a professional with lived experiences. In the process of transformation, these mental health care services employed professionals who pay attention to working in a relational way in order to support personal recovery. The included participants involved merely a small sample of people living in the Netherlands. It's uncertain whether the results of this study can be generalized or transferred to other countries and/or more traditional contexts.

Since the number of professionals who use experiential knowledge professionally remains still limited, it seemed logical to reach service users by inviting them through these professionals. This, however, also has limited its representativeness. Participants may have given socially desirable answers about their professional, even though the researcher who conducted the interviews tried to reassure participants that given answers would not affect their professional's status, nor the provided service. We reasoned that disclosing the researcher's personal background with mental distress stimulated authentic responses.

Another limitation: due to the COVID-19 measures, only five participants were able to participate in the focus group discussion after the interview rounds, even while working in a small group facilitating an in-depth exchange.

Bearing these limitations in mind, we experienced that findings were recognized and supported throughout the different project-groups and they substantiate other findings from studies on recovery-based and trauma informed care.

Conclusion, implications and future directions

Findings suggest that service users positively value the use of experiential knowledge by social workers, nurses, and humanistic counselors as an additional (re)source. It contributes to their process of recovery through a relationship that they perceive as supportive and empowering because the mental health worker's personal experiences show resilience in coping with distress, providing hope and encouragement. Insights from this study support findings from other researches about trauma informed care and recovery oriented care, thereby strengthening the body of evidence on helpful relationships.

The study's results underline the relevance of integrating lived experiences in the practice of mental health professionals. In order to further explore its meaning for users, we provide some implications and give suggestions for future research and practice.

First of all, it is important to raise awareness among mental health professionals about the relevance of experiential knowledge for the quality of their services. Secondly, for those who desire to use their personal lived experiences, training opportunities and ongoing peer consultation should be accessible, in order to add competences to their body of knowledge.

Thirdly, it is noted in this study that mainly professionals with a social work or nursing background came to the fore with the desire to integrate personal experiences. However, as an effect of this research project, academic professions such as psychiatrists and psychologists also started to express interest in the subject. It became clear that their current professional codes of conduct emphasize the risks of bringing in lived experiences, and form a barrier to harnessing experiential knowledge. Since the further development of trauma-informed recovery-oriented care requires all mental health professionals to share a common ground, we recommend exploring how the academic professions can also integrate experiential knowledge into their work.

Acknowledgements

We are very grateful to all the service users who participated in the study, to their professionals with lived experiences and to the student-researchers Nicky van Dam and Sarah Ebrahem who helped with the focus group in September 2020. We also thank the members of the advisory board for commenting on this article.

Funding

This research was financially supported by the University of Applied Sciences Utrecht, The Netherlands, grant number: HRD/BB-kab/2018-455.

Author contributions

Simona Karbouniaris: conceptualization, design, methodology, funding acquisition, investigation, project administration, data management, formal analysis, interpretation, supervision, writing original draft, writing review and editing.

Jean Pierre Wilken: conceptualization, design, methodology, funding acquisition, investigation, data management, formal analysis, interpretation, supervision, writing original draft, writing review and editing.

Alie Weerman: conceptualization, design, methodology, investigation, formal analysis, interpretation, supervision, writing review and editing.

Tineke Abma: conceptualization, design, methodology, investigation, formal analysis, interpretation, supervision, writing review and editing.

All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of interest statement

The authors have no conflicts of interest to disclose.

Ethical statement

This manuscript is the authors' original work. The study was reviewed and approved by the Medical Ethics Review Committee of VU University Medical Center (registered with the US Office for Human Research Protections as IRB00002991; FWA number: FWA00017598).

All participants participated in the research voluntarily and anonymously, and provided their written informed consent to participate in this study.

Data are stored in coded materials and databases without personal data, and the authors have policies in place to manage and keep data secure.

References

Abma, T. A., Leyerzapf, H. & Landeweer, E. (2016). Responsive Evaluation in the Interference Zone Between System and Lifeworld. *American Journal of Evaluation, 38*(4), pp. 507–520.

Abma, T. A., Visse, M., Hanberger, A., Simons, H. & Greene, J. C. (2020). Enriching evaluation practice through care ethics. *Evaluation, 26*(2), pp. 131–146.

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J. & Wright, M. T. (2019). *Participatory research for health and social well-being.* Cham: Springer International Publishing.

Abma, T., Cook, T., Rämgård, M., Kleba, E., Harris, J. & Wallerstein, N. (2017). Social impact of participatory health research: collaborative non-linear processes of knowledge mobilization. *Educational Action Research, 25*(4), pp. 489–505.

Anthony, W. A. (1993). Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. *Psychosocial Rehabilitation Journal, 16,* pp. 11–23.

Arman, M., Ranheim, A., Rydenlund, K., Rytterström, P. & Rehnsfeldt, A. (2015). The Nordic Tradition of Caring Science: The Works of Three Theorists. *Nursing Science Quarterly, 28*(4), pp. 288–296.

Baart, A. (2004). What makes care good care? *Journal of Social Intervention, 3,* pp. 14–26.

Banks, S. & Brydon-Miller, M. (2018). *Ethics in Participatory Research for Health and Social Well-being: Cases and Commentaries.* Abingdon: Routledge.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *Bmj, 322*(7294), pp. 1115 – 1117.

Bordin, E. S. (1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research & Practice, 16,* pp. 252–260.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology Virginia. *Qualitative Research in Psychology, 887, pp.* 77–101.

Butler, L., Critelli, F.M. & Rinfrette, E.S. (2011). Trauma informed care and mental health. *Directions in Psychiatry, 31,* pp. 197–210.

Byrne, L., Roennfeldt, H., Davidson, L., Miller, R. & Bellamy, C. (2022). To disclose or not to disclose? Peer workers impact on a culture of safe disclosure for mental health professionals with lived experience. *Psychological Services, 19*(1), 9.

Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2019). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory and Health, 17*(3), pp. 307–330.

Cavanagh, A., Wiese-Batista, E., & Lachal, C., Baubet, T., & Moro, M.R. (2015). Countertransference in Trauma Therapy. *Journal Traumatic Stress Disorders Treatment 4, 2*(2).

Cronin, E., Brand, B.L. & Mattanah, J.F. (2014). The impact of the therapeutic alliance on treatment outcome in patients with dissociative disorders. *European Journal of Psychotraumatology, 5*(1) 22676.

Feinberg, A.E. (2015). Relationships that appear to contribute to the development of an earned-secure attachment. [Master thesis]. Smith College, Northampton.

Fisher, J. (2017). *Healing the Fragmented Selves of Trauma Survivors: Overcoming Internal Self-Alienation.* New York, NY: Routledge.

Frambach, J.M., van der Vleuten, C. P. & Durning, S. J. (2013). AM last page. Quality criteria in qualitative and quantitative research. *Academic Medicine, 88*(4), 552.

Harris, M., & Fallot, R.D. (Eds) (2001). *Using Trauma Theory to Design Service Systems. New Directions for Mental Health Services.* San Francisco, CA: Jossey-Bass.

Holttum, S. (2017). Research watch: is social inclusion for service users increased when mental health professionals "come out" as service users? *Mental Health and Social Inclusion, 21*(2), pp. 73–79.

Huntington, Nicholas Moses, D.J. & Veysey, B.M. (2005). Developing and implementing a comprehensive approach to serving women with co-occurring disorders and histories of trauma. *Journal of Community Psychology, 33*(4), pp. 395–410.

Institute on Trauma and Trauma-Informed Care. (2015). Retraumatization infographic. Retrieved from http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html

Karbouniaris, S., Abma, T., Wilken, J. & Weerman, A. (2020). Use of experiential knowledge by mental health professionals and its contribution to recovery: literature review. *Recovery in Mental Health, 3*(4).

Karbouniaris, S., Weerman, A., Dunnewind, B., Wilken, J.P. & Abma, T.A. (2022). Professionals harnessing experiential knowledge in Dutch mental health settings. *Mental Health and Social Inclusion 26*(1), pp. 75-88.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J. & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry : The Journal of Mental Science, 199*(6), pp. 445–452.

Leemeijer, A. & Trappenburg, M. (2016). Patient Centered Professionalism? Patient Participation in Dutch Mental Health Professional Frameworks. *Professions & Professionalism, 6*(2), pp. 15–19.

Lincoln, Y. & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage Publications.

Ljungberg, A., Denhov, A., & Topor, A. (2015). The Art of Helpful Relationships with Professionals: A Meta-ethnography of the Perspective of Persons with Severe Mental Illness. *Psychiatric Quarterly, 86*(4), pp. 471–495.

Ljungberg, A., Denhov, A. & Topor, A. (2016). Non-helpful relationships with professionals – a literature review of the perspective of persons with severe mental illness. *Journal of Mental Health,*

25(3), pp. 267–277.

MacNeil, C. & Mead, S. (2005). A narrative approach to developing standards for trauma-informed peer support. *American Journal of Evaluation, 26*(2), pp. 231–244.

Marsman, A. (2021). *Beyond dis-ease & dis-order.* [Doctoral dissertation] Maastricht University.

Meadows, L.M. & Morse, J.M. (2001). Constructing evidence within the qualitative project. In A.J. (Eds. Morse, J.M., Swanson, J.M., & Kuzel (Ed.), The nature of qualitative evidence, pp. 188–202.

Reeves, E. (2015). A Synthesis of the Literature on Trauma-Informed Care. *Issues in Mental Health Nursing, 36*(9), pp. 698–709.

Richards, J., Holttum, S., & Springham, N. (2016). How Do "Mental Health Professionals" Who Are Also or Have Been "Mental Health Service Users" Construct Their Identities? *SAGE Open, 6*(1).

SAHMSA. (2014). *Trauma-Informed Care in Behavioral Health Services. Treatment Improvement Protocol (TIP)* Series 57. HHS Publication no. (SMA) 13-4801. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Stanford, S., Sharland, E., Heller, N.R., & Warner, J. (2017). *Beyond the risk paradigm in Mental Health Policy and Practice.* London: Palgrave Macmillan UK.

Straussner, S. L.A., Senreich, E., & Steen, J.T. (2018). Wounded healers: A multistate study of licensed social workers' behavioral health problems. *Social Work, 63*(2), pp.125–133.

Vos, de J.A., Netten, C., & Noordenbos, G. (2016). Recovered eating disorder therapists using their experiential knowledge in therapy: A qualitative examination of the therapists and the patients view. Eating Disorders: The *Journal of Treatment & Prevention, 24*(3), pp. 207–223.

VSNU (2018). *Dutch code of conduct for research integrity.* Retrieved from https://www.universiteitenvannederland.nl/files/documenten/Nederlandse%20gedragscode%20wetenschappelijke%20integriteit%202018.pdf

Weerman, A. (2016). Lived experience care and service providers. *Stigma, addiction & existential transformation.* [Doctoral dissertation]. Vrije Universiteit Amsterdam.

Weerman, A., & Abma, T. (2018). Social work students learning to use their experiential knowledge of recovery. An existential and emancipatory perspective. *Social Work Education, 38*(4), pp. 453–469.

Weerman, A., De Jong, K., Karbouniaris, S., Overbeek, F., Van Loon, E., & Van der Lubben, P. (2019). *Professional use of experiential expertise.* Amsterdam: Boom.

West, M. (2017). Self-disclosure, trauma and the pressures on the analyst. *The Journal of Analytical Psychology, 62*(4), pp. 585–601.

Wilken, J.P. (2010). *Recovering care: A contribution to a theory and practice of good care.* [Doctoral dissertation]. Amsterdam: SWP.

Yalom, I. D. (2002). *The gift of therapy: An open letter to a new generation of therapists and their patients.* New York, NY, US: HarperCollins Publishers.

Appendix A

Topic List Interviews
Opening
Aim and estimated duration of the interview
Consent about audio recording
Member check procedures
Introduction
Could you please tell me something about yourself?
How long have you been in care here?
What's the main reason for seeking professional help?
Professional with lived experiences
How long have you been in contact with professional with lived experiences?
How did you get in touch with him/her?
How does he/she help you? Did you notice any changes with regard to the help over time?
Your professional was involved in a project and training on how to use his/her lived experiences. In what way, if it all, has this been topic in your conversations? Did your professional share any insights regarding her/his personal recovery process? What did you learn or understood from that?
What is the meaning of being helped by a professional with lived experiences for you?
When is it helpful to receive help from such a professional? Are there times when you would rather not receive his/her help? When?
Recovery
What does experiential knowledge contribute to care as usual? What is it based on? Could this be offered by another/regular professional? Why?
In what way might professional disclosure be related to your recovery process?
Do you currently have contact with other practitioners, who don't work with experiential knowledge? How are they involved? To what extent does their approach differ from your professional with lived experiences' one?
Do you currently have contact with experts by experiences? How are they involved? To what extent does their approach differ from your professional with lived experiences' one?
How would recovery-oriented care ideally be organized? What are your thoughts on the recruitment of more lived experience professionals?

Appendix B

Topic List Focus Group Interview
Opening
Aim and estimated duration of this focus group
Consent about audio recording
Introduction of all participants
Presentation of findings from interviews
How do findings resonate with participants? Additional insights?
Please provide follow up: how's your current condition? Are you still in contact with professional? What symbolizes/symbolized the contact with him/her?
How does your recovery process evolve, with regard to personal recovery, social, clinical recovery?
In what way did your professional with lived experiences contribute to your current condition?

Appendix C

Training Professional Use of Experiential Knowledge

This 1-year post-bachelor training consists of 16 training days focusing on professionals' recovery story, and collectively reflecting on key themes, such as shame, stigma, vulnerability and resilience. It is open to professionals who hold a bachelor's or master's degree Social Work/Nursing/Humanistic Counselling. The training offers directions to profit from experiential expertise in a professional context (Weerman & Abma, 2018).

Competences for professionals who use their lived experiences as additional expertise (Weerman et al., 2019, p. 79):
Has an open attitude to others and uses personal lived experiences in an appropriate fashion
Is able to connect ones' personal lived experience anchored in recovery while working
Is able to share the personal narrative in a socially relevant manner
Is able to put personal experiences into perspective
Is able to provide hope as a positive role model
Is able to provide an entrance to experiential knowledge stemming from recovery, stigma and empowerment
Is able to recognize, strengthen and stimulate users' strengths
Is an expert in dealing with distress and recovery by using dialogue and reflection techniques
Is competent in attuning to felt nuances, details and experiences of people living with distress or who learn to live with a disability or vulnerability
Offers hope and holds confidence that recovery is possible
Realizes that recovery takes sometimes place by taking small steps which may be invisible for the outside world'

Reflection II "(Non) existence"

I fell in love with yoga when I was 23, which is when I learned to befriend my body again, to inhabit it from inside out and sense its wholeness. Quite similar to dancing. Some day my therapist and I kind of coincidently found out that we would be attending the same dance weekend in the upcoming month. I'd like to revisit a discussion we had about how the personal touches the professional. And if our relationship at all, exists outside the therapy room, especially after meeting each other in public several times. He didn't seem amused after finding out we would be attending the same weekend. So, I invited him to share more about his apparent struggles.

Therapist: *"I'd rather not meet you there. Did you already book your spot? Meeting each other out there makes things more complicated in a way."*
I listen to this as an insinuation to cancel the weekend. While my eyes run over the bookshelf in his masculine looking office, I feel his challenge of holding a relational space in the outside world. It's either a heavy load of internalized stigma or other discomfort, that he is carrying. After a while and with a strong voice,

I say: *"What do you mean, do you feel discomfort?"*

Therapist: *"Oh well, it's not discomfort, but rather…. what should I say when others ask me, how we are related? what should I then say? I can not say I am your psychiatrist, I can not share any information. And any additional question makes things even more complicated."*

I: *"Yes you can. I feel confident in whatever answer you would give. I don't mind them knowing. I'd rather not hide it, that feels awkward to me. Just be real, be you."*

Therapist: *"You are quite exclusive in this regard. Many of my patients would rather avoid meeting me, I've had this case of a lady who was shocked when seeing me….Okay, but what should I say then?"*

I: *"You can always refer them to me and I'll respond to any questions?".*

I see his search, his sense of not knowing, his unsettlement and yet I also feel there is more to it. I feel a role reversal happening, with me being very patient and having no expectations about possible outcomes in this conversation. Giving him space to overthink and feel, how he can adapt to the situation of seeing me outside the therapy context. And so I continue:

I: *"What does it mean to you, if we meet, and if it happens to be that people ask?".* He looks at me, and says: *"There is stigma everywhere, people judge…"*

I: *"…which we will sustain, unless we decide to have a different take on this".*

Therapist: *"And also, I have all these strong feelings popping up, parental countertransference like feelings, that I want to take care of you. And so I can't do that. To me you will always remain a patient".*

This dichotomy almost burns my heart. It means that I can only be his patient. And it means not any other kind of relationship co-exists except for the one defined in the therapy room. This conception has left me devastated in the past. However, I start wondering to what extent this might be related to the rigidness of a traditional patient-therapist relationality.

How do professionals with lived experience relate to stigma and how do they navigate their ways to shape the relationship more horizontally? I also question whether personality style and different types of professions might be of influence in harnessing lived experiences in a mental health context. Are there perhaps specific qualities to hold such a relational space? How can professionals work with embodied knowledge? In what ways does that affect them personally? What challenges do they face? I took these questions along as an inspiration for my next two studies.

Chapter 4

Professionals harnessing experiential knowledge in Dutch mental health settings

Karbouniaris, Simona
Weerman, Alie
Dunnewind, Bea
Wilken, Jean Pierre
Abma, Tineke

Published in: Journal Mental Health & Social Inclusion, 2022

Abstract

Purpose

This study aims to explore the perspectives of mental health professionals who are in a process of integrating their own experiential knowledge in their professional role. This study considers implications for identity, dilemmas and challenges within the broader organization, when bringing experiential knowledge to practice.

Design/methodology/approach

As part of a participatory action research approach, qualitative methods have been used, such as in-depth interviews, discussions and observations during training and project team.

Findings

The actual use of experiential knowledge by mental health care professionals in their work affected four levels: their personal–professional development; the relation with service users; the relation with colleagues; and their position in the organization.

Research limitations/implications

Because of its limited context, this study may lack generalizability and further research with regard to psychologists and psychiatrists, as well as perceptions from users, is desirable.

Social implications

According to this study, social change starts from a bottom-up movement and synchronously should be facilitated by top-down policy. A dialogue with academic mental health professionals seems crucial to integrate this source of knowledge. Active collaboration with peer workers and supervisors is desired as well.

Originality/value

Professionals with lived experiences play an important role in working recovery- oriented, demonstrating bravery and resilience. Having dealt with mental health distress, they risked stigma and rejections when introducing this as a type of knowledge in current mental health service culture. Next to trainings to facilitate the personal–professional process, investments in the entire organization are needed to transform governance, policy and ethics.

Introduction

Over the past decades in The Netherlands, like in other countries, the traditional problem-oriented approaches in mental health care shifted to a more recovery-oriented perspective (Delespaul, e.a., 2016). At the same time evidence-based practices became dominant in clinical mental health care, which led to a standardization of mental health treatment. The latter led to a growing criticism on evidence-based practice, because of underrating the variety of users and the context of health care (The Council for Public Health and Society, 2017). Especially the past decade the evidence based model and clinical relevance of bio-markers for Mental Health practice are increasingly under pressure (van Os and Kohne, 2021).

In The Netherlands and abroad, this led to discussions about the hierarchy of knowledge, which places randomized controlled trials (RCTs) and systematic reviews of RCTs at the top and the views of clinicians and patients at the bottom, marginalizing both professionals and users voices (Faulkner, 2017). As professional and private life have oftentimes been separate areas in mental health practice and experiential knowledge is generally not incorporated nor validated, these developments evidently influence one another. Traditionally, mental health professionals, were expected to stay distant, which led to the marginalization of a group that has seen the other side of the table (Fox, 2016). Professionals have split their identity in a personal part kept secret to themselves and a professional part. Banks (2012) states that this separation is not only meant for the protection of the professional but also exists for the benefit of the user, who should not be burdened with personal troubles – even when conquered – of the person counselling him or her. However, refraining from personal experiences entirely may also lead to alienation and a distant relationship (Byrne *et al.,* 2017). The construction of a mental health professional incorporating lived experiences implies a shift of taking this “new” source of knowledge into account. This means more than a coming-out with a disorder or a disruptive life event and can be challenging in a mental health care setting that is oftentimes still dominated by a positivistic, empirical-analytical culture (Weerman, 2016).

The medical model is known for its deficit orientation, prioritizing the system needs for standardized, measurable, outcomes over the individual priorities of service users (Byrne *et al.,* 2015; Slade, 2012).

Novel policy attempts to reform the mental health field, show several interesting developments and innovations in which the experiential knowledge of mental health professionals is (re)discovered. Besides peer support workers, a wider movement across traditional disciplines, from social workers, nurses to psychologists and psychiatrists became interested in acknowledging experiential knowledge. Both the Division of Clinical Psychology and the Royal Australian and New Zealand College of Psychiatrists value lived experiences of, respectively, psychologists and psychiatrists, as it can provide a vital contribution to stigma reduction (British Psychological Society, 2020; Royal Australian and New Zealand College of Psychiatrists, 2016).

Even though it is considered a personal choice to transform personal (such as emotional and intuitive) lived experience into experiential knowledge (Grundman *et al.,* 2020), the professionalization of experiential knowledge in The Netherlands currently rises and several universities integrated experiential knowledge in their Social Work curricula (Weerman and Abma, 2018). Professionals started to actively use this "new" (re)source during encounters with service users, colleagues and managers. As little is known about how professionals with lived experiences reflect on the process learning to use experiential knowledge in their work, in this article we will focus on the personal–professional process of transforming lived experiences to experiential knowledge. What dilemmas and challenges do professionals face?

Design and methods

This study took place in three Mental Health (MH) organisations in the North-Eastern part of The Netherlands from 2017 to 2020. A participatory action research approach (Abma *et al.,* 2019) was used to contribute to the implementation of experiential knowledge in the practice of psychiatry by an action–reflection–learning cycle. Responsive evaluation is a particular version of participatory action approach; one that values the multiple perspectives of stakeholders and dialogue to come to mutual understanding (Abma *et al.,* 2016; Abma *et al.,* 2020). In this participatory study, we worked with professionals from all three MH organizations who were invited to explore the professionalization of experiential knowledge and took part in the project as "co-researchers". Additionally academic researchers collaborated as "participating actors" in the learning communities. See Table 1 for their roles in the various phases of the study.

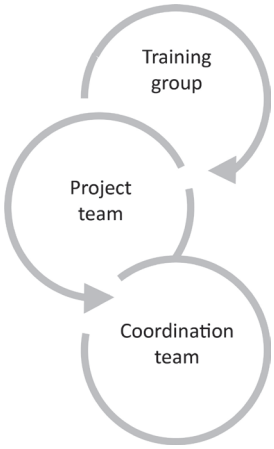
Table 1. *Participation matrix*

	Academic researchers in their role as 'participating actors'	**Participants in their role as 'co-researchers'**
Phase 1 Initiation and planning	Formulating and developing design and topic list interviews	Setting up teams in own organisations and creating action plans
Phase 2 Execution	Completing interviews Support social actions	Bring social experiments and actions to practice Discuss first findings in training and project teams
Phase 3 Evaluation	Facilitating learning, reflection and social change in the broader context	Evaluation and redefining action plan based upon reflections
Phase 4 Closing	Dissemination of project results in professional and scientific publications, policy and conferences	Contributing to professional publications, policy and conferences

Procedures

The set-up of the research was emergent, covering four iterative phases (initiation and planning, execution, evaluation and closing) accordingly to the participatory process. First of all, professionals participated in a post-bachelor training targeting the professionals to use lived experiences at work. Three researchers were part of the training group (Figure 1) to stimulate the "action-, reflection-, and learning-cycle." The participants practiced a core profession of nurse, social worker or humanistic counsellor. During the training sessions, the researchers worked in an interactive and collaborative way on the professionalization and implementation of experiential knowledge in participants' organizations. Next to the training-sessions, all professionals joined project-teams that were set up locally in the three concerned MH organizations. These joint collaborations consisted of professionals with lived experiences and their colleagues, i.e. peer workers, human resource-colleagues, managers and policy makers. Thirdly, in the coordination team the coordinating professionals with lived experiences from each organization participated to inspire and exchange upon the setup of plans. This led to specific strategies that targeted again the local organization, such as an authorized role-description for "Professionals with lived experiences" and actions to improve visibility and open up the debate in the participating organizations.

Figure 1. *Action-, reflection-, and learning-cycle in three contexts*



Subsequently, in-depth interviews were held in 2017, 2018 and 2019, using a topic list with topics held relevant within the context of the project (included in Appendix). Each interview had a duration of 60–75min which took place at the workplace. All interviews were first transcribed, then summarized and returned to the individual participant for first a first validation (member check).

Braun and Clarke's (2006) thematic analysis approach was used to identify, analyse and reflect on possible patterns or themes that emerged during the interviews and during discussions in the training and project team. This approach involves familiarization, coding and generating initial themes, reviewing and eventually defining them.

Participants collectively reflected and discussed findings while being part of the broader learning community (training group), which helped in the process of sense-making and analysis. Themes that emerged repeatedly were discussed and reflected on with the participants and consequently captured as relevant.

The majority of the participants also actively contributed to annual conferences as part of the research project. These were organized in collaboration with two other health organizations, as part of a larger consortium, aiming to exchange practices and build on (creative) co-constructions of this "new" type of knowledge. Participants of the conference were able to exchange good practices and collaboratively set an agenda for the future action-plan of the concerned consortium.

Participants

The participants (co-researchers) were working in a variety of recovery oriented in- and outpatient settings, as displayed in Table 2. Their ages varied from 27 to 60 year, amongst whom 12 female and 3 male. As part of the research, all participants followed a 1 year post-bachelor training in working with experiential knowledge. This one-year training consists of 16 trainings focusing on theory, narrating recovery stories, collective discussions and reflections on key themes, such as shame, stigma, vulnerability, resilience and exchanging about action plans (Table 3).

Table 2. *Participant characteristics (N = 15)*

Participant	Gender	Age-category	Professional	Mental health setting
1	M	46-55	Nurse	High Intensive Care (inpatient) and Intensive Home treatment (outpatient)
2	F	36-45	Social worker	Supported living
3	M	56-65	Humanistic counsellor	Both inpatient and ambulatory
4	F	56-65	Humanistic counsellor	Both inpatient and ambulatory
5	F	36-45	Social worker	Supported living
6	F	46-55	Nurse	Supported living and treatment
7	F	36-45	Nurse	High Intensive Care (inpatient)
8	F	36-45	Social worker	Daycare program
9	F	56-65	Social worker	Daycare program
10	F	26-35	Social worker	Supported living
11	F	26-35	Social worker	Supported living
12	F	36-45	Social worker	Daycare program

Participant	Gender	Age-category	Professional	Mental health setting
13	M	56-65	Nurse	Supported living and treatment
14	F	26-35	Nurse	High and medium intensive care (inpatient)
15	F	46-55	Nurse	FACT team

Table 3. *Post-bachelor training programme (1 year)*

Session 1-2	Session 3-4	Session 5-6	Session 7-8	Session 9-10	Session 11-12	Session 13-14	Session 15-16
Writing and presenting personal recovery story	Writing and presenting personal recovery story	Body of knowledge on experiential expertise	Body of knowledge on experiential expertise	Exchanging about actions, impact and evaluation	Exchanging about actions, impact and evaluation	Creating of products Dissemination activities	Creating of products Dissemination activities
Theory of change	Create action plans	Finishing action plans	Discussion and reflection	Discussion and reflection	Discussion and reflection	Discussion and evaluation	Discussion and evaluation

The training offers directions to benefit from lived experience in a professional context by transforming lived experiences to experiential knowledge and bringing this knowledge to practice (Weerman and Abma, 2018). After the termination of the training, the group continued in a follow up group to further exchange upon actions, reflections and learned lessons.

Quality procedures

A number of different approaches to the critical appraisal of qualitative research have been described over the years. During the interviewing and analysis, the criteria of Lincoln and Guba (1985) were taken into account: “credibility”, “authenticity”, “transferability”, “dependability” and “confirmability” (Lincoln and Guba, 1989). The researchers met these criteria by joining professionals in their daily work-setting, in order to gain a deepened understanding of the context and work (prolonged engagement). Participants received a summary of the interview with the question if they recognized the script and had any additional reflections (member check). Triangulation (capturing and respecting multiple perspectives using various methods and sources) contributed to the dependability and confirmability of the study. As part of transferability findings were discussed in the learning community. Findings were also presented in two Applied Universities and its meaning for other organizations and contexts was further explored. The first three researchers kept a log of field notes in which important steps and changes were reported, as part of an audit trail.

Ethical considerations

According to the Medical Ethics Review Committee of VU University Medical Center (registered with the US Office for Human Research Protections as IRB00002991; FWA number: FWA00017598) the Medical Research Involving Human Subjects Act did not apply to our research.

In addition to the informed consent and confidentiality, various additional ethical principles were taken into consideration during this project: Working on mutual respect, participation, active learning, making a positive change, contributing to collective action, and personal integrity (Abma *et al.,* 2019; Banks and Brydon-Miller, 2018). All participating organizations and involved professionals were selected according to their intention and willingness to be part of a larger project striving to further develop experiential knowledge. Approval was obtained for the activities and the publication of findings. Ethical guidelines as well as dedicated time within our research team meetings and conversations with critical friends and peers were helpful to discuss issues of power, ethics, and responsibilities.
The Dutch code of conduct for research integrity (VSNU, 2018) as well the research code of VUmc have be taken into account. In conformity to European privacy regulations (General Data Protection Regulation) all data has been stored in a protected environment. Sensitive data (such as the written summaries) amongst participant and researcher have been transferred by email with encryption.

Findings

All participants are familiar with mental health distress in their background, having suffered from depression, suicidality, eating disorder, dissociation, burn-out, post-traumatic stress disorder, psychosis, bipolar disorder and/or addiction. Some of the participants have roots in families where trauma or emotional neglect took place, sometimes as a Child of Parents with a Mental Illness (COPMI). This contributed to their motivation to work in a mental health care setting. Some of the participants decided to make a career change after a relapse and started the training as part of their reintegration. Others were determined to work as a mental health care professional with lived experiences from the beginning.
The actual use of experiential knowledge by professionals affected four levels: their personal-professional development; the relation with service users; colleagues and; the broader organization.

Personal–professional development

First of all participants report that the training formed a solid base and led to increased awareness and insights on how to work with personal experiences in a professional context. Participants positively evaluated being part of a group where there is space for sharing their personal recovery journey. Although some expected to receive concrete guidelines during the training, in how to work with lived experiences, participants say they benefitted from the reflective practice at the heart of the training. Joint reflections contributed to the transfer from lived experiences to experiential knowledge.

Participants faced the following struggles when bringing this type of knowledge to their mental health work-context: (fear of) rejection, stigma and shame, imbalance and fatigue, uncertainty and confusion about professional identity.

The first struggle in using experiential knowledge concerned the fear of rejection, shame and stigma. They faced a paradox between feeling proud on being a survivor, versus feeling ashamed because of their background:

> *I have the feeling that they look different at me, which is why I avoid certain colleagues. When someone asked me to open up it at first provoked a sense of shame in me. [P11]*

The fear of rejection became so intense for some, that it became difficult to manage feelings of shame and self-stigma. The appearing social stigma in the context of mental health was often topic of discussion in the trainings:

> *It's as if Mental Health contexts carry a double layer of stigma, while it should be the opposite. I used to think it would be a resort where I would find ultimate understanding. How can we care for people while holding on to distorted images? [P3]*

Secondly half of the professionals were confronted with imbalance and fatigue at the start of the training:

> *It's a very intense process and I will need to work through my own issues a bit further, which evokes a lot of emotions. [P6]*

> *I really had to learn how to divide my energy and not become too much emotionally involved. It's a process, but it definitely improves over time. [P7]*

Thirdly, working with experiential knowledge in some cases interfered with complex trauma and adverse childhood experiences, that became reactivated. In some cases, working in Mental Health contexts functioned as a coping mechanism, because professionals learned to dissociate and refrain from personal experiences in the past:

> *I wasn't aware of the impact of the relationship with my father until I started this training and I am feeling really triggered by it right now. [P2]*

Even though three participants (P2, P5, P6] dropped out of work during or after the training, others reported signs associated with "post-traumatic growth", referring to the joint crisis and resilience they relived when reflecting on their personal-professional pathway.

Despite these struggles that came to the fore, the growing awareness of an existential, embodied, intuitive source of knowledge was helpful in sense-making processes with users:

I feel the space to concentrate on deep human suffering such as the loss of a parent who was abusive. [P4]

Some reflected on it as part of an ongoing process of personal recovery and professional development, while others report about an actual integration of the personal-professional identity. This ultimately led to increased self-compassion and self-acceptance:

I've come a long way but it definitely made me stronger, I feel so much more secure in my working practice. [P6]

Even though many report this process to be non-linear, the majority experienced feelings of pride, respect and being able to break the stigma and taboo at work:

This is who I am, it's completely me and I finally don't feel the urge anymore to hide that specific side of my Self. It's a birthright of freedom. [P7]

Relation with service users

Participants gave examples of how their experiential knowledge affected the relationship with service users. This concerns four pros: mutual recognition, embodied knowledge as an important resource, feeling less stigmatized and feeling hopeful towards recovery, which will also be further explored in a separate study upon the perspectives of service users. Few examples also indicated that some users prefer the traditional professional role, considering the professional as an "expert".

First of all, participants oftentimes received positive feedback from service users, after revealing their background and struggles with mental distress and/or addiction. This not only resulted in strong rapport, but also hope and felt understanding, because "the professional knows what he is talking about":

I oftentimes feel more connected to some of the users than to my colleagues and I can also give practical tips on how to cope with certain distress. [P10]

Secondly, participants explained that they developed an extra sensibility in relation to users, stating a professional with experiential knowledge can easily empathize with and attune to users' needs, feelings and conditions through the use of experiential knowledge:

I am much more aware of the intuitive and embodied knowledge I have and which helps me to resonate with users, a very powerful tool! [P13]

I can detect first signs of early psychosis, because I recognize things from personal experience. [P1]

Together with service users, participants search for ways to make sense of what has happened in the past. As part of this co-production, participants sensed they could contribute to the recovery process of users, especially when it comes to meaning making:

I enjoy working in a narrative fashion with users and frame things in meaningful ways. [P15]

Thirdly, the experiential knowledge that is derived from lived experiences brings in alternative perspectives and insights, that facilitate processes of destigmatization, normalization and humanization, e.g. taking voices seriously by exploring their meaning:

People tend to pathologize behaviors that I would consider as natural diversity. I often talk about the odds of my father, who suffered from bipolar disorder but from whom I learned most important lessons of life. [P15]

Fourthly, participants typically stimulated users' agency and empowerment and thereby their recovery-process. Oftentimes participants chose to postpone judgements, while facilitating learning processes and avoid decision-making without users' consent or active participation. Professionals who harness experiential knowledge serve as a positive role model, because they represent and model both vulnerability and resilience in one:

I want users to feel my confidence and hold hope for their future. [P5]

However, in a minority of the cases, participants were confronted with negative attitudes from service users who preferred to hold on to the perception of an 'unimpaired professional':

Some users don't appreciate all that much self-disclosure and really want you to be present as a professional, which should definitely be taken into account!. [P3]

Users need to be able to relate to me. If the gap is too large or too small, I cannot serve as a positive role model. [P10]

Participants underlined they continuously have to make estimations to what extent service users can identify themselves with the revealed living examples and what is helpful in this regard:

There is a group of users that feels even less confident about their personal chances when they see me working, living the life I have now. They get insecure about their capabilities because they tend to compare too much. [P12]

They indicate that the level of inter-relational proximity requires precision and that experiential knowledge has to be used in an adequate and professional way, in order not to trigger role-confusion.

Colleagues

Participants shared that they faced both positive as negative responses from colleagues. First of all, their coming out stimulated colleagues in the team to open up as well and became more responsive to a users' perspective and showing solidarity:

> *After I started talking openly, a few colleagues individually shared details from their personal lives, which I appreciate because if we want to realize a broader climate-change, more openness and safety are vital. [P9]*

These responses were marked as conditional to feel supported and mandated to work with this "new" source of knowledge:

> *One of the psychiatrists in my team particularly values my input and asks my opinion from a service users perspective. This active support of an authority was what we really needed. [P14]*

Participants believe that working with one's personal narrative and lived experiences requires a lot of reflexivity. The use of experiential knowledge in this regard became an important topic in some of the teams, during team-meetings, moral case deliberations and evaluations.

However, participants also faced negative responses and the following topics were distilled: devaluation, unfamiliarity with experiential knowledge and negative experiences with peer workers.

First of all, a coming out about a mental health and/or addiction background in their team several times led to further silencing rather than openings in the concerned teams, which participants attributed to unfamiliarity and taboos. Not being part of one home-team (due to flex-contracts) appeared to be a double complexity in this regard:

> *I don't always feel confident enough to expose my experiential expertise, because I am not part of the team and not sure how colleagues receive my input. [P7]*

Secondly, another recurring theme appeared to be the disqualification and devaluation when sharing one's vulnerability. Some colleagues looked down on professionals who presented their former status as a user and devaluated their current competency.

Colleagues were wary of possible risks or adverse side-effects, such as too much personal involvement:

Thirdly, some peer support workers felt intimidated by traditional professionals entering 'their' field of expertise.

> *There is still a lot of tension between me and the formal peer support workers here. It's like I have to prove my status and background as a former user to them! [P6]*

Lastly, some mental health workers associated the introduction of professionals using experiential knowledge, with previous struggles during the introduction of the peer workforce, sometimes resulting in a negative connotation:

We all have seen peer workers dropping out, derailing or malfunctioning because they get easily triggered on a personal and emotional level. [P12]

Impact in the organization

All participants shared a political mission to influence the working culture and the training offered back up in this regard. In each organization the mission and/or vision statement was reviewed specifically on the positioning of experiential knowledge. This resulted in a growing awareness that acknowledgement of this new source is needed by incorporating it in mission and/or vision documents. A positive of attitude of directors seemed crucial for a transition in this direction:

Once we thought that experiential knowledge was a welcome addition to care as usual, now we know that it's an essential source and I am very glad our director actually supports this mission. [P10]

This led to a further validation of the use of experiential knowledge, whilst other challenges came to the surface. These challenges were associated with the established hierarchic culture in which some values conflict with notions of emancipation, empowerment and inclusion. The identified challenges included: system and risk-management, operational policy and role of managers.

Participants report having minor chances to change the climate on an individual basis due to time and regulation restrictions, stemming from production-norms and standardization of care based upon evidence based and principles. They struggled with the rigidness of the medical model based upon avoiding risks, which often did not meet users' needs:

I need confidence. This role fits a jacket to me, but many colleagues still need time to adjust to the idea that lived experiences can nourish my professional work. [P6]

Collective actions that were organized bottom-up, such as disclosing one's personal background on a personal poster in public spaces in the organization, were not always fostered:

It's just all about the way I – and thereby also in general users here- am being perceived. One of my colleagues said it was exhibitionistic to expose myself in this manner. She believes it might burden users but I believe she feels endangered in her position! [P8]

For most participants however, the lack of safety and support from a close by manager was a more hindering factor in the professionalization and expansion of experiential knowledge. While in most teams the supervisors were well informed about the use of experiential knowledge, there was a lack of involvement of managers. This manifested in a lack of operational policy of experiential knowledge in the organization, despite apparent vision and mission statements:

I am glad that the board of directors of my organization supports this development, but I have to deal with the lack of knowledge and support from my direct manager. [P1]

Originality/value

In addition to peer support workers, professionals with lived experiences play an important role in working recovery oriented. The identified contributing factors match with those seen in peer workers: providing hope and inspiration and supporting users to make sense of and take control over their lives (Repper *et al.,* 2013). However, given that all involved professionals practiced a core profession of nursing, social work or humanistic counselling, they incorporated experiential knowledge in a broader body of knowledge. While the use of experiential knowledge by traditional professionals is scarcely accepted and the debate on how to corporate it in meaningful ways is still ongoing, the participants in this study came to the fore in their new role as professionals harnessing experiential knowledge, demonstrating bravery and strength. The training and follow up group not only facilitated personal–professional growth and extensive self-awareness about the use of experiential knowledge with regard to users, it also influenced the relationship with colleagues and the organization culture they were part of. Aiming for transformation on both micro and meso level seems a pivotal combination. Having dealt with mental health distress in their past, professionals risked stigma and rejections when introducing this as a type of knowledge in their mental health practice. They were challenged by ambivalent responses from colleagues and by a culture still mainly focusing on risk-management. Especially psychologists and psychiatrists seemed unfamiliar with this type of knowledge, sometimes devaluing it, despite positive statements on the contributions of lived experiences of several representative bodies (British Psychological Society, 2020; Royal Australian and New Zealand College of Psychiatrists, 2016). Also, in some teams former dissatisfying experiences with peer support workers impacted the current view on working with this type of knowledge.

Giving space to lived experiences not only implies a transformation of our understandings of mental health distress, but also affects policy, governance style and ethics of the entire organization. It takes a determined mind and a reflexive practice to work through this, with the back-up from open-minded colleagues and supervisors. Solely integrating experiential knowledge to policy has not been sufficient (Byrne *et al.,* 2017), but contributing to an open and safe work climate that supports dialogues, can make a difference and awakens social consciousness.

Social implications

After the rise of the recovery movement, its notions seems to be plateauing and the current model of recovery makes mental health distress an explicit problem of individualized identity, rather than an effect of structural inequality (Harper and Speed, 2013). Although the assumption had been that the employment of peer workers automatically contributed to a broader culture of change and disclosure for mental health professionals, this seems not to be sufficient (Byrne *et al.,* 2021). Whereas traditional professionals harnessing experiential knowledge built on to these efforts, they also faced challenges to further sensitize their environment while undergoing a personal-professional transformation.

This transformation resembles novel thoughts on professionalism and uncovers existing paradoxes attached to experiential expertise: at times being an "upgrade", while other times considered a "downgrade".
A discussion about the distinctions between academic (psychologists, psychiatrists) and applied mental health professions (nurses, social workers) seems vital to overcome the possible risks that professionals with lived experiences are exposed to when opening up about their double identity. Miranda Fricker invigorates this debate through her concept of epistemic injustice, stemming from structural inequalities of power (Fricker, 2007). While professionals with lived experiences seem well positioned to be political advocates for service users, they also remain depended on those who have final decision power in mental health system, oftentimes managers, psychiatrists and psychologists. The latter seem less invested in using experiential knowledge, possibly because of conflicting interests or more inadvertently due to "a blind spot". This results in social exclusion and silencing of tacit knowledge, which also brings us to Foucault (1982), who introduced the concept of parrhesia, which means "freedom of speech". In line with parrhesia, truth is not related to objectivity and evidence but to morality. It imposes moral questions on power definitions: what or who is at stake when certain knowledge is in- or excluded? Even though all professionals may have "best" intentions, there is an evident division between those with a reputation as an expert and those who are not believed to have valid expertise. Professionals with lived experiences question this dynamic, by embodying a living example of "therapatients" (Goldberg *et al.,* 2015).

Organizations and individuals that aim to harness lived experiences in a professional manner, could benefit from a participatory action project (Abma *et al.,* 2019). The collective power of a project group of professionals with lived experiences helps to transform feelings of shame, blame, stigma into strengths and encourages participants to speak up and share testimonies from users perspective. This however is only a first investment and needs to be paired with collective changes targeting a change of culture. In our project we therefore creatively referred to "spicy" principles of Political-critical, Existential, Practical, Personal, Ethical and Relational, captured with the acronym "PEPPER" (Weerman *et al.,* 2019).

Through these principles one can build on a climate that supports varying perceptions and voices. Professionals with lived experiences may in fact contribute to the expansion of experiential knowledge in the broader organization 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 topdown policy.

Limitations

This study has made it evident that the use of experiential knowledge by traditional Mental Health professionals is considered a new but meaningful exploration, that contributes to a renewed recovery movement. However, the current study was conducted locally and there are only few similar comparable studies that focus on both the personal–professional process as well as changes in the broader organization. Also, the context where the professionals are working and to what extent it is recovery oriented, trauma and user informed should be taken in to account in follow up studies.

Even though all participants in this study claimed to work in a recovery oriented setting, existing processes of stigma and shame in the working culture seemed a hindering factor during the implementation of experiential knowledge by professionals.
Additionally, little is known about how users perceive the use of experiential knowledge by established professionals. It seems of value to further explore the perspectives of users this regard, since many of them also "grew up" in a traditional system with predefined user-practitioner roles, especially related to psychologists and psychiatrists. This will be subject to research in a subsequent study of the authors.

Declaration of interest statement

The authors report no conflict of interest.
The authors would like to express gratitude to the professionals with lived experiences.
The authors also thank the members of the advisory board for commenting on the article.

References

Abma, T.A., Leyerzapf, H. and Landeweer, E. (2016). Responsive evaluation in the interference zone between system and lifeworld. *American Journal of Evaluation, 38*(4), pp. 507-520.

Abma, T.A., Visse, M., Hanberger, A., Simons, H. and Greene, J.C. (2020). Enriching evaluation practice through care ethics. *Evaluation, 26*(2), pp. 131-146.

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J. & Wright, M.T. (2019). *Participatory Research for Health and Social Well-Being.* Cham: Springer International Publishing.

Banks, S. (2012). *Ethics and Values in Social Work.* Hampshire: Palgrave Macmillan.

Banks, S. and Brydon-Miller, M. (2018). *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries.* Abingdon: Routledge.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology Virginia. *Qualitative Research in Psychology, 887,* pp. 77-101.

British Psychological Society (2020). Statement on clinical psychologists with lived experience of mental health difficulties. Available at: www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy-Files/Statementonclinicalpsychologistswithlivedexperienceofmentalhealthdifficulties.pdf

Byrne, L., Happell, B. & Reid-Searl, K. (2015). Recovery as a lived experience discipline: a grounded theory study. *Issues in Mental Health Nursing*, *36*(12), pp. 935-943.

Byrne, L., Happell, B. & Reid-Searl, K. (2017). Risky business: lived experience mental health practice, nurses as potential allies. *International Journal of Mental Health Nursing, 26*(3), pp. 285-292.

Byrne, L., Roennfeldt, H., Davidson, L., Miller, R. & Bellamy, C. (2021). To disclose or not to disclose? Peer workers impact on a culture of safe disclosure for mental health professionals with lived experience. *Psychological Services 19*(1), 9.

Delespaul, P., Milo, M., Schalken, F., Boevink, W. & Van Os, J. (2016). *Goede GGZ.* Leusden: Diagnosis

Faulkner, A. (2017). Survivor research and mad studies: the role and value of experiential knowledge in mental health research. *Disability and Society, 32*(4), pp. 500-520.

Foucault, M. (1982). The subject and power. *Critical Inquiry, 8*(4), pp. 777-795.

Fox, J. (2016). Being a service user and a social work academic: balancing expert identities. *Social Work Education, 35*(8), pp. 960-969.

Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of Knowing.* Oxford: Oxford University Press.

Goldberg, M., Hadas-Lidor, N. and Karnieli-Miller, O. (2015). From patient to therapatient: social work students coping with mental illness. *Qualitative Health Research, 25*(7), pp. 887-898.

Grundman, S.H., Edri, N. and Stanger Elran, R. (2020). From lived experience to experiential knowledge: a working model. *Mental Health and Social Inclusion, 25*(1), pp. 23-31.

Harper, D. and Speed, E. (2013). Uncovering recovery: the resistible rise of recovery and resilience. *Studies in Social Justice, 6*(1), pp. 9-26.

Lincoln, Y. and Guba, E.G. (1985). *Naturalistic Inquiry.* Newbury Park: Sage Publications.

Lincoln, Y. and Guba, E.G. (1989). *Fourth Generation Evaluation.* Beverly Hills: Sage Publications.

Repper, J., Aldridge, B., Gilfoyle, S., Gillard, S. Perkins, R. & Rennison, J. (2013). *Briefing: peer support workers: theory and practice.* ImROC, available at: www.centreformentalhealth.org.uk/pdfs/ImROC_peer_support_workers_theory_practice.pdf

Royal Australian and New Zealand College of Psychiatrists (2016). *The contribution to practice made by psychiatrists who have a personal experience of mental illness.* Available at: www.ranzcp.org/newspolicy/policy-and-advocacy/position-statements/psychiatrists-with-lived-experience-mental-illness

Slade, M. (2012). Recovery research: the empirical evidence from England. *World Psychiatry, 11*(3), pp. 162-163.

The Council for Public Health and Society (2017). No evidence without context. About the illusion of evidence-based practice in healthcare. Available at: www.raadrvs.nl/documenten/publicaties/2017/06/19/zonder-context-geen-bewijs

Van Os, J. and Kohne, A.C.J. (2021). It is not enough to sing its praises: the very foundations of precision psychiatry may be scientifically unsound and require examination. *Psychological Medicine, 51*(9), pp. 1-3.

VSNU (2018). *Dutch code of conduct for research integrity.* Available at https://www.universiteitenvannederland.nl/files/documenten/Nederlandse%20gedragscode%20wetenschappelijke%20integriteit%202018.pdf

Weerman, A. (2016). *Ervaringsdeskundige zorg- en dienstverleners. Stigma, verslaving and existentiële transformatie.* [Doctoral dissertation]. Vrije Universiteit Amsterdam.

Weerman, A. and Abma, T. (2018). Social work students learning to use their experiential knowledge of recovery. an existential and emancipatory perspective. *Social Work Education, 38*(4), pp. 453-469.

Weerman, A., De Jong, K., Karbouniaris, S., Overbeek, F., Van Loon, E. and Van der Lubben, P. (2019). *Professioneel Inzetten Van Ervaringsdeskundigheid.* Amsterdam: Boom.

Appendix

Topic list interviews
Opening
Aim and estimated duration of the interview
Consent about audio recording
Member check procedures
Introduction
Could you please tell me something about yourself and with regard to current work, function, responsibilities, organization and previous work-experience
Education background
Professional use of experiential knowledge
Reason(s) to start training "experiential knowledge"
Implications of a professional use of experiential knowledge
Differences and commonalities between peer support workers and professionals using experiential knowledge
Actual use of experiential knowledge
First time explicitly using lived experiences and concerned motives
Use of this type of knowledge embedded in a role as nurse/social worker/humanistic counsellor
Personal values and mission as a professional
Lessons learned from the training and new insights, changes over time
Example on the use of experiential knowledge in current practice (considerations, when, how)
Complicating and facilitating factors
Possible outcomes for users
Collaboration with peer support and/or other professionals
Closure
Responsive evaluation procedure

Chapter 5

Explorations on the use of lived experiences by psychiatrists: facilitators and barriers

Karbouniaris, Simona
Boomsma-van Holten, Marjolein
Oostindiër, Antoinet
Raats, Pascal
Prins-Aardema, Cecil
Weerman, Alie
Wilken, Jean Pierre
Abma, Tineke

Published in: Journal Mental Health & Social Inclusion, 2023

Abstract

Purpose

This study aims to explore the perspectives of psychiatrists with lived experiences and what their considerations are upon integrating the personal into the professional realm.

Design/methodology/approach

As part of a qualitative participatory research approach, participant observations during two years in peer supervision sessions (15 sessions with 8 psychiatrists with lived experiences), additional interviews as part of member feedback and a focus group were thematically analysed.

Findings

Although the decision to become a psychiatrist was often related to personal experiences with mental distress and some feel the need to integrate the personal into the professional, the actual use of lived experiences appears still in its early stages of development. Findings reveal three main considerations related to the personal, professionality and clinical relevance comprising 11 facilitators and 9 barriers to harness lived experiences.

Research limitations/implications

This study was conducted locally and there are no similar comparable studies known. It was small in its size due to its qualitative nature and with a homogeneous group and therefore may lack generalisability.

Practical implications

Future directions to further overcome shame and stigma and discover the potential of lived experiences are directed to practice, education and research.

Originality/value

Psychiatrists with lived experiences valued the integration of experiential knowledge into the professional realm, even though being still under development. The peer supervision setting in this study was experienced as a safe space to share personal experiences with vulnerability and suffering rather than a technical disclosure. It re-sensitised participants to their personal narratives, unleashing its demystifying, destigmatising and humanising potential.

Background

Like all physicians, psychiatrists have a privileged position in society and in the context of mental health care: they have status, expertise, considerable power and are granted access to the most intimate parts of patients' lives. But with these privileges come "darker" consequences (Gerada *et al.,* 2018). Entrance to medical school is determined by selection procedures and typically starts off with homogenising influences to neutralise the impact of social differences among medical students (Beagan, 2000). For some students this socialisation entails letting go of prior conceptions that do not match the medical professional identity (Beagan, 2000).

Specifically, the relational dimension of the work is strongly mediated: during pre-clinical years there is rarely any patient contact while being immersed into a largely biologically oriented medical framework. Then, during residencies, patient contact is thoroughly controlled by protocolised clinical procedures (Brincat, 2006). Few components of the current curricula focus on the emotional landscape of medical students, leaving those struggling with personal issues, isolated (Shapiro, 2011). In learning therapy emotions –one's own and others' – ought to play an important role in the personal–professional development. However, medical trainees are known to avoid professional help for their own struggles (Hankir *et al.,* 2017) even though they suffer from higher rates of psychological distress and suicide attempts than the general population (Beyond blue, 2013).

Historically, reservations on self-disclosure date back to the earliest years of traditional psychoanalysis in which the therapist was supposed to be impenetrable to the patient, acting like a mirror (Peterson, 2002). Thereafter, psychodynamic theories considered selfdisclosures as possibly harmful for patients. In spite of that the rise of the humanist movement in the 1960s advanced the argument that self-disclosure could be therapeutic, as also emphasised by feminist and self-help movements. In addition, Jung (1963) introduced the concept of the wounded healer and the ability to draw from wounds appropriately in therapy and warning for possible splitting of the helping professionals.

Surprisingly, there are few detailed reports about what it means for a therapist to process, resolve or recover from a wound in such a way that it might enhance, rather than interfere with, providing effective psychotherapy. Psychotherapists are often wary about the recovery status of the wounded healer: "at worst, we judge, and at best, we worry" (Zerubavel and Wright, 2012). Nowadays narrative, humanistic and existential orientations all have different takes on the effect of therapeutic self-disclosures (Zur, 2007). Perceived benefits vary from a strong therapeutic alliance to the decrease of feelings of shame and stigma (Karbouniaris *et al.,* 2020). Several new approaches to therapeutic self-disclosure surfaced towards the end of the 20th century and reframed it as boundary-crossing rather than violating, referring to its possible benefits (Psychopathology Committee of the Group for the Advanced of Psychiatry, 2001).

Even though lived experiences are often part of the decision to pursue psychiatry, medical trainees often feel insecure to disclose and worry about ramifications from educators and colleagues (Adame, 2011).

Shapiro (2011) states that medical education overall is characterised by its persistent ignoring, detaching and distancing from emotions. In recent years much has been written on the exposure to stress in medical school and the risk of burnout due to mental distress (Swensen and Shanafelt, 2020; Yang and Hayes, 2020). Tacit rules of the so called "hidden curriculum" in the Dutch professional culture concern hard working norms and trainees are expected to meet high quality physician performance achievements (Van den Goor, 2020) prioritising professional career above private life in a period in which age peers developmentally focus on different aspects of life. Next to general stressors of residencies (e.g. fatigue and sleep disruption, frustrations from working with demanding patients, facing unresolved outcomes, poor peer support), psychiatry training in particular has its own relatively unique set of challenges, including adversities such as suicides (Brenner *et al.,* 2018; Duarte *et al.,* 2020). In addition to the high achievement culture in many mental health services there is the pressing problem of being understaffed (Brittlebank *et al.,* 2016). Heavy workloads and reorganisations, as part of the marketisation of health care, hamper a humanistic practice and negatively affect the calling as a doctor (Van den Goor, 2020). As a head of the team or organisation, they face end-responsibilities and are legally governed by disciplinary regulations. Such responsibilities permeate indeed all aspects of life, as one may be constantly occupied. Over time psychiatrists develop a deep-rooted sense of professional identity "the medical self" which allows them to do the work as demanded, but becomes dominant and one is never "off-duty" (Gerada, 2022).

Peer supervision settings form an acknowledged hallmark of the professional setting to facilitate learning and develop a balanced and healthy professional identity. Key is to establish an emotionally-safe environment which seems often not naturally established (Walkman and Williston, 2015). Hence, the exploration on how to use lived experiences may not be a matter of subject in these settings and thus may remain unacknowledged. Novel policy attempts to reform the mental health field show several interesting developments and innovations in which the value of lived experiences of nurses and social workers are discovered. The Division of Clinical Psychology and the Royal Australian and New Zealand College of Psychiatrists value the lived experiences of, respectively, psychologists and psychiatrists, stating "lived experiences can provide a vital contribution to stigma reduction" (British Psychological Society, 2020; Royal Australian and New Zealand College of Psychiatrists, 2016). Yet, psychiatrists are commonly not educated in recovery and resilience principles, neither in working with lived experiences professionally. In this study, we will focus on the perspectives of a group of Dutch psychiatrists with lived experiences: What are their considerations upon the use of lived experiences in their clinical practice? Which facilitators and barriers do they face?

Design and methods

Design

This study originated as part of a large ongoing participatory research project initiated in The Netherlands in 2017. The project aimed at the professionalisation of experiential knowledge by professionals working in mental health services, specifically targeted at the values and ethics from the perspective of patients. Therefore, the participating mental health organisations decided to further stimulate the reflective use and integration of experiential knowledge by psychiatrists in their clinical practice, as part of a collaborative

learning network. One of the goals was to involve lead professionals, which is why a group of psychiatrists was invited to form a peer supervision group. This group consisted of eight members, and was set up in the beginning of 2020.

The first and second author initiated the group, after which the first author guided the group, using a qualitative participatory approach (Abma *et al.,* 2017; Abma *et al.,* 2019). While the goal of the group was to exchange ideas on the use of lived experiences in a consultation setting with peers, it also promoted collective learning and integration of professional and personal knowledge. The first author, being an expert-by-experience herself, created a safe atmosphere and guided and structured the meetings by using a peer supervision method.

Next to the peer supervision group, the researchers additionally conducted three in-depth interviews with the participants to gain a rich and multi-layered understanding of the context, culture and complex process of the participants. Several qualitative methods (participant observations, interviews and a focus group) were used to collect and triangulate a wide variety of data. Data was collected during 15 peer supervision sessions. During the aforementioned activities, three psychiatrists became actively involved as co-researchers from this article (authors 3, 4 and 5). They helped to interpret data, co-presented at conferences and have co-written the manuscript.

Methods and data collection

Participant observations during the peer supervision sessions (1) from March 2020 to June 2022 (2), three interviews and a focus-group (3) were part of the data collection.

Open and active participant observations of in total 30 hours were held during 15 peer supervision group meetings. The first researcher immersed herself into the context of the psychiatrists. In the peer supervision group (n = 8), a supportive atmosphere was established. Each meeting, one of the members was invited to share a dilemma or struggle both work related and personally. Even while the themes discussed in this peer supervision group seemed not exceptional or different from regular peer supervision groups, they were thoroughly reflected in the context of one's background. After each meeting, a reflection was written by the facilitator and sent to the participant for validation/member check. This was often perceived as helpful in further processing and reflecting on the presented issue. Few meetings had been organised remotely because of the measures of the pandemic, after which the members expressed a strong preference to meet live, even if that could take up to 2 h travel time. Over time one member stopped attending, because one of the other members became her supervisor. Another member became long-term ill and was not able to work. The group decided to select and invite one new member.

In addition, three in-depth interviews with a duration of 60–75 min each took place at the workplace of the interviewee. These interviews were used to thoroughly gather additional insights and reflect on the personal background of and with the participants. Purposeful sampling was used to value the multiple perspectives of these participants and as a form of dialogue to come to mutual understanding (Abma *et al.,* 2016; Abma, 2020).

All interviews were transcribed, then summarised and returned to the individual participant for a first validation ("member check").

Lastly, a focus group of 2 h with psychiatrists and the researchers was organised to check findings with representatives of the group. All psychiatrists were invited for this meeting and four actually attended the meeting. The strategies developed for research purposes were part of an action and reflection cycle which involved brainstorming/thinking, planning, doing and reflecting. Rather than being a static, linear process, these phases were intertwined and generated a cyclical process of praxis (action and reflection) that provided opportunities for change. Table 1 provides definitions for each phase and example strategies used in each of these phases.

Table 1. *Action Reflection Process and Related Strategies*

Action Reflection process phase	**Strategies**	**Whom involved?**
Brainstorming/thinking 1. Identify who we want to reach (lead professionals) 2. Identify how to reach	1. Set up of peer supervision group for psychiatrists with lived experiences 2. Top down mailing and warm recruitment at conference	1. Authors 1, 2, 4, 6 2. Directors of the involved mental health care organizations + authors 1, 2
Planning 1. Planning of meetings 2. Determining whom will facilitate 3. Determining method used for peer supervision meetings 4. Planning of interviews 5. Planning focusgroup	1. Collaboratively establishing group 2. Proposal to let group be facilitated by expert by lived experience researcher 3. Discussing several peer supervision methods	1. Author 1, author 2 and all participants
Doing 1. Organizing a reflection space to explore how to use lived experiences as part of this profession 2. Establishing a social and safe climate	1. Facilitating peer supervision group + interviews 2. Promoting interactions in between peer supervision sessions	1. Author 1 2. Author 1, author 2
Reflecting 1. What is the common central theme? 2. Did we meet our goals? 3. How can we reach those who are not involved?	1. Evaluation meetings 2. Focus group interview 3. ,,	1. Author 1 and all participants 2. Authors 1, 2, 3, 4, 5, 6 3. All authors and all participants

The combination of data methods supported an iterative process in which outcomes of the interviews formed the input for the group consultations and vice versa. The data provided rich and multi-layered understanding of the context, culture and complex process of the participants.

The participants were working in different mental health in- and outpatient settings, as displayed in Table 2. Their ages varied from 37 to 65 years, amongst whom five female and three male.

Analysis

As part of an interpretive phenomenological analysis, Braun and Clarke's (2006) thematic analysis approach was used to identify, analyse and reflect on possible patterns or categories that emerged during the interviews and during discussions in the project team.

All data was triangulated by using this approach involving familiarisation, coding and generating recurring themes, reviewing and eventually defining them. In their double role, researchers and participants as part of a learning community, collectively reflected and discussed findings, which helped in the process of sense-making and analysis. Themes that emerged repeatedly were discussed and reflected on with the co-researchers and at the end of the project, a focus group was organised to discuss all results which helped to deepen the team's understanding and further led to the identified categories.

For example, there was discussion about the difference between disclosing and sharing. Disclosure was not only associated with a technical intervention, it was also referred to as verbally revealing information, while some of the participants experienced that disclosure sometimes shifted to "sharing" in the sense of mutuality.

Quality procedures

Several quality procedures were used to enhance credibility, authenticity and dependability of the data (Lincoln and Guba, 1989). First of all, these criteria were met by inviting the participants through different itineraries: partially via the broader research project and partially via in-person recruitment at the annual national congress for psychiatrists. This seemed helpful in reaching different psychiatrists and gaining trustworthiness. We searched for psychiatrists who had interest in and/or direct experience themselves with mental distress or via relatives.

Secondly, joining professionals over a longer period of time in the peer supervision group (2.3 years), helped gaining a deepened understanding of the context and work ("prolonged engagement"). Participants received a summary after the interview or group session to check if they recognised the script and had any additional reflections ("member check").

Table 2. *Participant characteristics*

Participant	Gender	Age	Mental health setting	Peer supervision group	Additional interview	Focusgroup
1	F	56-65	Geriatric inpatient care	x		
2	M	46-55	Ambulatory addiction treatment	x	x	x
3	F	56-65	Private sector	x	x	x
4	F	46-55	Private sector	x		x
5	M	46-55	Bipolar treatment	x		
6	F	36-45	Child and adolescent treatment	x		x
7	F	46-55	Psychosis treatment	x	x	
8	M	46-55	Adolescent in and outpatient treatment	x		

Thirdly, the active engagement of three psychiatrists as co-researchers (authors 3, 4 and 5) in the analysing and writing process further sharpened and validated findings. The first author kept a log of field notes and memo's in which important steps and changes were reported, as part of an audit trail. Triangulation ("capturing and respecting multiple perspectives using various methods and sources") contributed to the dependability and confirmability of the study.

Lastly, as part of transferability findings were discussed in the research team and related advisory board. Findings were also presented during an annual conference for psychiatrists in The Netherlands (April 2022) and the NHS International Wounded Healer Conference in London (March 2022) which fostered the transferability of findings.

Ethical considerations

According to the Medical Ethics Review Committee of VU University Medical Center (registered with the U.S. Office for Human Research Protections as IRB00002991; FWA number: FWA00017598) the Medical Research Involving Human Subjects Act did not apply to our research.

The Dutch code of conduct for research integrity (VSNU, 2018) as well the research code of VUmc has to be taken into account. In conformity to European privacy regulations (General Data Protection Regulation) all data has been stored in a protected environment. Sensitive data (such as the written summaries) amongst participant and researcher has been transferred by email with end-to-end encryption. In addition to the informed consent for the interviews and confidentiality, various additional ethical principles were taken into

account during this project: working on mutual respect, participation, active learning, making a positive change, contributing to collective action and personal integrity (Abma *et al.,* 2019; Banks and Brydon-Miller, 2018). The involved professionals were invited for the interviews and peer consultations as part of the research project striving to further develop experiential knowledge. Ethical guidelines as well as dedicated time within our research team meetings and conversations with critical friends from the advisory board were helpful to further evolve discussions of power, ethics and responsibilities.

Findings

In answer to the research question we identified three main considerations related to the personal, professionality and clinical relevance comprising 11 facilitators and 9 barriers to harness lived experiences. Table 3 provides an overview of these facilitators and barriers.

Facilitators and barriers related to the personal

The choice to become a psychiatrist and work in mental health care was largely rooted in a personal background and struggle with mental health. The majority of the psychiatrists in the peer supervision setting openly shared about their issues from the beginning, e.g. in having dealt with depression, eating disorder, parents with psychiatric disorders, insecure attachment and (relational) trauma.

The supervision group facilitated a safe space, enabling to non-judgementally discuss the relation between personal background, training/residencies and current work setting with peers (F1). However, most of the participants did not share their personal background in their daily working context as the cultural norm is not to be open, which appeared to be one of the important barriers (B1). Especially the implicit and sometimes explicit permeating messages about the possible harmful effects as well as striving for professional objectivity, impeded the opportunity to reveal more of the self at work (B2).

Table 3. *Overview of facilitators and barriers*

	Personal	**Professionality**	**Clinical relevance**
Facilitators (F)	1. Sharing and non-judgmentally reflecting on illness and recovery themes in safe peer group setting	4. Connecting overarching personal themes to their patients' recovery	6. Quality of relationship with patients
	2. Feeling convenient and confident in revealing personal experiences	5. Share and critically reflect with supportive colleagues	7. Reframing and socially validating experiences of patients
	3.Investing in personal-professional development and well-being		8. Not speaking out might be contra productive
			9. Structure of working context to not become overly involved was helpful
			10. Balancing out the amount of disclosure
			11. Catalyse openness and stimulate destigmatization among colleagues
Barriers (B)	1. Cultural norm of not disclosing in daily working context	6. Lack of acknowledgment of experiential knowledge in psychiatric discipline	9. Underestimated status of drawing on lived experiences
	2. Implicit and explicit messages about possible harmful effects as well as striving for professional objectivity	7. Institutional and disciplinary pressure as lead professional, role ambiguity and fear for loss of status	
	3. Low diversity tolerance in training and peer supervision culture	8. Negative associations regarding the use of lived experiences and vulnerability	
	4. Involving the personal can be seen as boundary crossing		
	5. Limited trained in recovery and resilience principles		

Participant 1: “Am I actually allowed to share and connect to patients on a personal level, I wondered at first?”

Even though all participants attended at least one other peer supervision group next to this one, they also clarified that these groups often did not tolerate the involvement of their personal narratives with mental distress (B3). Involving the personal was considered transgressive and made the impression of violating professional codes of conduct (B4).

Participant 3: “Previous peer supervision groups felt unsafe and the topics discussed remained very superficial. My personal disclosures were looked at as ‘acting out’. But in this group, I can really be myself, as a whole with all my issues and I don’t feel alienated anymore.”

Along those lines the training culture was frequently perceived as a barrier in exploring possible benefits of lived experiences and incorporating them into the professional realm. Participants state they were very limited informed in recovery and resilience principles (B5).

While learning therapy made participants aware of occurring countertransference processes it did not support a coming out nor an explicit use of lived experiences in clinical practice, and sometimes made it more burdensome. Participants sometimes for the first time, started sharing about their “patient identity” and mental distress. Sharing this in presence of peers, made them feel less ashamed and burdened. It facilitated the realisation that working with personal experiences requires that one feels sufficient convenient and confident in doing so (F2). Consequently, they became aware of the importance to invest in a personal–professional development and they realized how difficulties in reaching out for professional help earlier sometimes led to the tendency to self-diagnose and self-treat (F3).

Participant 6: “It has been difficult to accept help for myself, which perhaps has to do with some kind of parentification, but I eventually found a trusted learning therapist.”

Facilitators and barriers related to professionality

A lack of acknowledgement of experiential knowledge as a valuable (re)source in the psychiatric discipline was perceived mostly as a barrier (B6). Sharing collective narratives of recovery processes unrelated to specific psychiatric problems was often perceived as irrelevant in the working context and therefore risked a devaluation of one’s professionality.

Yet, the psychiatrists with lived experiences explored how overarching personal themes connected to their patients’ recovery, such as knowing how to cope with existential loneliness and alienation and the effort needed to rebuild one’s life after a period of crisis (F4).

Participant 2: “I often recognise the way people need to re-establish their lives, during and after treatment, and even though I never dealt with substance abuse, I can see parallels with my own recovery.”

Participants learned to value lived experiences as complementary to other sources of knowledge, and in this sense the possibility to critically reflect with supportive colleagues on harnessing lived experiences was paramount (F5). They emphasised the importance of having sufficient awareness of intention and function when drawing on lived experiences.

All stated however that the conditions to study and work professionally with lived experiences are currently suboptimal. Balancing out one's personal and professional development during their residencies often led to negative evaluations.

Participant 7: "When some of my issues came to the surface, I immediately was assessed negatively by my supervisor. We are supposed to be a role model in mastering all of our emotions."

The institutional and disciplinary pressure in work, as head of a team or medical director hinders participants to work with experiential knowledge. Participants fear for a loss of status, role-ambiguity and possible devaluation (B7). They argued that especially colleagues associated the use of personal experiences with "vulnerability" and "weakness", undermining the presumed neutrality of the physician, rather than seeing the strengths or qualities that might come along as well (B8).

Facilitators and barriers related to clinical relevance

Participants expressed clinical relevance to drawing on lived experiences, despite its underestimated status in the field (B9). Most of them attributed relevance to the quality of the relationship with patients which they identified as most important facilitator (F6).

Participant 5: "I was one of the few to whom she was able to securely and safely attach, her loneliness resonated with me. I felt I did well, sharing on such human level."

Participants mentioned that patients may benefit from the personal contact, as it enhanced a social function in validating their experiences and may decrease loneliness or estrangement. They searched for ways to re-frame personal distress and transfer it to meaningful insights for patients, sometimes by normalising their experiences (F7). For instance, they looked at the affective and ethical meanings of lived experiences.

Alternatively, they began questioning whether not being transparent about personal issues might be equally harmful and counterproductive (F8). Not speaking up about these issues may lead to unattendance in how the personal becomes entangled with the professional.

Participant 8: "The moment you are unaware of countertransference processes and you don't reach out to reflect, your lived experience might get in the way."

Accordingly, participants explored the value of involving their lived experiences in both psychotherapy and medical consult settings with patients who seemed open to input from their practitioner. Some clarified that the structure of their work setting was helpful in this regard, to not become over-involved (F9). Balancing out to what extent personal information was used to provide hope and recognition, seemed crucial (F10).

Participant 4: "I saw a female patient in treatment for psychosis after sexual trauma. I needed to make the right estimation whether my experience could be helpful to her, and to what extent I would reveal about myself. I realised that my experiences with treatment and medication could make her feel less ashamed."

Aside its impact on the recovery and healing of the individual, participants considered it to be insightful for colleagues as well, as it could catalyse openness and stimulate destigmatisation (F11). Especially for trainees who aim to incorporate lived experiences this seemed challenging because of their junior position.

Discussion

To our knowledge this is the first study researching the considerations upon the use of lived experiences by psychiatrists. Despite previously expressed acknowledgments of self-disclosure from nationwide professional bodies (Psychopathology Committee of the Group for the Advanced of Psychiatry, 2001; Royal Australian and New Zealand College of Psychiatrists, 2016), this study reveals that the use of lived experiences by psychiatrists is rather exceptional. The emphasis on neutrality and standardised approaches, driven by harm and risk-reduction principles, divides the personal from the professional. There is an overall lack of education in methods and skills during the training period regarding harnessing lived experiences. Nowadays primary curriculum in The Netherlands is prevailed by psychopharmacology and (cognitive behavioural and psychodynamic) psychotherapy, leaving psychiatrists unequipped to adequately integrate their lived experiences.

Due to the introduction of experts by experience in the workforce, established mental health professionals are becoming more and more aware of the value of personal stories in the professional arena. Consistent with our previous findings upon the use of experiential knowledge by nurses and social workers (Karbouniaris *et al.,* 2022) some psychiatrists acknowledged the value of using personal experiences. They underline that this can contribute to the recovery of patients, and can provide hope and inspiration, supporting patients to make sense of their experiences and take control over their lives. At the same time the psychiatrist profession entails its own typical challenges. At a system level, the psychiatrist is supposed to be a medical leader subject to disciplinary regulations, which leaves little room for being human and showing imperfections. Medical expertise is often deficit-laden and pathologising and sustains stigmatised views on psychiatry and ignores the freedom for different subjective narratives (Harper and Speed, 2012). Hence it largely ignores the relational and humanistic aspects of the physicians' work.

Findings from this study confirm that psychiatrists who desire to engage their lived experiences need to first become aware of internalised framings such as the stigma and burdens associated with mental health conditions. The peer supervision group seemed especially helpful in this regard.

Limited research exists focusing on the professional identity and "self" of psychiatrists and these studies have pointed out that the fluid nature of professional identity over time tends to shift from a reliance on technical expertise to one's own experience, values and knowledge that integrates professional and personal identities (Borchers *et al.,* 2014). Peer supervision settings are not only a mandatory part offering space for discussion with colleagues to review difficult or challenging decisions with others, they also allow room for reflection (van den Goor, 2020). The current peer supervision setting offered a space for such "deliberative practice". It re-sensitised participants to their personal narratives, unleashing its demystifying, destigmatising and humanising potential. While the peer supervision group might be seen as an attempt to re-sensitise professionals for their personal frame of reference, some argued to de-personalise the use of lived experiences and emphasise its collectiveness, searching for universal values and existential issues (e.g. fear of loneliness) that connect psychiatrists to the lifeworld of their patients.

Contractionary to social workers who were stimulated to reflect and discuss those reflections with patients as part of a deliberative practice (Karbouniaris *et al.,* 2022), psychiatrists seem to be caught in the object–subject dualism. Trained as both medical expert and psychotherapist, their traditional perception on epistemology seems to undermine knowledge derived from lived experiences.

However, consistent with Martin *et al.* (2020), sharing histories of personal vulnerability can lessen stigmatised views on mental health. This requires the psychiatrist to pass the "medical gatekeeper era", and start searching for a moral and normative professionality (van Os and Gülöksüz, 2022). This consequently corresponds with changing perceptions on the profession of the participating psychiatrists with lived experiences, taking into account relational ethics, such as shaping the relationship horizontally and a virtue based practice. Our study shows that respectful spaces where professionals are invited to share their insights rather than technically disclosing or introspectively analysing seem crucial.

Originality

The aim of the current study was to explore the considerations upon the use of lived experiences by a group of Dutch psychiatrists. The main finding of this study is that psychiatrists with lived experiences stimulate the integration of experiential knowledge into the professional realm, even though the acknowledgement of this type of knowledge is still in its early stages of development. Facilitators and barriers on the use of lived experiences are related to the personal, professionality and clinical relevance. Psychiatrists from the peer supervision group positively explored the possible value of their lived experiences with stress, trauma, complex family histories etc. They looked for opportunities to process, reframe and harness its meaning for the recovery of patients. At the same time the fear that those insights are not perceived as "professional" and considered a devaluation of the profession, held them sometimes back to openly share their considerations. The peer supervision setting in this study stimulated to share personal experiences rather than technically disclosing. It led to mutual recognition and re-sensitised participants to associate their personal background to their clinical practice and stimulated a learning process on how to incorporate lived experiences in a constructive manner contributing to its demystifying, destigmatising and humanising potential.

Practical implications

To conclude, we suggest the following future directions for practice, research and education. Firstly, to overcome shame and stigma attached to personal vulnerability, and start discovering the positive sides and potential of lived experiences, the format of the peer supervision group has proven to be useful. Looking at related mental health professions such as nurses, psychologists and social workers could provide even more inspiration on how to incorporate lived experiences (van Zelst, 2020).

Secondly, there is a growing urgency to feed the current curricula for upcoming psychiatrists with recovery informed principles, including the reflective use of experiential knowledge.
Thirdly, we recommend more research on peer supervision to develop a framework how experiential knowledge can supplement and be integrated in the existing body of knowledge of psychiatry. Research is also needed to collect substantial evidence on the added value of experiential knowledge related to treatment outcomes. Future research to subtle forms of stigma, and collaboratively reflecting with psychiatrists on their perceptions of professionality, can stimulate changes in mental health culture.
Lastly, psychiatrists "coming out" with their personal experiences can act as ambassadors and positive role models, showing in real life how this can enrich the profession.

Limitations

The current study was conducted locally and there are no similar comparable international studies known. It was small in its size with a homogeneous group due to its qualitative nature and therefore may lack generalisability. In addition, it seems of value to further explore the perceptions of colleagues (psychiatrists and psychologists) who to date remain reserved in the development of using lived experiences.

References

Abma, T. (2020). Ethics work for good participatory action research. *Beleidsonderzoek Online, 6.*

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J. & Wright, M.T. (2019). *Participatory research for health and social well-being.* Cham: Springer International Publishing.

Abma, T.A., Cook, T., Rämgård, M., Kleba, E., Harris, J., & Wallerstein, N. (2017). Social impact of participatory health research: collaborative non-linear processes of knowledge mobilization. *Educational action research, 25*(4), pp. 489-505.

Abma, T.A., Leyerzapf, H. & Landeweer, E. (2016). Responsive evaluation in the interference zone between system and lifeworld. *American Journal of Evaluation, 38*(4), pp. 507-520.

Adame, A.L. (2011). Negotiating discourses: the dialectical identities of survivor-therapists. *The Humanistic Psychologist, 39*(4), pp. 324-337.

Banks, S. and Brydon-Miller, M. (2018). *Ethics in Participatory Research for Health and Social Well-Being: Cases and Commentaries.* Abingdon: Routledge.

Beagan, B.L. (2000). Neutralizing differences: producing neutral doctors for (almost) neutral patients. *Social Science & Medicine, 51*(8), pp. 1253-1265.

Beyond blue (2013). *National mental health survey of doctors and medical students.* Available at: www.beyondblue.org.au/docs/default-source/research-project-files/bl1132-report–-nmhdmss-full-report_web.

Borchers, P., Seikkula, J. & Arnkil, T. (2014). The need-adapted approach in psychosis: the impact of psychosis on the treatment and the professionals. *Ethical Human Psychology and Psychiatry, 16*(1), pp. 5-19.

Brenner, A.M., Balon, R., Guerrero, A.P.S., Beresin E.V., Coverdale, J.H., Louie, A.K. & Roberts, L.W. (2018). Training as a psychiatrist when having a psychiatric illness. *Academic Psychiatry, 42*(5), pp. 592-597.

Brincat, C. (2006). How medical training mangles professionalism: The prolonged death of compassion. *Professionalism in medicine: critical perspectives,* pp. 199-210.

British Psychological Society (2020). *Statement on clinical psychologists with lived experience of mental health difficulties.* Available at: www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy-Files/Statementonclinicalpsychologistswithlivedexperienceofmentalhealthdifficulties.pdf

Brittlebank, A., Hermans, M., Bhugra, D., Pinto da Costa, M., Rojnic-Kuzman, M., Fiorillo, A., Kurimay, T., Hanon, C., Wasserman, D. and van der Gaag, R.J. (2016). Training in psychiatry throughout Europe. *European Archives of Psychiatry and Clinical Neuroscience, 266*(2), pp. 155-164.

Duarte, D., El-Hagrassy, M.M., Couto, T.C.E., Gurgel, W., Fregni, F. & Correa, H. (2020). Male and female physician suicidality: a systematic review and meta-analysis. *JAMA Psychiatry, 77*(6), pp. 587-597.

Gerada, C. (2022). Doctors' identity and barriers to seeking care when unwell. *The British Journal of Psychiatry, 220*(1), pp. 7-9.

Gerada, C. (2018). *The wounded healer: report on the first 10 years of practitioner health service. Practitioner Health Service.* Available at: www.practitionerhealth.nhs.uk/media/content/files/PHP-reportwebversionfinal(1).pdf

Hankir, A., Carrick, F. & Zaman, R. (2017). The wounded healer: an anti-stigma program targeted at healthcare professionals and students. *European Psychiatry, 41*(1), pp. S735-S735.

Harper, D. & Speed, E. (2012). Uncovering recovery: the resistible rise of recovery and resilience. De-Medicalizing Misery II: Society, *Politics and the Mental Health Industry, 6*(1), pp. 40-57.

Jung, C.G. (1963). *Memories, Dreams, Reflections.* New York: Crown Publishing Group/Random House.

Karbouniaris, S., Abma, T., Wilken, J.P. & Weerman, A. (2020). Use of experiential knowledge by mental health professionals and its contribution to recovery: literature review. *Journal of Recovery in Mental Health, 4*(1), pp. 4-19.

Karbouniaris, S., Weerman, A., Dunnewind, B., Wilken, J.P. & Abma, T.A. (2022). Professionals harnessing experiential knowledge in Dutch mental health settings. *Mental Health and Social Inclusion, 26*(1), pp. 75-88.

Lincoln, Y. and Guba, E.G. (1989). *Fourth Generation Evaluation.* Beverly Hills: Sage.

Martin, A., Chilton, J., Paasche, C., Nabatkhorian, N., Gortler, H., Cohenmehr, E., ... & Neary, S. (2020). Shared living experiences by physicians have a positive impact on mental health attitudes and stigma among medical students: a mixed-methods study. *Journal of Medical Education and Curricular Development, 7,* 2382120520968072.

Peterson, Z.D. (2002). More than a mirror: the ethics of therapist self-disclosure. *Psychotherapy, 39(1)*, pp. 21-31.

Psychopathology Committee of the Group for the Advanced of Psychiatry (2001). Reexamination of therapist self-disclosure. *Psychiatric Services, 52*(11), pp. 1489-1493.

Royal Australian and New Zealand College of Psychiatrists (2016). *The contribution to practice made by psychiatrists who have a personal experience of mental illness.* Available at www.ranzcp.org/newspolicy/policy-and-advocacy/position-statements/psychiatrists-with-lived-experience-mental-illness

Shapiro, J. (2011). Perspective: does medical education promote professional alexithymia? A call for attending to the emotions of patients and self in medical training. *Academic Medicine, 86*(3), pp. 326-332.

Swensen, S. & Shanafelt, T. (2020). *Mayo Clinic Strategies To Reduce Burnout. 12 Actions to Create the Ideal Workplace.* Oxford: Oxford University Press.

Van den Goor, M. (2020). *Calling and comradeship: unravelling the essence of physician performance.* [Doctoral dissertation]. University of Twente.

Van Zelst, C. (2020). Integrating lived experience perspectives Into clinical practice in Badcock, J.C. and Paulik, G. B. T.-A.C. I. to P. (Eds), *A Clinical Introduction to Psychosis Foundations for Clinical Psychologists and Neuropsychologists.* Academic Press, pp. 687-703.

Van Os, J. and Gülöksüz, S. (2022). Schizophrenia as a symptom of psychiatry's reluctance to enter the moral era of medicine. *Schizophrenia Research, 242*, pp. 138-140.

VSNU (2018). *Dutch code of conduct for research integrity.* Available at https://www.universiteitenvannederland.nl/files/documenten/Nederlandse%20gedragscode%20wetenschappelijke%20integriteit%202018.pdf

Walkman, S.H. & Williston, M.A. (2015). The role of vulnerability and peer-supervision in establishing clinical competency. *Psychotherapy Bull, 50*(1), pp. 14-17.

Yang, Y. & Hayes, J.A. (2020). Causes and consequences of burnout among mental health professionals: a practice-oriented review of recent empirical literature. *Psychotherapy (Chicago, Ill), 57*(3), pp. 426-436.

Zerubavel, N. & Wright, M.O.D. (2012). The dilemma of the wounded healer. *Psychotherapy, 49*(4), pp. 482-491.

Zur, O. (2007). *Boundaries in Psychotherapy: Ethical and Clinical Considerations.* American Psychological Association. Washington: Routledge.

Reflection III "Fascination and flow"

I got fascinated by psychiatrists as professional beings, already at a young age. Not particularly because they felt safe. My first encounter dates back to me being 17 years and seeing a psychiatrist.
I was intrigued but also intimidated by his way of reasoning, his pace and his knowledge, although he clearly could not reach me. And after one year he gave up. I was too complex, too introverted and he probably realised my attachment issues were in the way of establishing rapport.

During my research, I felt again intrigued by some of the professionals whom I met, and followed for some time. I learned that many of them used a discretionary space to relate to their clients, often in very creative and unconventional ways. Some of them invested in 'positive risk taking', and made the contact more unconditional in a way.
It was interesting to guide the group of psychiatrists with lived experiences for more than 2 years. Their journey was critical at times, in experiencing vulnerability instead of mastery. Often in contrast to nurses and social workers who were already more accustomed to working with their lived experience. Despite their career and position, or perhaps due to these, feelings of fear and anxiety resonated throughout the group dynamics, when revealing personal stories. The flow of the group was compelling.
If only we could use this energy for the transformation of the services. If lived experiences are more validated, would they be able to contribute to system changes? Or would they feel hindered perhaps by possible disciplinary consequences?

Upon my leave from this group of psychiatrists I received a card with the following writing: "You are the noblewoman who offers a rose to the blind men and women who -luckily are capable of taking off the blindfold. Thank you for your enthusiasm, openness and effort in favour of us as psychiatrists with lived experience…."

Illustration 1. *The received card ("the blind play"- Cornelis Troost in 1740)*

Given the prematurity of integrating the personal into the professional realm, I wondered which actors and what kind of strategies would be needed to contribute to system change in the established services. What are current organisational struggles and how can we overcome these and look for ways to advance experiential knowledge? How can experiential knowledge become as essential as other knowledge types in mental health? These were some of the questions I tried to answer in the final study.

Chapter 6

Working with lived experiences in mental health: organisation challenges

Karbouniaris, Simona
Van Gaalen, Esther
Daniëls, Daantje
Weerman, Alie
Wilken, Jean Pierre
Abma, Tineke

Journal Mental Health Review
(submitted)

Abstract

Purpose

After the introduction of service users becoming peer workers to improve health care, established professionals have started using lived experiences with mental illness. While a shift towards recovery-oriented care has led to awareness of the lived experience perspective, mental health organizations are struggling to widely implement experiential knowledge.

Design

This multiple case study focuses on how to further develop and integrate experiential knowledge in three mental healthcare organizations and one addiction care organization in the Netherlands. A mixed-methods design was conducted, consisting of a descriptive case study and responsive evaluation.

Findings

The findings reveal that a substantial part of the workforce in mental health and addiction care is familiar with recovery from mental distress and trauma, yet only a small percentage makes explicit use of it. For the implementation of experiential knowledge throughout organizations, three areas are important: positioning of lived experiences, human resources management and professionalization.

Originality

The implementation of experiential knowledge within mental healthcare organizations requires a dialogical and action-oriented strategy to motivate and engage all stakeholders in a mutual learning process. This process should concern issues related to the positioning of lived experiences, the development of resources and the facilitation of professional development while balancing out formalization processes.

Purpose

Working with service users' lived experiences in mental health organizations is part of a broader recovery agenda that places more emphasis on person-centered care, personal recovery, social inclusion and empowerment than on traditional clinical medical outcomes (World Health Organization, 2015). Over the past 25 years, user- and survivor-led collaborations have featured internationally in major mental health policy and practice guidelines (World Health Organization, 2022). The lived experiences of service users have been acknowledged amidst large transitions such as the shift from institutional care to community care in Western countries (Castro, 2018; Casey, 2021).

The rise of experiential knowledge as a relevant source of knowledge was due to its ability to better relate to users' needs (Baillergeau & Duyvendak, 2016). Working with this type of knowledge is seen as a pathway to complement the often standardized evidence-based practice in a transition towards more person-centered care. To use experiential expertise, peer workers have been employed in mental healthcare, and their contributions to supporting others have gradually gained more recognition (Grundman, Edri & Stanger Elran, 2020). There is also growing awareness that a considerable number of professionals have been exposed to trauma and distress in their personal lives (Zerubavel & Wright, 2012). This overall trend has led to advances in legislation and government policies supporting shared decision-making and empowerment of service users (Casey, 2021).

The use of experiential knowledge in mental healthcare is based on acknowledging the unique character of this kind of knowledge, which is grounded in the experience of being mentally ill (Haaster *et al.,* 2013). Its uniqueness stems from what it is like to experience distress and be dependent on the care and support of others, as well as on reflections on the organization of care, public responses to mental illness, and, most importantly, the strengths required to give new meaning to the changes in one's life. Sharing these experiences can lead to a 'collective' knowledge base (Boertien & Van Bakel, 2012) and 'experiential expertise'. The following process model presents the evolution from 'lived experience' to 'experiential expertise' (Figure 1).

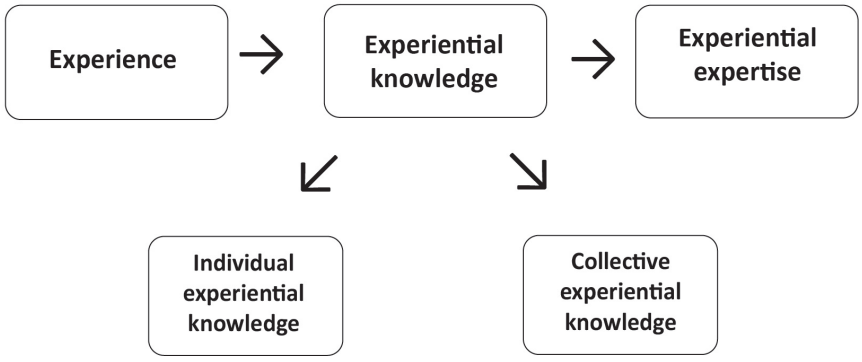


Figure 1. *Process model from experience to experiential expertise (Castro et al., 2019)*

While the recognition of the first person perspective has grown over the years, studies demonstrate that the mental healthcare system have yet to meaningfully incorporate experiential knowledge. For example, tensions have been described between peer workers and established staff about how much lived experience is enough to fulfil a role as a lived experience practitioner and what experiences are considered valuable (Roennfeldt & Byrne, 2020). Scholars have been critical of the co-optation of peer workers (Van Os, van Delden & Boevink, 2021) and its instrumental use in cutting services and expenses, reproducing neoliberal values of productivity, risk reduction and efficiency (Davidson *et al.,* 2006; Wigmore & Stanford, 2017; Aadam & Petrakis, 2020; Beresford & Brosnan, 2021). The interplay between marketisation logic, medicalization and professionalization has also led to new cost control and management strategies (Saks, 2020).

There is a need for a better understanding of how to position experiential knowledge within mental healthcare organizations to harness its values and contributions. In this case study, we examined how to further develop and integrate experiential knowledge in four different organizations. Therefore, we identified the lessons learned when implementing this type of expertise in mental health and addiction care organizations.

Design

Research setting

This study took place in three mental health organizations and one addiction care organization in the north-eastern region of the Netherlands from 2017 to 2022. All organizations were part of the PEPPER Consortium which stands for Practical, Existential, Political-critical, Personal, Ethical and Relational and consists of a collaboration of providers and universities aiming to incorporate the lived experience perspective into the 'standard of care' (Weerman *et al.*, 2019). The consortium invested in research, policy development and education such as training and peer supervision groups for 60 nursing professionals and social workers with lived experiences in addition to regular peer support. Psychologists and psychiatrists, managers and directors in the participating organizations collaborated to work on the changes needed for integrating experiential knowledge based on personal lived experience as the lived experience of (family) caregivers.

The organizations provide services to more than 45,000 clients in 75 different locations in the northeastern and central parts of the country. The workforce consisted of approximately 547 to 1221 full-time equivalent healthcare professionals working in the participating organizations. At the time of the study, only a small percentage (1–2%) of all working professionals were trained and qualified to complement their work with insights from lived experiences.

The research team consisted of four academic researchers (authors 1, 4, 5 and 6) and two executives (authors 2 and 3) from organizations 2 and 4, respectively. The first author collected the data, the fourth author led the learning community, and the fifth and sixth authors were involved as supervising co-researchers. The second and third author were involved as co-researchers in the implementation process. All authors disclose having either personal lived experience and/or have lived experience as a family caregiver caring for someone with mental illness or disability.

Methods

The four organizations were conceived as cases; each representing a demarcated unit of analysis (Abma & Stake, 2014). For this multiple case study, a mixed-methods design was conducted consisting of a case study and responsive evaluation in every organization to describe its context and stimulate the dialogue. The responsive evaluation was set up to stimulate a dialogue among stakeholders (executives and researchers) and generate mutual understanding within the organizations. Parallel a learning community with the executives (directors and managers) of the four organizations was established with a mixed group of participants to foster a process of action–reflection–learning.

Data collection and analysis

The following data was collected over a period of 5 years: written policy documents, interviews, observations, and reflections during different meetings as well as a questionnaire. See table 1 for the detailed list.

Table 1. *Data collection*

Data sources	Organisation(s)	Period
Desk-search on policy documents (mission, vision statements)	1,2,3,4	2017-2022
Content analysis HR and financial policy (eg. function and role descriptions)	1,2,3,4	2017-2022
In depth qualitative interviews with directors and managers	1,2,3	2019
Observations and reflections during periodically meetings of a learning community of directors and managers	1,2,3,4	2017-2022
Participating observations during bi-monthly project and peer supervision meetings	1	2017-2022
Questionnaire about organisation perspective	1,2,3,4	2021

Data analysis and sensemaking were both conducted by the researchers and discussed with the executives that functioned as a learning community, as aimed for in an emancipatory research approach (Abma *et al.,* 2019). A thematic analysis was used to identify, analyze and reflect on possible patterns or categories that emerged during discussions and interviews (Braun & Clarke, 2006). All data was triangulated by using this approach involving familiarization, coding, and generating recurring themes, reviewing and eventually defining them.

See table 2 for an illustration of the analysis scheme developed over time per theme. In addition to the analysis of available documents in the desk search, researchers and co-researchers in the learning community collectively reflected and discussed findings, which helped in the process of sense-making and analysis as well as steering the implementation. The themes that emerged repeatedly were discussed and reflected on with the co-researchers which helped to deepen the team's understanding and further led to the identified categories.

Table 2. *Illustration of analysing scheme*

Condensed meaning units	Source	Themes
Our organisation wants to contribute to a mentally resilient community by acknowledging human variety and emphasizing mutuality… (..) Our care is focused on recovery from day 1, with the environment of the service user, and with respect to his/ her needs.	*Mission- vision paper*	Positioning
We need this kind of expertise throughout the entire organisation, so not only in the provision of care, but also a policy officer, a lived experience advisor and in all other roles you could think of.	*Learning community*	Human resources
We decided to organize a seminar with two external experts who claim that training is not needed in order to use ones lived experiences. This has puzzled us, but eventually we came to the conclusion that professionalisation does require training	*Steering group*	Professionalisation-formalisation

Ethical considerations

According to the Medical Ethics Review Committee of VU University Medical Center (registered with the US Office for Human Research Protections as IRB00002991; FWA number: FWA00017598) the Medical Research Involving Human Subjects Act did not apply to our research. Approval was also obtained for the activities and the publication of findings from the ethical commission of the participating organizations. Sensitive data has been transferred by email with encryption. Besides informed consent and confidentiality, the ethical principles of participatory research were taken into consideration (Abma *et al.*, 2019; Banks & Brydon-Miller, 2018).

Findings

The central finding of this study is that the potential of experiential knowledge requires concrete actions and efforts at all levels within mental healthcare organizations, backed up by executives who invest in open, safe, creative, and destigmatizing spaces to sensitize lived experiences.

The implementation of experiential knowledge can be clustered in the following themes: positioning of lived experiences (a) human resources management (b), professionalization (c).

a) Positioning of lived experiences

As part of participating in a consortium that aimed to expand the use of experiential knowledge, all organizations committed to the positioning of experiential knowledge as a valid source of knowledge. At the onset of the research, in mid-2017, a quantitative survey (n=1728) was conducted (Weerman *et al.,* 2019). With a response percentage of 35%, it indicated that 46.9% of all professionals self-reported personal lived experiences with psychiatric, somatic, addiction, psychosocial, and/or financial problems. An even higher percentage of 82.6% reported being familiar with the aforementioned problems in the family line. This underlined that organizations have a large human capital of 'experiential knowledge', but also raised the question of how to translate this potential. Then most professionals used lived experiences either implicitly or not at all.

Through additional mission and vision documents, stakeholders were informed about the potential of experiential knowledge broadly. Oftentimes this was embedded in recovery-oriented approaches to care based on values such as mutuality, professional proximity, inclusion, empowerment, diversity, and an overall process of democratization.

"Our organization wants to contribute to a mentally resilient community by acknowledging human variety and emphasizing mutuality… (..) Our care is focused on recovery from day 1, with the environment of the service user, and concerning his/her needs" (organization 1).

By situating experiential knowledge as a relevant, valid, and complementary source next to scientific and professional knowledge, this type of knowledge received acknowledgment, also for the established workforce. This was supported by the involved executives formulating a personal statement promoting the strength of 'personal lived experiences' and led to intensive discussions about traditional notions of mental ill health, emphasizing vulnerability.

"Some entirely devaluated it (lived experiences) as a resource. We have had a heated conversation after which we eventually agreed to state: vulnerability in the bin!" (learning community 2021).

Ideological arguments and discussions on the surplus value of lived experiences and its risks were constantly enriched by concrete actions and reflections on learning experiences. The training was set up targeting the established mental healthcare professionals (such as social workers and nurses), and the recruitment and training of other staff members with lived experience took place. Also, some professionals opened up about their lived experiences in a role as (family) caregivers. Furthermore, the organizations made use of nonverbal expressions, such as art and dance, play and music, to create space for the unsayable and symbolize the value of experiential knowledge, to stimulate dialogues beyond words on the meaning of lived experiences [illustration 1].

Illustration 1. *Dance on spoken word and music of a professional with lived experiences during a conference*

Art students collaborated with trainers and professionals to explore different types of art to express and foster mutual learning processes on the nature and value of lived experiences. To some, this was a 'safe' way to communicate, whilst, for others, these artistic expressions were confronting, but it stimulated the mutual process of learning for all involved. To deal with hierarchy and established power relations the whole implementation needed to be strongly back-upped by highly motivated managers and directors who supported the implementation of lived experiences, and who promoted the involved lived experience practitioners as pioneers and innovators.

'Disruptive acts are needed in organizations as ours, which is why I decided to open up about my own lived experiences with psychosis during one of our organization building days' (executive organization 2).

The coming out of established professionals with lived experiences evoked criticism from peer workers because they feared losing their granted position. Others, such as psychiatrists and psychologists had the tendency to further distance themselves from the appearing lived experience perspective. This unfolded as a conflict at first, but over time led to the overall awareness and relevance to sensitize professionals for a lived experience perspective rather than discriminating or excluding a (sub)population. Some of the executives embodied a living example themselves, by speaking up about their mental distress during a work conference in 2018 and inspiring others to open up. Traditional professionals' readiness was tested, while in some cases the use of lived experiences did not comply with the framework of their professional identity. A thorough reflection on existing discussions about the transformation of lived experiences further stimulated the reflection and revealed a diversity of the use of lived experiences (Weerman, *et al.,* 2019). All these actions and conservations on the position of lived experience practitioners within the organization were key to fostering a learning process and revealed the importance of an action-oriented approach.

b) Human resources management

Initially, the development of a new function description versus an addendum in addition to the existing functions of nurses, social workers, and humanistic counselors, was discussed.

In all organizations a role differentiation (addendum) was developed, to complement the core profession.

Also, all organizations had set up peer supervision and recovery departments to facilitate lived experience practitioners and traditional professionals with experiential knowledge, after the training. Regulating and integrating experiential knowledge into mental health organizations seemed controversial in itself, as existing dynamics may remain dominant. To counter these existing hierarchies, experiential knowledge needed not only to be authorized in formal documents, a rich variation of personal recovery narratives on all layers of the organization showcased. E.g., posters that portrayed professionals with lived experiences were largely printed and exposed in the participating organizations, thereby narrating a diversity of recovery stories of professionals with lived experiences [illustration 2].

Illustration 2. *Posters exposition in organization 2*

In some organizations, this initially led to a lack of response. Eventually in one of the organizations, it not only led to silence and ignorance, it also evoked counter-responses from some clinicians claiming that the posters were self-indulging and too much exposure, and therefore regarded as unprofessional. This influenced the sense of safety on both sides: on the one hand, some clinicians seemed intimidated by the poster's actions, while on the other hand professionals with lived experience felt devalued.

"In the end, our head reached out, by preventing the removal of the posters and stating that apparently mental healthcare organizations are not completely prepared to deal with this confrontation" (professional, organization 2).

Another challenge faced was creating volume and allocating sufficient resources: only a small percentage of the established professionals came to the fore with their lived experiences. Even though all involved executives aimed to position experiential knowledge in their organization as a complementary resource, this apparently was not easily accomplished. Some professionals started doubting and needed additional support and resources, such as coaching.

"We need this kind of expertise throughout the entire organization, so not only in the provision of care, but also a policymaker, a lived experience advisor and in all other roles you could think of" (executives organizations 3, 4).

After differentiating the input of experiential knowledge in varying roles in care service provision, management, and policy, it appeared sometimes difficult to assess the level of competence and functioning in those using experiential knowledge. Subsequently, only specific lived experience practitioners were financially covered by Dutch healthcare regulations, which led to discussions and polarization. Some organizations, however, received local funding from the government which was less restrictive and supported all types and levels of professionals. An adequate embedment of peer workers and professionals with lived experiences in the organization was part of the challenge, while specifically claiming 'discretionary space'. There was an ongoing overall need to inform colleagues throughout the organization, e.g. about the desirable conditions.

"We questioned whether peer workers should operate solely or as part of a team. We like to use the metaphor of an orchestra to refer to the latter." (organization 3).

One of the most prominent challenges was the policy implementation by the concerned management. This required more effort and time than expected and even though some of the organizations seemed ahead, they sometimes backlashed due to personnel changes. Some managers were hesitant towards the positioning and professionalization or limited informed. Especially in larger organizations, there were difficulties to communicate and involving all layers, including middle management.

'You can't expect professionals to follow novel policy from a paper, and yet, we need to work both top-down and bottom-up when it comes to this implementation process' (organization 1).

Concrete plans on the team level allowed the organizations to work with experiential knowledge firmly on all layers of the organization. Inviting people to share their lived experiences facilitated a conditional safe space to talk about charged topics, but also led to discussions about the extent to which one should strive for openness. Sharing lived experiences with mental illness or addiction was easily associated with being 'non-professional'. Some organizations incorporated 'reflection time' in their daily team routine to pay attention to the lived experience perspective. Ultimately the goal was to create a culture in which experiential knowledge was recognized and appreciated.

At first, it seemed that there was little investment necessary for established professionals (nurses, and social workers) to be able to work with this type of knowledge. However, the process of harnessing experiential knowledge, its emotional labor, and (political) actions, required time and resources in terms of support and training. Again concrete actions and experiences were key to fostering a learning process throughout the organizations, both for professionals with experiential knowledge and the ones without such expertise.

c) Professionalisation

Investment in ongoing professionalization and formalization of experiential knowledge was considered relevant since merely "having lived experiences" was not sufficient in the complex context of these mental health organizations. Lived experienced practitioners could be exposed to heavy duties on the one hand, while on the other hand, the organization was not able to receive financial compensation for non-trained lived

experienced practitioners. Cooperating with traditional professionals was beneficial in this regard. Yet, this also led easily to interprofessional tensions and seemingly conflicted with the intention of working with lived experiences.

To legitimize the use of lived experiences as a valid source of knowledge by established mental health professionals, such as social workers, nurses, psychologists, and psychiatrists, the process of professionalization recycled in different dialogues both bottom-up and top-down between the concerned professionals, lived experience practitioners, policymakers, executives and client representatives. The dialogues were held in multidisciplinary teams and management teams, whereby stakeholders navigated how to make more space for experiential knowledge and how to further professionalization. This resulted in a few professionals with lived experiences, acting as 'ambassadors' and fulfilling a social changemaker role in their organization. Together with managers and other colleagues, they made efforts to bridge the so-called knowledge gap.

"It might be somewhat awkward, we can handle almost anything but when it comes to personal topics, there seems to be a knowledge gap among professionals" (organization 2).

All organisations searched for creative ways to improve the expertise, skills, and competence level of their entire workforce. They decided to structurally invest in training and peer supervision for professionals, while some also continue to work with voluntary peer support workers. This led to challenging discussions in the organisation: what is the necessity of training and does training improve the work or, conversely counterproductive leading to alienation and distancing from experiences? [illustration 3]

Illustration 3. '*A bag full of lived experiences' to promote the dialogue in teams*

"We decided to organize a seminar with two external experts who claimed that training is not needed to use one's lived experiences. This has puzzled us, but eventually, we concluded that professionalisation does require training" (statement steering group, 2021).

The organisations profited in some regards from the standard and guidelines of the Dutch novel quality system which was released in 2022 and initiated by the professional body of lived experience practitioners and the Dutch Ministry of Health, Welfare, and Sport.

It consisted of a generic module, national register, quality standard, and national learning plan on six education levels. This facilitated a further implementation of experiential knowledge. Yet, all directors and managers were also wary of formalisation.

"The most important realization I have had is that installing a formal structure might not lead to any desired result. We have been struggling with production and outcome pressures, struggling to connect to the reason why we are here. When peer workers came to the fore with critical questions and got supported by new structures and procedures, we also created opposition. We need to return to in-depth talking and dialogues about what we mean with inclusion, anti-stigma, recovery, and such before it will lead to instrumentalization" (organisation 2).

Altogether the need for a discretionary space and professional autonomy commonly promoted by the peer workforce became partially part of the organisational structures. For all organisations, the way forward was an emphasis on experiential knowledge as a valid source to draw from, by different actors and in different contexts.

Originality

This study describes the issues faced when implementing experiential knowledge in mental health and addiction organizations. The first identified theme underscores that, even though lived experience practitioners are part of the workforce, a broader implementation of experiential knowledge generates new issues in the positioning of lived experience practitioners within the organization. Findings elucidate that a substantive part of the workforce in mental health and addiction care is familiar with mental distress and trauma, yet only a small percentage makes explicit use of it. This might reflect the unease of the majority, who have insufficient training in this area and feel not mandated to work with this potential. As with all transformations, not only ideological arguments but also concrete actions, human resources management, and support were vital (second theme).

Support from executives and management was indispensable given the unfamiliarity and sometimes unpopularity of voicing lived experiences and established power relationships. Apart from the positioning and resources, it appeared to be crucial to keep an eye on the underlying intentions and motivation to prevent ending up in a process of bureaucratization and technical operation (Aadam & Petrakis, 2020). The implementation required a proper balance between regulations, measurements, formalization, and management on the one hand as well as meaning-making, motivation, and emotion-work on the other hand. This is in line with literature on change management and implementation strategies in general (Argyris & Schön, 1978), and the implementation of new programs within mental health care in particular (Weidema *et al.,* 2012, 2015).

Our study also emphasizes the importance of using nonverbal methods as part of the learning process. We have described how artwork collaboratively made by people with lived experiences and exhibited within public spaces stimulated dialogues on the nature and value of lived experiences. Art is helpful because it can reveal the unsayable; the pain, shame, and stigma that is hard to put into words. Art literally expresses the lived experiences in all its rawness, invites people to interpret and engage in what they see and

experience, and appeals to emotions. To bridge different perspectives, several arts-based methods were explored. Artworks can function as 'boundary objects' to stimulate the dialogue between those who are seen, and those who remain unseen, as well as holding these paradoxes (Groot & Abma, 2021). As the authors point out: 'A successful boundary object evokes emotions among those who created the objects and those encountering these objects. It personally moves people and creates an impulse for change and connects different life worlds. The more provocative the object, the more people feel triggered to foster change.' (Groot & Abma, 2021). An investment in a cultural change using art appeared to be helpful to go beyond the rational and touch upon the affective dimensions of change.

Practical implications

To address the variety of factors relevant to the implementation of experiential knowledge in mental health and addiction care, we offer a series of recommendations meant to guide executives, managers, and policymakers.

- Start with a mission and vision: acknowledge experiential knowledge as a unique and valid source of knowledge that should be visible in the organisation through artworks to foster dialogue and available for every service user.
- Identify the (potential) value of lived experiences in the teams.
- Stimulate all mental health professionals to be more open about their lived experiences and stimulate the dialogue between service users, all types of professionals, and other staff.
- Facilitate peer support and recovery-oriented and trauma-informed/sensitive environments in and outside the organisation.
- Educate and invest in experiential knowledge on all levels (policy, human resources management, clinical practice, outpatient services).
- Include lived experience practitioners in the Board of Directors and the Supervisory Board.

Limitations

This study is based on a qualitative analysis and describes the organizational perspective during a further implementation of experiential knowledge. The participating mental health and addiction care services were in the process of transformation to work in a more relational way supporting personal recovery. It's uncertain if the results of this study can be generalized or transferred to other countries and/or more traditional contexts. However, the insights may hold resonance and be partially transferable to related contexts.

Conclusions

The relevance of working with lived experiences is acknowledged in mental health and addiction care, but it requires implementation work to weave this source of knowledge into the organization. This includes mission and vision statements substantiated with ideological arguments on the surplus value of experiential expertise, but most of all this requires an action-oriented strategy wherein all actors involved are engaged in a mutual learning and reflection process.

Thus, it entails more than just a technical operation and includes the emotional labor of highly motivated executives to promote a culture of openness and overcome stigmatization amongst colleagues, investing in volume, resources, and training without losing the initial intention to work with experiential knowledge.

Creating an open and safe working environment, and further professionalization and creativity were all relevant for the integration of experiential knowledge as a valid source in the concerned organizations.

Acknowledgements

We are very grateful to the members of the advisory board for commenting on this article. We also thank the PEPPER consortium and Nicky van Dam for the pictures.

References

Aadam, B. & Petrakis, M. (2020). Ethics, Values, and Recovery in Mental Health Social Work Practice. *Mental Health and Social Work,* pp. 23-43.

Argyris, C. & Schön, D. (1978). *Organizational learning: A theory of action perspective.* MA: Addison-Wesley: Reading.

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. T. (2019). *Participatory research for health and social well-being.* Cham: Springer International Publishing.

Abma, T. A., & Stake, R. E. (2014). Science of the particular: An advocacy of naturalistic case study in health research. *Qualitative Health Research, 24*(8), pp. 1150–1161.

Baillergeau, E. & Duyvendak, J.W. (2016). Experiential knowledge as a resource for coping with uncertainty: evidence and examples from the Netherlands. *Health, Risk and Society, 18*(7–8), pp. 407–426.

Banks, S. & Brydon-Miller, M. (2018). *Ethics in Participatory Research for Health and Social Well-being: Cases and Commentaries.* Abingdon: Routledge.

Beresford, P., & Brosnan, L. (2021). Subjectivity, citizenship and mental health: UK service user perspectives. In: *Mind, State and Society: Social History of Psychiatry and Mental Health in Britain 1960–2010,* pp. 118-27.

Boertien, D. & van Bakel, M. (2012). *Handreiking voor de inzet van ervaringsdeskundigheid vanuit de ggz.* Utrecht: Trimbos.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology Virginia. *Qualitative Research in Psychology, 887,* pp. 77–101.

Casey, H. (2021). *Making A Difference : Service User and carer involvement in Social Work Education – a mixed methods approach within a participatory paradigm*. [Doctoral dissertation]. Durham University

Castro, E.M. (2018). *Patient participation and empowerment The involvement of experts by experience in hospitals.* [Doctoral dissertation]. Leuven: KU Leuven.

Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2019). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory & Health*, *17*, pp. 307-330.

Davidson, L., O'Connell, M., Tondora, J., Styron, T., & Kangas, K. (2006). The top ten concerns about recovery encountered in mental health system transformation. *Psychiatric services, 57*(5), pp. 640-645.

Groot, B. & Abma, T. (2021). Boundary objects: Engaging and bridging needs of people in participatory research by arts-based methods. *International Journal of Environmental Research and Public Health, 18*(15). pp. 7903.

Grundman, S.H., Edri, N. & Stanger Elran, R. (2020). From lived experience to experiential knowledge: a working model. *Mental Health and Social Inclusion, 25*(1), pp. 23–31.

Roennfeldt, H. & Byrne, L. (2020). How much "lived experience" is enough? Understanding mental health lived experience work from a management perspective. *Australian Health Review, 44*(6), pp. 898–903.

Saks, M. (2020). *Support workers and the health professions in international perspective. The invisible providers of health care.* Policy Press.

Van Haaster, H., Wilken, J. P., Karbouniaris, S. & Hidajattoellah, D. (2009). *Kaderdocument ervaringsdeskundigheid*. Utrecht: Landelijke Denktank Opleidingen Overleg Ervaringsdeskundigheid.

Van Os, J., van Delden, J. J. M. & Boevink, W. (2021). De stem van de patiënt in de psychiatrie: niet gehoord, cocreatie, coöptatie of parallelle organisatie?. *Tijdschrift voor Psychiatrie,* (2021/10), pp. 727-730.

Weerman, A., De Jong, K., Karbouniaris, S., Overbeek, F., Van Loon, E. & Van der Lubben, P. (2019). *Professioneel inzetten van ervaringsdeskundigheid.* Amsterdam: Boom.

Weerman, A., van Loon, E., van der Lubben, P., Overbeek, F. & Steen, R. (2019). Bewegingen in ervaringsdeskundigheid. *Participatie & Herstel, 1,* pp. 25–35.

Weidema, F. C., Molewijk, A. C., Widdershoven, G. A. M. & Abma, T. A. (2012). Enacting ethics: Bottom-up involvement in implementing moral case deliberation. *Health Care Analysis, 20,* pp. 1-19.

Weidema, F. C., Molewijk, A. C., Kamsteeg, F., & Widdershoven, G. A. (2015). Managers' views on and experiences with moral case deliberation in nursing teams. *Journal of Nursing Management, 23*(8), pp. 1067-1075.

Wigmore, B. & Stanford, M. (2017). Two Way Prayer: A lost tool for practicing the 11th Step. *Alcoholism Treatment Quarterly, 35*(1), pp. 71–82.

World Health Organization (2015). *The European Mental Health Action Plan 2013-2020*. Available at: http://www.euro.who.int/pubrequest.

World Health Organization (2022). *World mental health report: Transforming mental health for all.* Available at: https://www.who.int/publications/i/item/9789240049338.

Zerubavel, N. & Wright, M.O.D. (2012). The dilemma of the wounded healer. *Psychotherapy, 49*(4), pp. 482–491.

Chapter 7

General discussion

General discussion

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.

References

Abma, T. (2022). Patiëntparticipatie in een academisch ziekenhuis. *Waardenwerk, 90-91*(12).

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J. & Wright, M. T. (2019). *Participatory research for health and social well-being.* Cham: Springer International Publishing.

Beresford, P., & Brosnan, L. (2021) Subjectivity, citizenship and mental health: UK service user perspectives. Mind, State and Society: Social History of Psychiatry and Mental Health in Britain 1960–2010, pp. 118-127.

Blank, A., Finlay, L. & Prior, S. (2016). The lived experience of people with mental health and substance misuse problems: Dimensions of belonging. *British Journal of Occupational Therapy, 79*(7), pp. 434–441.

Borkman, T. (1976). Experiential Knowledge: A analysis of self-help groups. *Social Service Review, 50*(3), pp. 445–456.

Boumans, J. (2016). *Naar het hart van empowerment. Een onderzoek naar de grondslagen van empowerment van kwetsbare groepen.* Utrecht: Trimbos instituut.

Boumans, J., Kroon, H. & van der Hoek, B. (2023). *Ggz uit de knel.* Utrecht: Trimbos instituut.

Brugmans, J. (2020). *Revitalising disclosure.* [Doctoral dissertation]. Erasmus University Rotterdam.

Byrne, L., Roper, C., Happell, B. & Reid-Searl, K. (2019). The stigma of identifying as having a lived experience runs before me: challenges for lived experience roles. *Journal of Mental Health, 28*(3), pp. 260–266.

Caron-Flinterman, J. F., Broerse, J. E. W. & Bunders, J. F. G. (2005). The experiential knowledge of patients: A new resource for biomedical research? *Social Science and Medicine, 60*(11), pp. 2575–2584.

Carson, J. & Hurst, R. (2021). Mental health nursing and recovery: the C-CHIME model. *British Journal of Mental Health Nursing, 10*(2), pp. 1–3.

Castro, E. M. (2018). *Patient participation and empowerment. The involvement of experts by experience in hospitals.* [Doctoral dissertation]. KU Leuven.

Cohen, J. J., Cruess, S. & Davidson, C. (2007). Alliance between society and medicine: the public's stake in medical professionalism. *JAMA, 298*(6), pp. 670-673.

Dansby Olufowote, R. A., Fife, S. T., Schleiden, C. & Whiting, J. B. (2020). How Can I Become More Secure?: A Grounded Theory of Earning Secure Attachment. *Journal of Marital and Family Therapy, 46*(3), pp. 489–506.

Davidson, L., O'Connell, M., Tondora, J., Styron, T. & Kangas, K. (2006). The top ten concerns about recovery encountered in mental health system transformation. *Psychiatric services, 57*(5), pp. 640-645.

Faulkner, A. (2017). Survivor research and Mad Studies: the role and value of experiential knowledge in mental health research. *Disability & Society, 32*(4), pp. 500-520.

Fisher, J. (2017). *Healing the Fragmented Selves of Trauma Survivors: Overcoming Internal Self-Alienation.* Taylor & Francis.

Foucault, M. (1982). The subject and power. *Critical inquiry, 8(*4), pp. 777-795.

Freidson, E. (2001). *Professionalism, the third logic: On the practice of knowledge.* University of Chicago press.

Freire, P. (2020). *Pedagogy of the oppressed* (30th ed.). Continuum press.

Fricker, M. (2007). Epistemic Injustice: Power and the Ethics of Knowing. In Epistemic Injustice: *Power and the Ethics of Knowing.* Oxford University Press.

Gerada, C. (2022). Doctors' identity and barriers to seeking care when unwell. T*he British Journal of Psychiatry, 220(*1), pp. 7–9.

Glas, G. (2019). P*erson-centered care in psychiatry: Self-relational, contextual, and normative perspectives.* Routledge.

Habermas, J. (1982). *A reply to my critics.* UK: Macmillan Education.

Herman, J. L. (1997). *Trauma and recovery.* New York: Basic books.

Huber, M. A. & Bouwes, T. (2011). S*amensturing in de Maatschappelijke Opvang. De tegenstelling voorbij.* Utrecht: Movisie

Institute on Trauma and Trauma-Informed Care. (2015). R*etraumatization infographic.* http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html

IZA (2022). *Integraal Zorgakkoord: 'Samenwerken aan gezonde zorg'.* Den Haag: VWS/Dutch Ministry of Health, Welfare and Sport.

Jayawickreme, E., Infurna, F. J., Alajak, K., Blackie, L. E. R., Chopik, W. J., Chung, J. M., Dorfman, A., Fleeson, W., Forgeard, M. J. C., Frazier, P., Furr, R. M., Grossmann, I., Heller, A. S., Laceulle, O. M., Lucas, R. E., Luhmann, M., Luong, G., Meijer, L., McLean, K. C., … Zonneveld, R. (2021). Post-traumatic growth as positive personality change: Challenges, opportunities, and recommendations. *Journal of Personality, 89*(1), pp. 145–165.

Karbouniaris, S., Abma, T.A., Wilken, J.P. & Weerman, A. (2020). Use of experiential knowledge by mental health professionals and its contribution to recovery: literature review. *Journal of Recovery in Mental Health, 4*(1), pp. 4-19.

Karbouniaris, S., Boomsma-van Holten, M., Oostindiër, A., Raats, P., Prins-Aardema, C.C., Weerman, A., Wilken, J.P. & Abma, T.A. (2023). Explorations on the use of lived experiences by psychiatrists: facilitators and barriers. *Journal Mental Health and Social Inclusion 27*(1), pp. 66-80.

Karbouniaris, S. van Gaalen, E., Daniëls, D., Weerman, A., Wilken, J.P. & Abma, T.A. *(submitted).* Working with lived experiences in mental health: organisation challenges.

Karbouniaris, S., Weerman, A., Dunnewind, B., Wilken, J.P. & Abma, T.A. (2022). Professionals harnessing experiential knowledge in Dutch mental health settings. *Mental Health and Social Inclusion 26*(1), pp. 75-88.

Karbouniaris, S., Wilken, J. P., Weerman, A., & Abma, T.A. (2022). Experiential Knowledge of Mental Health Professionals. Service Users' Perceptions. *European Journal of Mental Health, 17*(3), pp. 23-37.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J. & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British journal of psychiatry, 199*(6), pp. 445-452.

Leemeijer, A. & Trappenburg, M. (2016). Patient Centered Professionalism? Patient Participation in Dutch Mental Health Professional Frameworks. *Professions & Professionalism, 6*(2), pp.15–19.

Logt, G. J. (2019, December). *Het belangrijkste voor therapeuten lijkt me dat je moet weten hoe je verandering bereikt.* Interview Kees Korrelboom. PsyXpert.

Marsman, A. (2021). *Beyond dis-ease & dis-order* [Doctoral dissertation]. Maastricht University.

Martin, A., Chilton, J., Gothelf, D. & Amsalem, D. (2020). Physician Self-disclosure of Lived Experience Improves Mental Health Attitudes Among Medical Students: A Randomized Study. *Journal of Medical Education and Curricular Development, 7,* 2382120519889352

Martinelli, T. F. (2023). *In search of recovery. Exploring frontiers of drug addiction recovery through people, pathways and policy.* [Doctoral dissertation]. Tilburg University.

Paxton, R. (2020). *White trauma: tracing trauma informed recovery and white supremacy in social work practice.* [Master thesis]. Ryerson University.

Poole, J. M., Jivraj, T., Arslanian, A., Bellows, K., Chiasson, S., Hakimy, H., ... & Reid, J. (2012). Sanism,'mental health', and social work/education: A review and call to action. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice, 1.*

Procknow, G. (2017). Silence or sanism: A review of the dearth of discussions on mental illness in adult education. *New Horizons in Adult Education and Human Resource Development, 29*(2), pp. 4-24.

Psychopathology Committee of the Group for the Advanced of Psychiatry. (2001). Reexamination of Therapist Self-Disclosure. *Psychiatric Services, 52*(11), pp. 1489–1493.

Ralston, A. S. G. (2019). *Philosophy in psychiatric practice.* [Doctoral dissertation]. Vrije Universiteit Amsterdam.

Rose, N. (1998). Living dangerously: risk-thinking and risk management in mental health care. *Mental Health Care, 1*(8), pp. 263—266.

Rouse, J. (1986). Merleau-Ponty and the Existential Conception of Science. *Synthese, 66*(2), pp. 249-271.

Saks, M. (2020). *Support workers and the health professions in international perspective. The invisible providers of health care*. Policy Press.

Stockmann, T., Wood, L., Enache, G., Withers, F., Gavaghan, L. & Razzaque, R. (2019). Peer-supported Open Dialogue: a thematic analysis of trainee perspectives on the approach and training. *Journal of Mental Health, 28*(3), pp. 312–318.

Stratford, A. C., Halpin, M., Phillips, K., Skerritt, F., Beales, A., Cheng, V., ... & Davidson, L. (2019). The growth of peer support: an international charter. *Journal of Mental Health, 28*(6), pp. 627-632.

Stuyver, D. (2022, March). *Ook jonge artsen zijn bevlogen, maar hun baan bepaalt niet hun identiteit.* Volkskrant.

Timmer, A. H. (2009). *Raakt het u? Herstel en ervaringsdeskundigheid in de ggz.* Groningen: Hanzehogeschool Groningen/Lectoraat Rehabilitatie.

Tonkens, E. (2021). De meeste zorgverleners deugen: Over botsende logica's in de zorg. *Professionaliteit in de zorg: Reflecteren op je professie*, pp. 97-105.

Twombly, J. H. & Schwartz, R. C. (2008). The integration of the internal family systems model and EMDR. *Healing the heart of trauma and dissociation with EMDR and ego state therapy,* pp. 295-311.

Van der Kolk, B. (2014). *The body keeps the score: mind, brain and body in the transformation of trauma.* Penguin Psychology.

Van Minnen, A., Hendriks, L., Kleine, R. de, Hendriks, G.-J., Verhagen, M. & de Jongh, A. (2018). Therapist rotation: a novel approach for implementation of trauma-focused treatment in post-traumatic stress disorder. *European Journal of Psychotraumatology, 9*(1), 1492836.

Van Os, J., van Delden, J. J. M. & Boevink, W. (2021). De stem van de patiënt in de psychiatrie: niet gehoord, cocreatie, coöptatie of parallelle organisatie? *Tijdschrift voor Psychiatrie,* (2021/10), pp. 727-730.

Van Os, J. & Gülöksüz, S. (2022). Schizophrenia as a symptom of psychiatry's reluctance to enter the moral era of medicine. *Schizophrenia Research, 242,* pp. 138–140.

Vinkers, C.H., Kuzminskaite, E., Lamers, F., Giltay, E. J. & Penninx, B. W. J. H. (2021). An integrated approach to understand biological stress system dysregulation across depressive and anxiety disorders. *Journal of Affective Disorders, 283,* pp. 139–146.

Voronka, J. (2015). *Troubling inclusion: The politics of peer work and people with lived experience in mental health interventions.* University of Toronto (Canada).

VvEd, Phrenos, Trimbos, & Akwa GGZ. (2022). *Generieke module ervaringsdeskundigheid.* Utrecht: Kenniscentrum Phrenos.

Wallin, J. W. (2007). *Attachment in psychotherapy.* The Guildford Press.

Weerman, A. (2016). *Ervaringsdeskundige zorg- en dienstverleners. Stigma, verslaving & existentiële transformatie.* [Doctoral dissertation]. Vrije Universiteit Amsterdam.

Wilken, J.P. (2010). *Recovering care: A contribution to a theory and practice of good care.* [Doctoral dissertation] Amsterdam: SWP.

Yalom, I. D. (2002). *The gift of therapy: An open letter to a new generation of therapists and their patients.* New York, NY, US: HarperCollins Publishers.

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.

Samenvatting

(Dutch summary)

Introductie

De moderne geestelijke gezondheidszorg wordt geconfronteerd met uitdagingen terwijl zij transformeert naar een herstelgerichte praktijk, waarbij steeds meer ervaringskennis professioneel ingezet wordt.

De integratie van ervaringskennis en ervaringsdeskundigheid is vooral problematisch vanwege de onderwaardering van ervaringskennis in het professionele domein en het voortbestaan van sterke hiërarchische en medisch georiënteerde institutionele structuren. Dit belemmert een verdere transformatie van de moderne geestelijke gezondheidszorg. Om die reden was dit onderzoek gericht op het positioneren van ervaringskennis, het waarderen, ontwikkelen en benutten ervan als (hulp)bron voor herstelgerichte zorg en organisatietransformatie.

De hoofdvraag van dit onderzoek luidde: 'wat is de waarde en vernomen impact van de ervaringskennis met psychische ontregeling van professionals en hoe kan de geestelijke gezondheidszorg ervaringskennis integreren?'

De volgende deelvragen kwamen aan bod:

1. Wat kunnen we leren van internationaal onderzoek over professionals die ervaringskennis benutten?
2. Wat is de waarde van ervaringskennis van professionals voor cliënten?
3. Met welke dilemma's en uitdagingen worden professionals in de geestelijke gezondheidszorg (verpleegkundigen, maatschappelijk werkers, geestelijk verzorgers, psychiaters) geconfronteerd wanneer ze persoonlijke ervaringen omzetten in ervaringskennis (inclusief de implicaties voor de professionele identiteit?)
4. Hoe kan ervaringskennis (verder) worden ontwikkeld en geïntegreerd in ggz-organisaties?

Methoden

Dit onderzoek vond plaats bij drie ggz organisaties en één organisatie voor verslavingszorg in Nederland. Uniek aan dit onderzoek was de samenwerking binnen het PEPPER-consortium[v] en de mogelijkheid om met cliënten, professionals, leidinggevenden en bestuurders samen te werken, waardoor meerzijdige perspectieven werden belicht. Ook uniek was dat de onderzoeker zelf ervaringsdeskundige is.

Daartoe verrichtten we een literatuurstudie en een empirische studie bestaande uit casestudies met participatief actieonderzoek, inclusief 'learning communities', diepte-interviews, participatieve observaties, responsieve evaluaties en auto-etnografie.

Bevindingen

Uit het theoretische deel van dit onderzoek blijkt dat de geestelijke gezondheidszorg wereldwijd nog steeds in een transformatie verkeert om de ervaringskennis van traditioneel opgeleide professionals betekenisvol te integreren.

[v] Het PEPPER consortium heeft als doel het gebruik van ervaringskennis en -deskundigheid te bevorderen en te professionaliseren.

Ervaringskennis wordt uiteenlopend geconceptualiseerd en vooralsnog spreken vooral verpleegkundigen en sociaal werkers zich uit over hun eigen ervaringen met psychische problemen. Slechts enkele eerdere onderzoeken hebben het herstel van cliënten onderzocht en wezen op een positieve betekenis, zoals het gevoel erkend en gehoord te worden, het vinden van vertrouwen en motivatie, en het verkrijgen van nieuwe inzichten in herstel en meer hoop.

Het empirische deel van dit onderzoek laat zien dat het gebruik van ervaringskennis verandering teweeg brengt. Ervaringskennis manifesteert zich in een compassievolle client-professional relatie. Cliënten waardeerden en benadrukten de relevantie van een gelijkwaardige relatie, waarin persoonlijke onthullingen ten aanzien van ontregeling en veerkracht van de professional een plek kregen. Daarop volgend stimuleerde dit het herstelproces van cliënten, tot op een existentieel niveau, en door het hervinden van hoop.

Niet verrassend bleek dat de mate van nabijheid in de relatie gebalanceerd en afgestemd te moeten zijn op de behoeften van cliënten en de persoonlijk-professionele werkstijl van de professional. Ongerichte onthullingen en over- betrokkenheid werden genoemd als 'rode vlag' in cliënt-professional relaties.

Verschillende ggz professionals binnen het consortium waren bezig met de integratie van eigen ervaringen in hun professionele rollen. Voor verpleegkundigen, humanistisch verzorgers en sociaal werkers, beïnvloedde dit niet alleen hun persoonlijk-professionele ontwikkeling en hoe zij zich verhouden tot cliënten en collega's, het had ook invloed op hun positie in de organisatie. In het bijzonder beïnvloedde het de beeldvorming waardoor deze professionals zich vaak trots voelden maar soms ook schaamden.

Terwijl het werken met ervaringskennis in sommige gevallen complexe trauma's en ingrijpende vroegkinderlijke ervaringen reactiveerde, lukte het andere professionals schijnbaar natuurlijk om hun eigen disbalans te integreren in hun professionele identiteit.

In tegenstelling tot de eerder genoemde beroepen, bevindt het gebruik van ervaringskennis onder psychiaters zich nog in een premature fase. Naast de overwegingen die alle ggz professionals maken bij het gebruik van ervaringskennis, waren zij ook benieuwd naar de klinische relevantie. Ze waren vooral bevreesd 'niet professioneel te zijn' en veroordeeld te worden door collega's. Door deze overwegingen in een intervisie setting te verkennen, ontdekten zij dat het delen met 'open-minded' collega's verschilt van zelfonthulling zoals geleerd tijdens de opleiding. Dit opende de weg naar het demystificerende, destigmatiserende en humaniserende potentieel van ervaringskennis voor deze groep.

Een verdere implementatie van ervaringskennis in het bestaande zorgaanbod vereist investeringen in het positioneren van ervaringskennis, human resource management en professionalisering. Het onderzoek laat zien dat sociale verandering start vanuit een bottom-up beweging en tegelijkertijd moet worden gefaciliteerd door top-down beleid. Het vereiste dialogische veranderingsstrategieën om alle betrokkenen te motiveren en betrekken in een gezamenlijk leerproces.

Discussie

Op een microniveau maakt relationele ethiek deel uit van de ingrediënten die horen bij het werken met ervaringskennis, net als het traumasensitief werken en een positieve risico-opvatting. Sommige cliënten gaven aan baat te hebben bij de helende en verbindende elementen in de relatie met hun professional en de daaruit volgende verworven gehechtheid.

Professionals (verpleegkundigen, sociaal werkers en humanistisch verzorgers) die hadden besloten om hun eigen ervaringen door te ontwikkelen naar ervaringsdeskundigheid werden geconfronteerd met een balanceeroefening, in die zin dat zij moesten omgaan met instabiliteit en her-stigmatisering door de kwetsbaarheid die omhoog kwam. De meerderheid ervoer echter post traumatische groei.

Voor clinici (psychiaters) bevond het gebruik van ervaringskennis zich nog in een beginfase, zij gebruikten de intervisie om bevorderende en belemmerende factoren te verkennen. Zij moesten zich verhouden tot collega-psychiaters die ernaar streven de zorg gedepersonaliseerd en gestandaardiseerd vorm te geven.

Op meso niveau concluderen we dat politiek kritisch activisme nodig is, en een brede veranderkundige aanpak in de organisatie. De bestaande dreiging van incapsulatie van kennisformalisatie is valide, echter, door discretionaire en reflectieve ruimte te faciliteren, kan ervaringskennis worden gelegitimeerd in plaats van gestandaardiseerd. Hoewel het moeilijk is om de leefwereld logica in een overheersend hiërarchisch discourse te introduceren, zoals dat dominant is in de ggz settingen, zou hier in moeten worden geïnvesteerd, zodat verschillende logica's naast elkaar kunnen bestaan en leiden tot gezamenlijk leren.

Op macro niveau, hebben we besproken dat naast de markt, bureaucratie en professionaliteit, een vierde macht is geïdentificeerd: 'samenwerking'. Deze vierde macht representeert belangrijke sociale en morele waarden, zoals rechtvaardigheid en zelf-ontplooiing. Een professioneel gebruik van ervaringskennis kan daar deel van uitmaken. Ook, kan het leiden tot een humanisering van zorg en kan het de herhalende, soms subtiele, systeem-ongelijkheid zichtbaar maken die ook in herstelgerichte praktijken speelt.

De implementatie van ervaringskennis in bestaande organisaties en systemen zal verdere investering en aandacht vereisen, gezien de complexiteit en contextafhankelijkheid. Het zal moeilijk zijn om de bestaande systemen te reconstrueren. Het huidige veld is steeds meer verdeeld in enerzijds herstelinitiatieven en anderzijds specialistisch aanbod, maar beiden hebben grote behoefte aan (professionele) ervaringskennis en deskundigheid.

Conclusie

Dit onderzoek heeft de relevantie aangetoond van het aanwenden van ervaringskennis door traditionele professionals in de geestelijke gezondheidszorg. Hoewel het gebruik ervan nog steeds minimaal plaatsvindt en organisaties moeite hebben om ervaringsdeskundigheid betekenisvol te integreren, wijzen de beschikbare kwalitatieve gegevens op positieve uitkomsten. Op basis van ons onderzoek wordt de waarde van ervaringskennis gevat in relationele ethiek, praktische en emotionele inzichten, existentiële

transformatie en emancipatorische politiek.
Concluderend heeft ervaringskennis van professionals een empathiserende, normaliserende, humaniserende, demystificerende, destigmatiserende en empowerende impact op de ggz.

Implicaties voor praktijk en onderzoek

Implicaties voor de praktijk betreffen het openen van ruimte voor het aanwenden van ervaringskennis door verschillende betrokkenen. Meer specifiek is er behoefte aan het includeren van ervaringskennis in onderwijs en trainingen. In de praktijk is het noodzakelijk ervaringsdeskundigheid als deel van 'evidence based practice' te benutten.

Ook zijn investeringen in trauma geïnformeerde herstelgerichte zorg van belang. Het aannemen en trainen van professionals met ervaringskennis is essentieel. Organisaties zouden moeten investeren in specifieke acties en open dialogen met verschillende betrokkenen, om veranderingen aan te brengen in het systeem dat het probleem (de scheiding van kennis) heeft gecreëerd.

Voor toekomstig onderzoek, bevelen we aan om ervaringskennis een plek te geven in alle fasen van het onderzoeks- en innovatieproces inclusief benadering en analyse. Toekomstig onderzoek zou specifieker moeten focussen op groepen die zich gereserveerd opstellen over dit thema, waaronder psychologen en psychiaters.

Ook zijn meer inzichten gewenst over wat er nodig is om verdere erkenning van ervaringskennis te verwezenlijken. Samenwerking tussen verschillende soorten professionals in teams zou het gebruik van ervaringskennis kunnen bevorderen en daarom is het vormgeven van gezamenlijk onderzoek en training nodig.

Ten slotte is verder onderzoek naar de impact van trauma en gehechtheid bij professionals met ervaringskennis relevant en hoe zij zich relationeel verhouden tot cliënten. Er is ook onderzoek nodig naar de bijdrage van non-verbale en lichaamsgerichte benaderingen, die specifiek relevant zijn voor degenen die door allerlei vormen van trauma zijn getroffen opdat 'embodied knowledge' kan worden benut.

Biography and Publications

Biography

Simona Karbouniaris was born on the Peloponnese in Greece in 1980 and moved to The Netherlands as a baby. She attended both Dutch and Greek primary schools in the Dutch provinces of Limburg, Brabant and Gelderland. After secondary school, she started studying social work in Nijmegen in 1998. She interrupted her studies to take up residence on the Mastic island of Chios and obtained her yoga teaching degree in Ashtanga-Vinyasa. After finishing her bachelor's degree in 2005, she was offered the position of junior researcher at the Centre for Social Innovation of HU University of Applied Sciences Utrecht.

Simona combined her work as a lecturer and researcher while working as a coordinator at the Ursula Centre for Eating Disorders in 2009 and studied social sciences at the LESI/ University of Humanistic Studies in 2010. She conducted different research projects related to mental health and community support. She started this PhD research in 2019.

Publications (2019-2023)

Karbouniaris, S. van Gaalen, E., Daniëls, D., Weerman, A., Wilken, J.P. & Abma, T.A. *(submitted).* Working with lived experiences in mental health: organisation challenges.

Karbouniaris, S., Boomsma-van Holten, M., Oostindiër, A., Raats, P., Prins-Aardema, C.C., Weerman, A., Wilken, J.P. & Abma, T.A. (2023). Explorations on the use of lived experiences by psychiatrists: facilitators and barriers. *Journal Mental Health and Social Inclusion 27*(1), 66-80.

Karbouniaris, S., Wilken, J. P., Weerman, A., & Abma, T.A. (2022). Experiential Knowledge of Mental Health Professionals. Service Users' Perceptions. *European Journal of Mental Health, 17*(3), 23-37.

Karbouniaris, S., Weerman, A., Dunnewind, B., Wilken, J.P. & Abma, T.A. (2022). Professionals harnessing experiential knowledge in Dutch mental health settings. *Mental Health and Social Inclusion 26*(1), 75-88.

Karbouniaris, S., Abma, T., Wilken, J.P., & Weerman, A. (2020). Use of experiential knowledge by mental health professionals and its contribution to recovery: Literature review. *Journal of Recovery in Mental Health, 4*(1), 4-19.

Not part of this dissertation:

Karbouniaris, S. & van Os, J. (in press). *Trauma begrijpen in 33 vragen.* Amsterdam: Lannoo campus.

Karbouniaris, S. (2023). Living the madness. *British Journal of Social Work 53,* 1916-1918

Boomsma - van Holten, M., Weerman, A., Karbouniaris, S., Van Os, J. (in press). The use of experiential knowledge in the role of a psychiatrist. *Frontiers in psychiatry*

Ten Napel-Schutz, M. C., Karbouniaris, S., Mares, S. H. W., Arntz, A. & Abma, T. A. (2022). Perspectives of underweight people with eating disorders on receiving Imagery Rescripting trauma treatment: a qualitative study of their experiences. *Journal of eating disorders,* 10(1), 188.

Karbouniaris, S. (2021). Fragmented selves: a first person account on trauma and dissociation. *Journal Archives of Psychiatry and Psychotherapy, 23*(3), 7–10.

Karbouniaris, S. & Van Os, J. (2021). Psychiatrists harnessing lived experiences: a risky business? *Psychiatric Times,* https://www.psychiatrictimes.com/view/harnessing-lived-experiences-risky-business.

Karbouniaris, S, Van Dam, N., & Vries, A. de (2021). Ik ga naar mijn werk en laat thuis. *Sozio, 3* (9).

Karbouniaris, S. & Witteveen, E. (2021). De ervaringskennis van de mantelzorger, over de kracht van ervaringsdeskundigheid. In: Witteveen, E., Siteur-Scholten A. & Brandts, M. (red). *Hartenkreten van mantelzorgers. Over de kunst van het samenwerken.* Gompel & Svacina, Antwerpen/ 'S Hertogenbosch.

Karbouniaris, S. & Vries, A. de (2019). De nieuwe zorgprofessional, traumasensitief en ervaringsdeskundig. *PsychoSociaal Digitaal, 12*(2), 12-17.

Weerman, A, Jong, de K., Karbouniaris, S., Overbeek, F., Loon, van E. & Lubbe, van der P. (2019). *Professioneel inzetten van ervaringsdeskundigheid.* Amsterdam: Boom.

Acknowledgements

Acknowledgements

Although this dissertation has been in many ways a personal project demanding seemingly endless hours behind my laptop, it would not have been possible without the support of those involved. I owe them my gratitude. First of all a sincere thank you to my core dream team, consisting of Tineke Abma, Jean Pierre Wilken and Alie Weerman, who have held confidence in me till the end, giving me the space to find and create my path. And thanks as well for the deepening, sharpening discussions and the fruitful collaboration together. Thank you for your guidance.

Furthermore, I would like to cordially thank Jan Sitvast, Dwayne Meijnckens, Dienke Boertien and Tom van Wel for their role and input as members of the advisory board. Thank you for your critical questions and suggestions to improve this research.

Thank you to all members and participants of the PEPPER consortium and especially Angela Melenhorst, Annemarie de Vries, Anna van Lübeck, Ingrid Bogert, Jiska Ouwerkerk, Mieke Biemond, Gerdien Pleysier and Joyce Lamerichs for the collaboration, engagement and willingness. Without you and your colleagues and especially clients, this project would not have been realised.

A special thank you to my dearest PhD buddies Martine Ganzevles, Paulina Sedney, Marieke ten Napel for the enduring support and Bram van Vreeswijk for the inspiring dialogues. Nicky van Dam and Sarah Ebrahem, many thanks for the cooperation!

Many more *critical friends* whom I'd like to thank: Jim van Os, Gustaaf Bos, Jerry Allon, Jeroen Kloet, Chris Nijboer, Erica Brettschneider, Olaf Galisch, Anouk Verhagen, Jeroen Kloet, Marlie van den Berg, Martin Pragt. I am profoundly grateful for all your engagement.

Thank you also to all *members of the PhD group i*nitiated by Leonard van der Kolk. Great to have followed the autoethnographic course together, with many creative writers, in particular my soulmate Alke Haarsma Wisselink.

My dear peers of the *VKT group:* Corinne Bronsink, Janice de Jager, Daniëlle Steentjes Soraya Kromhout, Pauly Ruijpers and Angela van de Luijtgaarden, many thanks for the inspiring meetings about lived experiences rooted in adverse childhood trauma.

Thanks to *my colleagues of University of Applied Sciences Utrecht* for your interest and the provided space to work on this research: Sascha van Gijzel, Will van Genugten, Mariët Brandts, Roy Leunen, Carla van Slagmaat, Gercoline van Beek, Jens-Daniel Berlinicke, Francien Bruggink, Joep Binkhorst, Jacoba Huizenga, Els Overkamp, Jeroen Knevel, Ard Sprinkhuizen, Han Huizenga, Mariël Kanne. We sometimes saw each other less often, but the connection remained.
A sincere thank you to head of the *Centre for Social Innovation* Nico de Vos, manager Dave Kuiper and supervisor Jacqueline van Ham for supporting me all the way. And, I will never forget data-specialists Simone Oostendorp, Dorine Korsten and Agnetha Fruijtier for your 'big-brain activities'. Also, huge thanks to Annemiek Rietbergen, Ellen Plasmeijer and Lydia Koningsveld for all hands on support.

Thanks for the ‘walks and the talks’ afar and nearby with my dearest friends Olaf Stomp, Natalia Ossef, Betsy Hershmann, Annelie van den Dool, Cor-Hilde Smits van Beijeren Bergen- Henegouwen and Björn Smits. Thank you Anita for the weekly yoga sessions that kept me fit. Many thanks for the inspirational dances Jaap Hofstra, Onno Jurgens and Peter Rombouts.

I am also very grateful to my parental body of therapists Martine and Jan, as well as co-therapist Chris for their guidance and the journey together.

A special thank you to my most steadfast friend Hester Blijleven with whom we exchanged children which made it possible to work on my PhD during weekends and outside normal working hours.

Finally, I want to express my gratitude to my family and especially my sisters Anna & Nancy in Greece and Australia. And last but actually my nearest and dearest love Pano and children Mylo & Alexi for having to put up with my seemingly unending study hours.