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

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Chapter 6

Working with lived experiences in mental health: organisation challenges

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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).

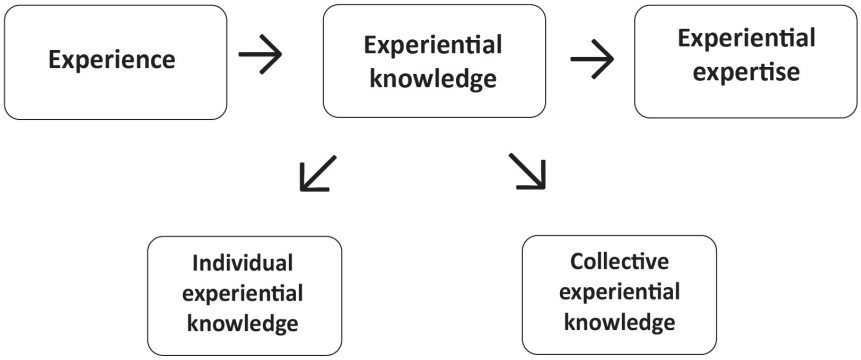

Figure 1. *Process model from experience to experiential expertise (Castro et al., 2019)*

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].

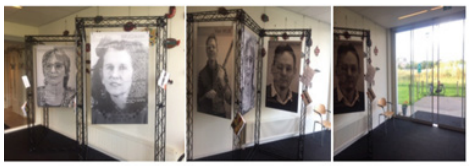

Illustration 2. *Posters exposition in organization 2*

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]

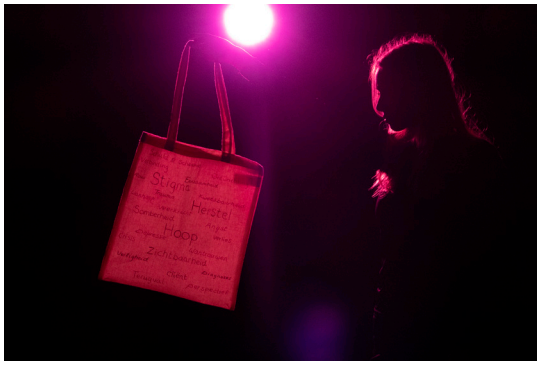

Illustration 3. *'A bag full of lived experiences' to promote the dialogue in teams*

"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.

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