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

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Chapter 3

Experiential knowledge of mental health professionals: Service users' perceptions



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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 *et 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)*

<p>What Hurts?</p> <p>A. System (Policies, procedures, “the way things are done”)</p> <ul style="list-style-type: none"> - 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 <p>B. Relationship (Power, control, subversiveness)</p> <ul style="list-style-type: none"> - 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
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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 where 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 possess. 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 dialogue, 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
<i>The moment I saw her, was the moment I knew we would fit well together.</i>	First contact	User-professional relationship
<i>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.</i>	Recognition and identification	User-professional relationship
<i>It's a way of levelling and I appreciate this authentic contact.</i>	Reciprocity	User-professional relationship
<i>He immediately knew what I meant when I felt immensely isolated as a human, I have felt left out in this community, totally lost.</i>	Lived experiences as an additional source	Learned lessons with distress and resilience
<i>He resonated with the desperateness and hopelessness of that felt sense.</i>	Well attuned use	Learned lessons with distress and resilience
<i>My professional helped me with my considerations to disclose about my depression upon return to my workplace.</i>	Practical insights	Learned lessons with distress and resilience
<i>She is like a source of inspiration to me, the way she navigates life.</i>	Positive role model	Stimulating users' recovery
<i>He helped me in resolving a part of the shame, because he made clear that it happened to me.</i>	Stigma reduction	Stimulating users' recovery
<i>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!</i>	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.

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Author contributions

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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.

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Appendix A

Topic List Interviews
<i>Opening</i>
Aim and estimated duration of the interview
Consent about audio recording
Member check procedures
<i>Introduction</i>
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?
<i>Professional with lived experiences</i>
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?
<i>Recovery</i>
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
<i>Opening</i>
Aim and estimated duration of this focus group
Consent about audio recording
Introduction of all participants
<i>Presentation of findings from interviews</i>
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 coincidentally 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 rigidity 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.

R2

