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Recipients' experiences with care

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The ethical imperative of trauma-sensitive care for electroconvulsive therapy (ECT)

Recipients' experiences with care

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ABSTRACT

Background: The empirical literature on the lived experience of electroconvulsive therapy (ECT) is limited, divergent, and largely focused on the experiences of procedures, (adverse) effects, information provision, or decision-making.

Aims: This study aimed to investigate aspects related to the lived experience and meaning-making of people who have had ECT.

Method: In-depth interviews with 21 women (21–65 years old) were analyzed using interpretative phenomenological analysis (IPA).

Findings: A subgroup of nine participants described more negative experiences with ECT. A common factor for these participants was the experience of trauma that remained under-treated. The superordinate themes identified were a lack of trauma-based and recovery-oriented treatment. The rest of the sample (12) expressed more positive experiences with ECT.

Conclusions: This study suggests that exploring more broadly the impacts of ECT at the long term offers insights that can help design more person-centered services aligned to the needs of the treatment recipients. Educational modules for mental health care staff should include, besides knowledge on the methods' effectiveness, additional evidence about treatment recipients' subjective concerns and the relevance of trauma and recovery-oriented care models.

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Introduction

Electroconvulsive therapy (ECT) can be an effective treatment for individuals who do not respond to psychopharmacological or therapeutic treatment (Lesage et al., 2016; Semkowska, 2021). Community sample studies show a lower remission rate (40%) than clinical trials, (50%) indicating the treatment is effective for some but not all patients (Brus et al., 2017). In Norway, the rate of use is lower than other countries, with an incidence of 2.4, and varies between regions (1.83 and 3.34), and the male-female ratio is 1:2 (Jarosch-von Schweder et al., 2011). ECT is usually administered in specialized ECT wards where specialized psychiatrists have predominant responsibility for the administration of treatment. The Norwegian Mental Health Act allows involuntary administration of pharmaceutical treatment and nutrition, but not ECT, for patients who lack consent capacity. In the lack of specific regulations, legal access to ECT without valid consent is grounded on the general rule of necessity in the Norwegian Penal Code. Norwegian national guidelines were issued in 2017 and are based on the National Institute for Health and Care Excellence (NICE) guidelines (Norwegian Directorate of Health, 2017).

Fear of adverse effects and inaccurate representations remain major impediments (Sienaert, 2016), although decades of research have aimed to improve safety and reduce cognitive adverse effects and stigma. There has been a reduction in the perception of ECT as harmful (Morgan et al., 2013) but the method remains stigmatized and polarized, between proponents of ECT who cite it as a lifesaving or last-resort method, with transient minor adverse effects, and abolitionists who point to the risk of brain damage (Anderson, 2021).

One aspect of the controversy is the inconclusive science around the mechanism(s) of ECT, although new findings are emerging (Mulders et al., 2020), and the extent of adverse effects on cognition, especially memory and the discrepancy between objective measures and subjective reports of memory loss (Semkowska et al., 2023; Vann Jones & McCollum, 2019). While quantitative clinical science tends to report more positive effects and short-lived adverse effects, laments about memory loss and poor information provision are more often reported in narrative and qualitative literature (Kring et al., 2018; Wells et al., 2022).

Although insufficient information and experience of adverse effects tend to result in more negative accounts,

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few studies have explored other factors. Researchers have underlined the need for more qualitative studies of lived experience and meaning-making (Fisher, 2012; Vann Jones & McCollum, 2019) to articulate an understanding of the treatment's cognitive, emotional and existential impact on selfhood and the practical lived life, especially at long-term. Wells' meta-synthesis identified only two studies exploring themes as power and gender bias in psychiatry (Wells et al., 2021). Moreover, some aspects of lived experience, such as clinical environment, altered sense of self and trauma, continue to be under-researched.

Studies have identified how lack of involvement, person-centered care, and poor therapeutic relationships in the ECT wards negatively impact the sense of self (Ejaredar & Hagen, 2013, 2014; Leslie van Daalen-Smith, 2011), quality of the treatment experience (Wells et al., 2022) and ultimately explain the polarized narratives of ECT (Knight et al., 2017).

None of the studies employed an explicit ethical frame to understand experiences with ECT. Furthermore, ethical debates have mostly focused on issues of informed consent or/involuntary treatment and have been informed by principle ethics (Blease, 2013; Surya et al., 2019). Qualitative insight in general, and especially phenomenological insights into ECT's effects on selfhood, have been peripheral if not absent in these ethical debates (Seniuk, 2018). In a care ethics perspective, which emphasizes relationships, context and actual experience, good care is defined by the alignment between patient needs and health care (Voskes et al., 2014). The available literature describes a lack of systematic knowledge on different aspects of lived experience and a lack of alignment from health care services toward ECT recipients' concerns (Coman, 2022; Kring et al., 2018; Wells et al., 2021). This evidence corresponds with reports from mental health care staff describing uncertain roles, lack of training and danger of performing care as a mechanical task (Lonergan et al., 2021).

Earlier calls to improve the care in ECT have referred mostly to involving family or relevant ones in treatment (Coffey & Coffey, 2016) but few studies have addressed how the clinical environment and care models influence the lived experience of ECT. Lack of insights in these topics is problematic in a time when ethical standards in psychiatric health care require lived experience insights to be integrated in the evidence base, and inform and reform services (Wells et al., 2022). Trauma-informed treatment and recovery-oriented care, increasingly promoted in psychiatric research and practice, aim to increase recipient autonomy by including insights from individuals' lived experience, focus on personal recovery rather than only clinical improvements and prevent re-traumatization in psychiatric care settings (Sweeney et al., 2018; Sweeney & Taggart, 2018). Although some of these elements are structurally built into psychiatry, the biomedical model of mental illness—often characterized by strong paternalistic caring styles—is still a prevailing care model. In Norway, trauma-informed care seems to be more broadly implemented in child and youth institutional care, schools and forensic psychiatry (Aas et al., 2019), psychological specialized services for traumatized

refuges (Opaas et al., 2020). The scant knowledge about implementation in inpatient adult psychiatry seems to be symptomatic of a European research lag on the topic, as most studies come from the United States or Australia (Vincenti et al., 2022).

The aim of this study was to explore experiences with ECT in the context of care settings and their influence on recipients' experiences.

Method

Data collection

An advertisement describing the study and asking for participants (18–66 years old) with various experience with ECT, was posted on the websites and social media channels of the Norwegian Institute of Health and Society's website and on those of a prominent national mental health users' organization. Sixteen participants contacted the researcher. The researcher also presented the study to the treatment team in three psychiatry departments in one of Norway's largest cities. Seven individuals contacted the researcher or granted permission to be contacted via phone; two participants later decided not to participate.

The aim was to interview participants three to six months after the last ECT to exclude any transitory memory problems. We did not have access to participants' medical records so the number of ECTs and the information participants received was self-reported.

Participants

None of the participants were hospitalized or undergoing ECT at the time of the interview. All participants were White, ethnic Norwegians from different regions of the country. None of the participants received involuntarily ECT; however, three of them received ECT while hospitalized under the Mental health law. Some reported that the seriousness of the condition and lack of response to other treatment led to some of them feeling pressure to undergo ECT but also motivated to try a last resort.

Table 1 Most interviews took place at the university facilities and were conducted between June 2017 and October 2018. Interviews lasted between 45 and 90 min, and were audio recorded and transcribed verbatim. A semi-structured interview guide was used. The interviewer invited participants to share their experiences with ECT procedures, effects, and information provision in relation to consent. After discussing these aspects of their experience, participants were also invited to talk about the personal meanings they ascribed to ECT and care experiences. Only one parent asked to be present in the interview and she supplied at times the participant's account at times.

User involvement

This project included a reference group comprised of two researchers, one psychiatrist, one user with previous experience, and one family member who were involved in discussing the interview guide and findings. The authors are

Table 1. Demographic characteristics of participants.

Characteristic	(n)
Gender	
Male	3
Female	18
Age range (at time of ECT)	18–65
18–19	3
20–30	7
30–40	7
40–50	2
50–60	0
60+	2
Diagnosis	
Unipolar depression	12
Postpartum depression	3
Bipolar disorder	6
Time of treatment	
2000–2010	8
2010–2018	13
Number of courses	
One course	12
Multiple courses	6
Unsure	3
Time since last course	
Within 6 months	3

researchers and not involved in any kind of therapeutic activity. Therefore, a user representative with previous ECT experience was involved in some interviews (13) to supply the interview with an “insider” perspective and make the flow of information more honest and personal (Gillard et al., 2010). However, the user representative did not speak about her own story unless asked (which she seldom was), in order to avoid influencing participants’ responses. The principal investigator (A.C.) conducted the interviews, and the user representative followed up with questions when relevant. A semi-structured interview guide was employed to safeguard any departure from the intended topics and to maintain research integrity. Participants gave their written consent before the interview.

Ethics

The project fell within the remit of health research and was approved by the Regional Ethics Committee for South-East Norway (no. 2017/2208). Participants signed a written consent form. We informed participants that they could talk to a clinical psychologist affiliated with the research institute if they experienced emotional distress after the interview. None of the participants used this service. We also checked for reactions after the interview by asking participants how they experienced retrieving their memories and talking about their experiences. The data were anonymized and stored in the university’s data protection system.

Analysis

The analysis of the data material was based on a phenomenological epistemological approach—more specifically, the interpretative phenomenological analysis (IPA) method.

The lack of sufficient phenomenological insights into the impact of brain-directed treatment on selfhood has been cited as a concern (Seniuk, 2018). Data was coded stepwise

from reading each interview to identifying codes and grouping them into broader meaning units (emergent themes) across interviews. When looking for similarities and divergences, the authors realized the accounts in this study could be classified into two subgroups based on participants’ emotional tone.

We identified a subgroup of twelve participants, who experienced antidepressant effect as stabilized mood, reduced rumination, or even improved reaction to the medication. Six participants reported no adverse effects at all, while the rest reported varying degrees of subjective memory complaints. These experiences made them ponder on the balance of costs and benefits (Coman, 2022). The positive accounts can also reflect this subgroups’ diagnostic profiles with more bipolar disorder diagnosis, post-partum- or depression with psychotic features, which might benefit more from treatment (Brus et al., 2017).

In the other subgroup of nine participants (the focus of this article), the accounts were more negative or critical, and all nine participants had in common the experience of some form of trauma. For eight participants, trauma was triggered by interpersonal events and for one it was triggered by a dramatic event, which affected the experience of ECT more negatively. Three of the participants reported antidepressant effect after ECT while the rest did not recall significant improvement and described adverse effects, especially to memory. While trauma was not an explicit topic in the interview guide, the participants brought it up and we therefore included it in the analysis. At this point, the rest of the interviews were excluded and a more in-depth analysis of the nine participants was conducted. This is more in line with an interpretative phenomenological approach, which centers on analyzing fewer cases to capture the essence of the treatment experience (Smith, 2019).

Main findings

THEME 1: trauma-insensitive care

Lack of trauma mapping

Most participants talked about undisclosed interpersonal traumas which took a long time to uncover; only one case of trauma was triggered by other events. Monica was in her late 30s when she was hospitalized and received ECT after a suicide attempt. Mental health was taboo for her at that time and she had long been coping through denial and physical activity. Her trauma was revealed later:

I think I had the diagnosis of depression until the last ECT when we figured out that it was [PTSD] (...) I remember I had a panic attack in the unit and we figured out that it was PTSD. (Monica, 47)

For many women, their disclosure of the trauma was accidental or occurred over a long period time, as with Christina:

The first time I was hospitalized, they even asked me what I thought was causing my distress, and I remember it was a resident, and I even said it but I put it nicely because I never

talked about it—I didn't have the language for it. (Christina, 37)

Both Christina and Monica preferred in retrospect the therapeutic approach to ECT. While Monica considered ECT's fast effect more potent than therapy at that time, Christina considered ECT as an inadequate treatment, although she acknowledged that ECT can be effective for refractory depression. She considered cognitive therapy as more helpful, as it gave her tools to cope, and trauma therapy as the most adequate treatment.

Maria described an experience of treatment where symptoms were medicated, and she felt pressure to undergo ECT, leading thus to her developing more negative feelings towards ECT: I've dealt with a few heavy symptoms—they call it symptom switch—without attending to the real cause. (Maria, 55)

Lack of understanding dissociation. A majority of women in the study described symptoms of dissociation, manifesting as delusions, voices, or hallucinations, which were understood and medicated as psychotic symptoms. Monica recalls,

I remember they were most interested in whether I heard voices, and I remember being so annoyed—they asked every time if I saw other people, and I thought it was so silly and idiotic (...) and that is why I also didn't want to tell them about the visions I had. They were not going to label me as crazier. (Monica, 47)

Eva had symptoms of anorexia that were also not seen in relation to previous interpersonal trauma. She works in the field of mental health care herself now and can reflect retrospectively on the changing treatment paradigms:

So the memories came back, but I didn't talk about them. They said, "You are here to gain weight, not to talk about traumas." (...) And I had what they understood as delusion—a lot [of thoughts] about the spiritual world—but I see now that it was the trauma (...). But it was just medicated as psychosis and not [seen as] something to talk about, and at that time we didn't talk about the content of psychosis. Today we do. (Eva, 36)

Emilie described the side effects of possibly poorly delivered trauma-informed care that led to dissociation.

"...the psychologist I had seemed very nice and cared about me, but he was very into childhood trauma and kept asking [about it], and I just got worse and worse and started to dissociate. (Emilie, 23)

THEME two: lack of recovery-oriented care

Existential issues following ECT

A few participants articulated some existential concerns. Josephine's sense of self was affected by the serious adverse effects. For Helen, who had experienced early trauma and chronic depression, while ECT alleviated her depressive symptoms, repeated treatment pushed forward existential questions about the nature of the self, treatment, and

depression that she felt health professionals were not aware of or ready to discuss.

(...) what is a human after all, when somebody can push a button and give me a shock and I come out and see things differently? Who am I? Was it all wrong from the beginning? What is happening? I think it's difficult. (Helen, 67)

Poor therapeutic alliances. All participants in this study experienced varying relationships with the ward staff (often more present in their everyday struggles) or their clinician, with whom they had a different power relationship. All participants reported a general lack of being "seen."

In that clinic, I could easily get the feeling of being a difficult patient, like that I wasn't cooperative enough or something—I felt that there. I never felt that from the two other psychiatrists I had—they never communicated that to me, there was no negative thing, [no] not being cooperative enough thing. (Helen, 67)

Emilie also did not experience full engagement in her treatment decision, saying "I feel ECT came out of the blue, the psychiatrist did not really have time for me!" However, she later experienced better care from a different team. Josephine, who experienced serious adverse effects and a great deal of coercive treatment, did not describe good therapeutic relationships:

I wasn't afraid of my co-patients—they were psychotic and could be aggressive, but I was afraid of the health staff because they understood so little. You could see that they had read somewhere that this is how it is, but they didn't manage to see me as a person (...) and the more you said against it, the worse it was. You didn't get far. (Josephine, 29)

Some women—especially those who self-harmed—encountered negative attitudes, and they were seen as manipulative and bothersome. Maria described situations with little containment of negative emotions from health staff:

I struggled a bit with dissociation and psychosis—not so much now because I can tackle it better now. But that is when I think one needs some calmness and care that this isn't so dangerous. Okay, if you lose it, it's not the end of the world if somebody stands by your side quietly and tolerates it, tolerates the whole me—not just hurries to reduce these dangerous symptoms but "meets" them (...). Of course, sometimes it escalates, so it is okay to take some calming meds for a while, but not like a permanent medication. (Maria, 55)

Feeling overmedicated

Many women in this study were prescribed more medications concomitantly, which is standard practice, and many participants found the right medication and felt satisfied with its effects. However, many women described receiving more than two antidepressants concomitantly and conveyed side effects, which often were not monitored,

unacknowledged, unmonitored, or accepted passively. Tina stated that she had experienced anxiety and suicidal thoughts after being prescribed Ritalin for ADHD and was therefore put on Cipralex for anxiety. She tried to convey to the health staff that she experienced her thoughts as alien and different than usual.

I felt actually, and I said that all the time in that period, that I did not recognize my own thoughts, my head's own way of working. I told them many times. So I changed the clinician and I got a new medical team that concluded I took too many medications that were not the right ones, and too high doses and that it looked like adverse effects. (...) The improvement came later. (Tina, 28)

Emilie also described complicated pharmaceutical treatment, little validation, and hegemonic relationships. Her mother, who was present in the interview, recalls:

The chief doctor that took over removed all the medications, and he is the only one who concluded in the medical record, thank God, that she had gotten worse from the medications and removed all of them. (...) Only one year later, a young training physician thought they should take some blood tests and uncovered that she has two gene mutations that make her body process meds differently. (Emilie's mother)

Hospital stay as containment. Many women talked of a desire for a more modern form of psychiatry where care has a broader target than just the sick self and could include physical exercise or daily activities that foster meaning-making, coping, and a healthy sense of self. The poor facilities, from bed allocations to interior, and psychological climate made participants experience the hospital more as a place for containment rather than recovery and growth.

I work in the field [of mental health] now and I see that we think differently today. Had it been today, I wouldn't have been hospitalized for so long—two and a half years. I lost much of my school time. (Eva, 36)

I wasn't allowed to listen to music, which is my biggest passion; it was supposed to be good for me to be isolated in a room without the possibility to get fresh air (...), not to have any impressions, to be isolated? (Josefine, 29)

Few participants articulated that the treatment provided them with coping skills, emotional regulation, or stabilization strategies.

Lack of preventive psychosocial interventions. Some women expressed how they would have liked the option of alternative treatments that may prevent acute episodes and invasive treatments like ECT in an acute psychiatric setting.

Alternatives such as respite houses would protect family, who may find the situation burdensome and would relieve the sufferers from stigma and guilt.

I wish that in such a situation, for example, there was medication-free treatment. It doesn't have to be something very structured, but a setting one can go to, where you don't have to take lithium or ECT but can just get some simple help for a while. (...) You can get very lonely in such a situation because

you're unable to socialize—and then trying to protect your loved ones from the most negative parts, it gets very lonely. (Helen, 67)

Discussion

For the participants in this study, experiences of ECT were characterized by a sense of receiving a biomedical treatment inadequate for their complaints. This finding resonates with evidence about cases of overtreatment or undertreatment, when patients with mild depression for which ECT is not a strong indication, receive ECT, while younger patients with clearer indication may be undertreated and deprived of adequate treatment (Nordanskog et al., 2015). The first superordinate theme describes a lack of specific trauma-informed treatment. One participant explicitly characterized ECT as traumatic due to involuntary treatment and serious adverse effects that impacted her selfhood. The rest of the participants did not explicitly describe ECT using terms that previous studies have reported, such as “barbaric” (Orr & O'Connor, 2005) but as an experience that they would rather not have had. All the participants in this study's second subgroup experienced interpersonal trauma that contributed to their mental stress, but they experienced poor trauma mapping and possibly delayed trauma disclosure. This finding resonates with evidence that health staff often do not ask about trauma and feel inadequately trained or supported to respond to trauma disclosure (Hepworth & McGowan, 2013). Delayed trauma disclosure might have reduced trust, affected the therapeutic alliances, and deprived staff and patients of empathy, support, and delivery of adequate treatment (Sweeney et al., 2018; Sweeney & Taggart, 2018).

International studies show that even if the integration of trauma care is indicated, only a minority of community and hospital clinicians and mental health nurses are being familiar with applying trauma-informed treatment methods (Brewerton et al., 2019; O'Dwyer et al., 2021). Although more efforts are put into aligning services aligned to evidence-based recommendations and more modular approaches to treatment (Hagen et al., 2019), there is scarce knowledge in the European context (Vincenti et al., 2022), Norway included, about implementation and health professionals' attitudes on trauma-based care in inpatient psychiatry in general. Our findings align to other studies' findings showing how many practices and procedures in inpatient psychiatry are experienced as counter-therapeutic, can do harm and might not follow even a “universal trauma precaution” (Muskett, 2014).

The second main theme, lack of recovery-oriented care conveys an experience of inadequate care, with a major focus on medicating symptoms and clinical improvement rather than on relevant aspects of personal recovery. Some women in this study described how health staff engaged in reducing symptoms but to a lesser extent in exploring the meaning of the symptoms of hearing voices, experiencing delusions, or seeing hallucinations and their relation to early traumatic events. Recent literature supports more positive engagement with these symptoms, as they can explain the

content of voices, delusions, or hallucinatory psychotic symptoms (Berry et al., 2023). Emerging evidence confirms that dissociation is interpreted as psychotic symptoms and medicated with higher doses of antipsychotic and mood stabilizers in individuals with developmental trauma (Bloomfield et al., 2020). Adequate care requires health staff to establish a holding therapeutic environment where intense feelings are contained and processed, not only medicalized (O'Dwyer et al., 2021). A predominant biomedical model of care characterized by a focus on clinical aspects, as symptom reduction and adherence to medication, less engagement from mental health professionals in patients' subjective concerns, including trauma history, leads to instrumental therapeutic relations (Lonergan et al., 2021), less engagement of patients and thus dissatisfaction (Bloomfield et al., 2020). Truly, the quality of encounters with health professionals explains the polarization of accounts. This study's accounts confirm how good encounters with supportive and connected health staff can mediate negative earlier meetings experienced with the system of psychiatric care or even adverse effects of ECT (Knight et al., 2017).

Few participants articulated existential concerns about ECT's effects, but this is a relevant dimension of the treatment; undergoing direct brain interventions like ECT might feel like a failure or may indicate that something is wrong with a person, in a different way than taking medication or psychotherapy (Sadowsky, 2017). This resonates with findings from three previous studies describing how a prevailing biomedical model approach can create "a bystander effect" and silence women's ability to construct their own narratives using other terms than the medical (Ejaredar & Hagen, 2013; Leslie van Daalen-Smith, 2011; Orr & O'Connor, 2005).

The current study supports earlier evidence about the lack of services aligned to the needs of treatment recipients for personalized care and evidence-based treatment (Hagen et al., 2019). Specifically, ECT recipients need updated information, post-treatment assessment and support to deal with grief processes or psychological formulations and meaning-making processes after ECT (Ejaredar & Hagen, 2014; Fisher, 2012; Knight et al., 2017). Moreover, this study's findings resonate with findings from other studies that underscore the importance of psychosocial factors, not only medical, to facilitate recovery, which is in line with the relational recovery approach (Wells et al., 2022).

Implications for practice and research

The current study extends previous studies' recommendation for additional training and educational modules for health staff, on treatments' effectiveness, to include experienced based knowledge about the distresses and concerns patients may experience during and post-ECT (Jackson-Blott et al., 2019; Lonergan et al., 2021). Insights of lived experiences of ECT and work models for health staff are necessary so that health services can design services that are relevant to the need of the patient, support and help individuals manage the impacts of ECT (Coman, 2022; Wells et al., 2022).

Further, this study suggests that additional training to implement trauma-sensitive and person- and recovery-oriented care, might improve the experience of ECT. In general, given major depressive disorder is a common psychiatric condition that arises following trauma, trauma-related treatments should also be considered for these individuals (Bird et al., 2021). Further research needs to investigate health staff's experience with implementing recovery- and trauma-informed care models in ECT care settings.

Strengths and limitations

This is the first Norwegian study of lived experiences of ECT that also included user involvement. To the authors' knowledge, no studies have employed a theoretical ethics frame to understand lived experiences of ECT.

This study has some limitations. Literature indicates how participants recruited through clinics might have more positive accounts (Philpot et al., 2004). Many participants in this study were recruited through university sites and a large mental health organization, yet we might have recruited individuals motivated to tell stories of discontent to a neutral person. Critical accounts tend to be related to longer time since last ECT (Philpot et al., 2004), however the median time-period since last ECT for our sample was 5 years. It is not only the time aspect, but also the experience of trauma, that might explain the more negative accounts. Furthermore, this study only touched briefly on the topic of trauma but more in-depth explorations of trauma might have revealed different perspectives or themes. For example, we did not directly explore whether those participants who did not explicitly use the term "traumatic" about the experience of ECT, experienced "re-victimizing". Lastly, some participants reported also subjective memory complaints which might also have render the experience and attitudes towards ECT increasingly negative. This trend is in line with earlier studies showing better information and preparedness for side effects might mitigate complains about ECT (Coman, 2022; Seniuk, 2018; Wells et al., 2018).

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“re-victimizing” or re-traumatization (Rasmussen, 2015). This study does not include the perspectives of the health-care staff on their experience with employing trauma-informed care in this specific setting. Lastly, this study’s sample has only women of Norwegian ethnicity, so the study is not representative of the population’s diversity. Nevertheless, this underscores the relevance of the gender-specific interventions associated with trauma-informed care that is often not addressed in clinic and research (O’Dwyer et al., 2021).

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