

Exploring The Feasibility of Neurofeedback for Trauma-Affected Refugees – A Qualitative Study

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Abstract

Background

The use of Neurofeedback (NF) to assist individuals in learning to regulate their brain wave activity have shown promising results in reducing symptoms of posttraumatic stress disorder (PSTD). However, few studies have focused on the patient experience with NF and even fewer take on the perspective of refugees. Thus, this study aimed to evaluate the feasibility of an NF-based intervention for trauma-affected refugees focusing on aspects relevant for optimizing the NF experience and clinical practice.

Methods

This qualitative study was a part of an NF feasibility study carried out at CTP, offering 34 trauma-affected refugees 12 sessions of NF. In the qualitative part of the feasibility study, a subsample of eight participants was interviewed. Using in-depth semi-structured interviews, the participants' thoughts and expectations prior to participating in NF treatment as well as their experiences with the treatment after a few training sessions were examined. The analysis was carried out in four steps, using a hermeneutic and phenomenological approach.

Results

The analysis resulted in three main themes: 1) Positivity despite unfulfilled expectations 2) Understanding of the NF treatment 3) Facilitating factors for feasible NF treatment.

Conclusion

The results show that facilitation of successful treatment was challenged by both the participants' misaligned expectations of the treatment outcome as well as their comprehension of the NF equipment, which did not match the actual capabilities. This underlines the importance of clear communication, including the adjustment of participants' expectations regarding what symptoms the NF treatment protocol is designed to treat. Furthermore, the importance of thorough, repetitive, and understandable information about the NF equipment's capabilities was highlighted. Our results demonstrated how the participants found NF to be an acceptable and recommendable method of treatment even though they did not benefit from it. Finally, valuable knowledge regarding factors enhancing the feasibility was discovered, including prioritizing breathing exercises, a spacious NF treatment room and personalization of the NF treatment protocol.

Trial registration:

Background

As a result of armed conflict and persecution, the number of forcibly displaced individuals worldwide is rising and has now reached a record high level. It is estimated by The UN Refugee Agency (UNHCR) that the number has surpassed 80 million at the end of 2020. Approximately 26.3 million of these people are considered refugees (1). The refugee experience is characterized by exposure to multiple stressful events both before, during and after displacement, making trauma-affected refugees susceptible to developing mental health disorders. Indeed, existing evidence shows that mental disorders are highly prevalent in refugees, and post-traumatic stress disorder (PTSD) is one of the most common conditions (2–5).

Over the past years, several systematic reviews have been published, investigating the effect of different forms of pharmacological and/or psychological treatment interventions for trauma-affected refugees (6–11). Some of the interventions were found superior compared to others, however the reviews were all characterised by a limited number of included studies, small sample sizes, high level of statistical heterogeneity, and GRADE-ratings (Grading of Recommendations, Assessment, Development and Evaluations) (12) showing very low to moderate quality. This knowledge of challenges and limitations cast uncertainty on the results and questions the transferability to the population of refugees at the Competence Centre for Transcultural Psychiatry (CTP) characterized by high level of symptom severity, comorbidity, chronicity of illness, long duration of exile and a low level of functioning (6, 7, 13). At CTP, five randomized controlled trials (RCT's) have been carried out during the past 10 years to examine the effectiveness of different forms of treatment for trauma-affected refugees suffering from PTSD. This includes antidepressant medication, psychotherapeutic treatment as well as physiotherapy (13–17). All the previous RCTs have presented significant pre- to post-treatment differences showing small to medium effect sizes. None of the tested interventions have shown superiority in decreasing PTSD symptoms, indicating that treatment at CTP is in fact efficient, but a new more convincing form of treatment is needed. Of great importance of this new and innovative treatment is not only the potential for a bigger effect size, but also the patient's perspective, including thoughts, expectations, experiences receiving the treatment and perceived benefit.

An alternative and non-invasive approach, which has shown promising results with patients suffering from PTSD, is neurofeedback (NF) (18, 19). NF is a subtype of biofeedback intended to help individuals learn how to control their physiological responses by providing them with a continuous real-time report of their biological activity. In NF, the targeted biological parameter is neurological activity and is performed using electroencephalography (EEG) as brainwave measurement (20–22). As illustrated in Figure 1, the brainwave activity is fed back to the individual as an audio-visual signal (e.g., a scenic video with background music), assisting him/her to increase awareness of the process and the feedback loop is created.

Brainwaves are measured in hertz (Hz, cycles per minute) and occur at many different frequencies depending on the state of mind. In NF, electrodes are placed on the scalp and while an EEG is recorded, the participant is presented with visual and auditory contents from a computer monitor. The electrical current from the brain is recorded by the electrodes, and the brain is not exposed to any input electricity. Every time the brainwave activity changes to the desired frequency, it is reflected on the computer monitor, giving the participant an audio-visual signal that serves as a reward. The learning mechanism is believed to be operant conditioning. Through repeated reinforcement, the participant is trained over time to gradually influence and change the dysregulated neurological activity from e.g. being hyper-aroused and alert towards a more relaxed state of mind (23).

NF studies have shown positive clinical effects in reducing PTSD symptoms among patients suffering from PTSD related to combat or childhood trauma (18, 19) as well as among patients suffering from chronic treatment-resistant PTSD (24). However, the evidence for NF treatment for trauma-affected refugees is scarce. Only three peer-reviewed papers investigating NF for trauma-affected refugees have been published so far; two case studies (25, 26) and a pilot study (27) - all carried out at New South Wales Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) in Australia. Even though findings from STARTTS provide preliminary indications that NF is effective in reducing PTSD symptoms, the transferability is challenged by the poor methodological quality (small sample size and lack of randomization) as well as the samples' demographic composition which differ from the population of patients at CTP (13–16). Thus, NF studies with a representative population, larger sample sizes, and ideally a more rigorous methodology are needed. As a step in this direction, the CTP conceived a longitudinal feasibility study, testing NF for trauma-affected refugees. The study contains both a quantitative and a qualitative substudy and in this paper, the qualitative substudy, examining the feasibility of the treatment is presented.

Very little is known about patients' experiences with NF treatment (28–34). To the best of our knowledge, only a few studies with a patient perspective applying a qualitative approach to evaluate NF treatment have been published, and only in one un-published case study the focus was on the refugee patient (35). Thus, this research adds to the literature by shedding light on the experience of NF in a largely un-explored group of patients.

The aim of this qualitative substudy was to evaluate the feasibility of NF with trauma-affected refugees by examining the participants' thoughts and expectations prior to participating in NF treatment, as well as their experience with the treatment after a few training sessions. The main area of focus was the clinical practice of conducting successful NF, including the identification of aspects that might optimise the experience of NF, making it more feasible as well as acceptable to the participants.

Methods

The Neurofeedback intervention

34 participants were included in the NF feasibility study carried out at CTP and they were all offered the NF intervention containing 12 NF training sessions. Every session started off with 2-3 minutes of breathing exercise, focusing on deep breaths and low respiratory rate. The purpose was to calm down the participant before the NF training, but also to instruct and encourage the participants to practice the exercises at home. Afterwards, the training sessions continued with 12-20 minutes of NF training. The protocol for the NF treatment was a replication of the setup of recent NF studies for chronic PTSD (24, 36), designed to help participants decrease the frequencies of brainwave activity which is associated with drowsiness and hyperarousal and in contrast increase the frequencies, which is associated with a calm and relaxed state (23, 24). The treatment commenced in January 2019 and finished in March 2020.

Qualitative design and approach

The study was guided by a qualitative longitudinal design, using a hermeneutic and phenomenological approach (37–40) to investigate the participants' preunderstanding and expectations regarding the NF treatment and their experience with the treatment in two separate interviews, before and during treatment respectively. By doing so, the participants were given the opportunity to express in their own words what aspects of the NF treatment that they found most important and thereby contribute with pivotal information regarding the feasibility. Central to the hermeneutic approach is the preunderstanding, and early in the process the first author wrote down her own preunderstanding, in order to make it explicit and apparent. Inspired by the phenomenological approach, she was in that way able to put aside her own preunderstanding and make room for the interviewee's 'lifeworld'. Afterwards, the researcher combined her own preunderstanding with the new knowledge about the participants' understanding and horizon, resulting in a new understanding or a 'fusion of horizons' (40).

Recruitment of participants

Participants were eligible for the NF feasibility study if they met the following criteria: 18 years or older, refugee or a person who had been family reunified with a refugee, diagnosed with PTSD (ICD-10 diagnosis F43.1) and experienced a psychological trauma in another country than Denmark. Participants were excluded if they had a current abuse of drug or alcohol (F1x.24-F1x.26), were diagnosed with a severe psychotic disorder (F2x) or a manic disorder (F30.1-F31.9). Thus, these criteria were also applicable for the current subsample.

Every participant in the study was considered a possible interview candidate for the qualitative substudy. In total, eight interviewees were purposefully chosen in order to get maximum variation and heterogeneity among the participants and thereby yield the richest data from different participants with diverse cultural backgrounds (41–43). As presented in Table 1, the interviewees represented both genders, aged 40-61, five different countries of origin, hence variations in mother tongue. Out of the eight participants, five needed an interpreter for the interview as well as for the NF training sessions. All the participants, who were invited to participate in the interviews accepted. The first interview participant was designated "P1", the second "P2" etc.

Table 1
Description of participants

Participant	Gender	Age	Country of origin	First language	Interpreter	Completion of interview A	Number of completed NF sessions before interview B
P1	Female	48	Iran	Farsi	No	Yes	-
P2	Male	40	Syria	Arabic	Yes	Yes	3
P3	Male	43	Nigeria	English	No	Yes	7
P4	Female	48	Syria	Arabic	Yes	Yes	3
P5	Female	48	Iraq	Arabic	Yes	Yes	4
P6	Male	45	Iran	Farsi	No	Yes	3
P7	Male	47	Somalia	Somali	Yes	Yes	3
P8	Male	61	Syria	Arabic	Yes	No	12

Interviews

A semi-structured interview method (43) was applied. The participants were invited to two interviews: one before the first NF training sessions (interview A) and one during the treatment course between session three and twelve (interview B). Open questions reflecting the objectives were asked followed by clarifying questions depending on the interviewee's response. Three themes were examined in interview A: 1) thoughts and expectations, 2) acceptability, and 3) reservations and information needs. In interview B, the focus was on the following two themes: 1) satisfaction, and 2) feasibility and accept. Three participants (P2, P6 and P7) decided to withdraw from the quantitative substudy after only three completed NF training sessions. P2 left the study because he believed he could feel an electrical current going through his head during the training sessions, and P7 explained that for him, the NF treatment had resulted in severe nightmares. P6 did not think the first three NF training sessions had helped him, and he was convinced the completion of the remaining training sessions would make no difference. However, P2, P6 and P7 all agreed to take part in interview B. P1 did only participate in interview A and P8 did only participate in interview B. The number of completed NF training sessions before interview B is listed in Table 1. All the interviews were audiotaped and subsequently transcribed verbatim by the first author. Each interview lasted between 25 to 46 minutes and were all collected between February and May 2019 by the first author. All interviews were first translated to Danish, and all quotations have been translated from Danish to English.

Data analysis

Data was analysed by the first author together with one of the other authors (HLA). The analysis was carried out in four steps using a hermeneutic and phenomenological approach formulated by Dahlager and Fredslund (40), based on Gadamer's and Giorgi's philosophies (37–39). In *Figure 2*, the process of analysis is illustrated as well as the resulting four themes from the initial analysis. In order to identify the themes most illustrative for optimization of clinical practice, the data was reanalysed and recombined into new themes.

Findings

The data analysis finally resulted in three main themes capturing the essential aspects of both interview A and B, representing the participants' reflections on the NF: 1) Positivity despite unfulfilled expectations 2) Understanding of the NF treatment 3) Facilitating factors for feasible NF treatment. The themes are closely related and intertwined and at some points overlapping.

Theme 1: Positivity despite unfulfilled expectations

The participants had several explanations and motivators regarding their willingness to participate in the study. All the interviewees expressed hopes and expectations that the treatment method could improve their mental health, and this was the overall reason why they agreed to try NF treatment. Naturally, they all wished that the treatment could bring relief to the symptoms that seemed to bother them the most in their everyday life. What was perceived as the most debilitating symptoms varied across respondents. P4 emphasized flashbacks and P1 pointed out concentration deficits. Both P2 and P6 mentioned their depressive symptoms:

"For instance, I expect and hope that my depressive moments and the thoughts about my past that interfere with my present thinking may get better. Improving this is what I hope and expect from the treatment." (P2, interview A)

Some of the interviewees had wishes that did not concern specific symptoms connected to their PTSD, e.g., P5 who wanted to get rid of her bad habits. When she was asked if there was something, she hoped the treatment to improve, she noted:

"Yes, of course. I have some bad habits that I wish to change. For instance. I always bite my nails. And I'm always looking in my purse. These are the kind of things that I wish to change". (P5, interview A)

An additional example was P7, who struggled with the fact that he very easily got emotionally affected when confronted with violence and torture on TV and the internet. He hoped the treatment could toughen him mentally, in this regard. In addition, many of the participants pointed out the novelty of the NF treatment to be a reason for trying it. In this regard, curiosity was a motivating factor. Words such as "exciting", "interesting", and "mysterious" were used by the participants to describe their reflections about the treatment. P6 expressed his initial thoughts about NF as:

“Mysterious and something new. You know, it makes you happy. A good feeling about it, and maybe it can help me? As you have mentioned, I have nothing to lose. I am taking the maximum dose of antidepressants right now; I cannot take any more medicine. And I have had so many psychotherapy sessions. But now I would like to take the chance.” (P6, interview A)

The quote illustrates the general tendency among the interviewees, that they have tried different types of treatments before NF, without sufficient effect, however. For that reason, they were very eager to get better, sparking a willingness to try anything, as exemplified by P1:

“As I have said, I would like to know more. I know that this treatment is going to help me. And even if it does not help me, at least I have done something. Because not doing anything is worse than doing something.” (P1, interview A)

P1 was convinced she would benefit from the treatment, which gave her a willingness and a drive to participate in the treatment. She thought that doing something about her problems was better than not doing anything.

Despite these promising expectations of the treatment, most of the participants reported in interview B that the NF treatment did not bring them relief of symptoms. The participants were asked if the treatment so far had met their expectations and except P3, all the participants who completed interview B, expressed disappointment regarding the treatment outcome, e.g. P4:

“My expectation was that it would change my mental state. But it hasn’t changed anything.” (P4, interview B)

As stated in the quote, P4 expected her mental state to change, but it did not and thus her expectations were not met. When P8 was asked directly, if the treatment matched his expectation, he declined. P6 explained that he had assumed he would feel an impact from the treatment, but he did not. Even though the participants did not benefit from the treatment, they could all agree on two things: 1) They believed that the treatment could help other trauma-affected patients and 2) They would recommend NF to others. As an example, P7, who expressed positivity and enthusiasm for the treatment program and encouraged the researchers to continue:

“I think it’s a really good program that you have started. I think you should continue the investigation. Maybe it is me, who has so much trauma with me. Maybe others could benefit. It is different how people react and what symptoms they have. “

(P7, interview B)

Even though P7 considered himself too traumatized to benefit from the treatment, he believed others could. The common idea among the participant that NF was recommendable and potentially helpful to others, indicated that even though NF was not a suitable match of treatment for them, the participants

did have a positive view on the conduction of the training sessions and regarded NF as an acceptable form of treatment.

Theme 2: Understanding of the NF treatment

The second theme deals with the participants' understanding of the NF treatment, including their ideas and expectations regarding the level of detail the NF device was capable of measuring. Even though the participants received the same information about NF (oral as well as written), they reported very different interpretations of what they imagined the NF training sessions would involve. P5 believed the NF treatment could treat the dysfunctional brain activity and correct harmful activity of the cells and tissue:

"It affects the activity in the brain and the tissue and cells. It corrects that activity." (P5, interview A)

Similarly, P2 expected the NF equipment to provide information about his brain function in different states of mind:

"To find out how it looks when you are nervous, when you are scared, when you are happy. When you are in different states of minds" (P2, interview A)

When P7 was asked about his expectations of the treatment, he answered that he expected the NF training sessions to entail an examination of how his brain reacts:

"You explained to me, that you are going to examine how my brain reacts. That is how I have understood it." (P7, interview A)

The quote demonstrates how many of the participants expected to get answers to questions about their brain function, and they believed the NF device made it possible for the therapists to reply to these questions in details. P1 expected the NF training sessions to involve her sitting in front of a screen, while the NF therapist investigates her brain:

"... And then he told me, that you sit in front of a screen and that you can see how stressed I am and what is going on in the brain. And I am looking forward to that. Because I really want to know why." (P1, interview A)

P1 expected the NF training to result in her getting information about what happens in her brain and how stressed she was. Like P1, many of the participants were determined to figure out an explanation for their mental illness, and P1 was excited about the NF treatment because she believed it could provide her with the answers she needed. This reflects the common understanding of the capabilities of the NF equipment among the participants, believing the equipment allowed the NF therapist to examine the brain and investigate the functioning and dysfunction.

Theme 3: Facilitating factors for feasible NF treatment

Theme 3 emphasizes how different aspects of the NF treatment appeared to have a pivotal impact on the overall experience of the NF treatment. When the participants were asked what part of the NF treatment

they valued the most, the breathing exercises stood out. All the participants found the exercises very useful, helping them relax and stay calm. P7 explained:

"You have taught me an exercise on how I should breathe. This has actually helped me, and I feel and sense of calmness in my body. To breathe this way calms me. I use this technique and it helps me - some nights if I cannot sleep, I use the breathing exercise, and then I feel calm." (P7, interview B)

As demonstrated in the quote, the participants did not only benefit from the breathing exercises during the training sessions but also afterwards at home, e.g. to help falling asleep. Some of the participants experienced the exercises to be helpful throughout the day when exposed to stressful situations. P2 sometimes felt uncomfortable in school and he used the breathing exercise to calm himself:

"I do that too. And especially I do it when I feel restless and uncomfortable at school. (...) I do it at school and find it really helpful." (P2, interview B)

Thus, to varying extents, the interviewed participants all learned to take home elements from the training sessions and managed to implement them into their everyday life as a coping strategy, helping them to handle their anxiety.

Aside from the breathing exercises, another decisive factor was the physical attributes of the training environment. In the beginning of the study, the NF training sessions took place in a small room (approx. 6-7 sqm) with relatively dim lighting. After a couple of months, the treatment was moved to a bigger and well-lit office space (approx. 20 sqm) overlooking a garden. Without exception, all participants considered the size of the room to have a significant influence on the atmosphere, and when asked directly, they all preferred the new and larger room. P6 did not understand why, but he felt a pressure on his chest when he was in the smaller room:

"Yes, the size of the room. I do not get it, I do not understand what it is. It is like, there is pressure on my heart." (P6, interview B)

In the same way, P4 felt cramped in the small room and found it too dark. It reminded P3 of torture and the larger more spacious office calmed him down. He explained his thoughts using the following words:

"Last time, it was a small room. And then it was like, you remembered the torture. But in the room we are in now... there is more space. It calms me down" (P3, interview B)

This calming effect of the bigger room as well as the breathing exercises illustrated how different components of the NF training sessions affected the participants' state of mind. Another element was the music used as the auditory part of the feedback signal during the NF treatment. P6 was surprised how much this music affected his mood. He suggested the NF participants should be allowed to pick a music genre themselves, in order to make sure the music did not make them uncomfortable or reminded them of something unpleasant. P6 proposed the same procedure when selecting the videos used for the NF training. He emphasized the importance of the therapist knowing details about the participants'

background, in order to adjust the content of the videos to the individual, e.g. someone who had lost a child would not like watching videos of children:

Yes, I would like some better pictures. And more realistic – actually, just as realistic as possible. Nature or something like that. And maybe you should ask the participants about their background, because someone who has lost a child, would not like to have shown pictures of children. I think you need to be specific. You need to be more individual and ask the participants the question: What makes you happy? (P6, interview B)

Similarly, P8 emphasized the importance of choosing the right video to avoid evoking uncomfortable memories and harming the participant. He encouraged the NF therapists to consider what thoughts and feeling the videos could possibly induce for the participant:

Maybe it would be wise to pay attention to the movie clips and pictures, showed during the training sessions. How they can possibly bring back old memories for the patient. You have to choose something that does not harm or create a wound. The therapists ought to consider whether the movie clip will create happiness or grief for the patient. E.g., if I hated the colour red, don't show a picture with red colours." (P8, interview B)

According to the participants, this idea of tailoring the NF treatment for each individual participant would allow the NF therapist to take care of the participants' needs the best possible way.

Discussion

This study aimed to evaluate the feasibility of NF treatment for trauma-affected refugees. It is one of the first to explore the experience of NF using a qualitative research design and the first to take perspective of trauma-affected refugees. From the analysis of the conducted interviews, three illustrative themes regarding optimization of clinical practice appeared. In the first we discovered the participants' expectations of the NF treatment as well as their thoughts of NF as being a relevant and acceptable treatment form to themselves and to others. The second theme demonstrated how the participants' understanding of NF, did not match the capabilities of the equipment. And the third theme presented several elements that seemed important for an overall positive NF treatment experience. These results will be discussed in the following.

Discussion of themes

The participants were all very hopeful and expected key symptoms related to PTSD to improve during the NF treatment. They all had a clear idea of which symptoms they wanted the treatment to ease, some related to their PTSD, and some, non-related. As stated above, hyperarousal was one of the two main symptoms this NF treatment protocol was targeted to reduce and therefore, the participants' hopes and expectations for the treatment attest to a misunderstood comprehension of the treatment. This misunderstanding results in the participants being disappointed in the treatment as their expectations

were not met, emphasizing the importance of adjusting expectations prior to the treatment. This is in line with findings from a meta-analysis about expectations in regards to successful psychotherapy by Constantino et al (44), encouraging therapists to explicitly evaluate the patient's outcome expectations at the beginning of the treatment and respond accordingly, in order to handle and adjust their expectations in the best possible way. Therefore, to prevent disappointment with the treatment outcome, as well as potential withdrawal, we emphasize the importance of the NF candidates receiving clear information about what symptoms this kind of NF treatment is aimed at reducing.

Our results demonstrated how the participants' understanding of the NF method resulted in the participants expecting the NF treatment to provide detailed knowledge about their brain function. However, these expectations did not match the capabilities of the NF device. A possible explanation for this misunderstanding might be the information given to the participants before engaging in the study. Due to the complexity of the subject, the NF researchers decided to adjust the level of detail in the instructions about the NF treatment. This attempt to make the treatment easier to understand resulted in the researchers giving a simple and tangible explanation of the background for the NF treatment, and the level of detail was kept to a minimum. Thus, this brief introduction might inevitably have affected the participants' idea of NF. Their expectations to the NF equipment's capabilities included phrases such as "what is going on in the brain", "examine how my brain reacts" and "want to know why", reflecting a desire to seek an explanation for their mental illness. They expected the electrodes to detect what was physically wrong with their brain and believed that the computer could provide them with a visual understanding of their brain activity, similar to a brain scan. This indicates that the message about health technology and health treatment was not communicated sufficiently by the NF therapists, emphasizing the importance of the participants being well-informed about the equipment capabilities.

Another influencing factor regarding the participants' misunderstanding of the NF equipment capabilities might be the participants' health literacy (HL). WHO defines HL as *"The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health."*(45). Research show that limited HL significantly affects health. Low HL is among other things associated with higher rates of morbidity, more hospitalizations and rehospitalization, poor adherence to medication, riskier health-related behaviour, and premature death, resulting in an overall worse health status (46). Resettled refugees are more vulnerable to have low HL, as they have to navigate a new country, language and culture as well as dealing with resettlement stressors, including uncertainty concerning the safety of relatives, unemployment, poverty, uncertainty about asylum status, and temporary residence as well as perceived stigma (47–49). Owing to displacement as well as a precarious living situation in their home country, many refugees have had a disrupted education (50), hence a standard knowledge base cannot be assumed. Furthermore, it is known that ethnic minorities in Denmark often have different perceptions of illness compared to the majority population (51). E.g. Jinn possessions, evil eye and black magic are used as explanation of mental symptoms among Muslims (52–54). This calls attention to the importance of providing thorough and understandable information about NF to prospective NF candidates. This is in line with a recent paper by Sijbrandij (55), describing that it might require more work informing refugee patients about the pros and

cons of participating in a study, compared to the native population. Similarly, in a paper by Riggs and colleagues (48), discussing how to improve health literacy in refugee populations, it was emphasized that the provision of information given to refugees, ought to be modified. As Riggs and colleagues suggest, this can be done using the *teach-back method*, which is an evidence-based communication strategy, where the health professionals ask the patient to summarize in their own words what has just been explained to them (56). This method can advantageously be used for future NF candidates to ascertain if communication has been successful.

Beyond HL, the perception and interpretation of the provided information may have relied on personal motivation. As noted, some participants were very eager to put their faith in a new intervention, whether based on an extensive anamnesis or the novelty and promising results of NF. Taken together, then, the misunderstood capabilities of the NF equipment may stem from inadequate verbal information, which was in turn potentially perceived and interpreted based on personal motivation, as well as level of HL. As an unavoidable consequence, most of the participants did not achieve what they expected from the treatment, which might have influenced their understanding of NF, as being an insufficient form of treatment, which did not meet their expectations. Thus, clear communication and adjustment of expectations towards the NF capabilities are essential to better the participants' prerequisite for engaging successfully in the treatment.

The results from our study highlighted the participants' reflections of the NF treatment acceptability. In healthcare literature the definition of acceptability vary considerably, however as argued in a review by Sekhon et al, acceptability is an indication of which extent participants receiving a healthcare intervention consider it to be appropriate (57). Our result showed that even though the participants did not find NF beneficial to themselves, they were all under the impression that NF could in fact be helpful to other patients. In addition, the participants would all recommend NF to others. We find these statements to be strong indicators of NF being an acceptable form of treatment. Even though the participants in our study found the intervention acceptable, the majority of the participants did not find NF beneficial, which for some participants resulted in withdrawal from the intervention. This illustrates that acceptability is an essential but not adequate condition for a successful intervention, nevertheless when a intervention is perceived as acceptable, the participants are more likely to comply to the treatment (57–59). However, to increase the number of accomplished training sessions, we argue that besides acceptability there is a need to move focus on factors affecting the feasibility.

Our results shed light on how three aspects of the NF treatment stood out as essential in regards to promoting the feasibility; 1) The breathing exercises, 2) a spacious and bright NF treatment room, and 3) personalized selection of NF stimuli.

1) The breathing exercises were described by the participants as calming and helpful to reduce anxiety during the training session as well as during the day. This was indeed intended, as breathing exercises are an important element in meditation and mindfulness and the calming and relaxing effects of these are described in the literature (60, 61). Moreover, in a study on meditation and neurofeedback,

Ebrandmeyer and colleagues point out similarities between the two therapy forms, as both are mind-body therapies with a calming effect (62). It remains unclear to what extent the NF training in our study contributed to the calming effect of the breathing exercises. However, the relaxing impact of the breathing exercises gave the participants positive associations with the NF treatment, which seemed to improve their chances of persisting with the training and completing the 12 NF sessions.

2) The results in this study demonstrated that the move of location to a bigger and brighter room promoted the feasibility as it generated a nicer atmosphere, perceived to have a calming impact. This is in line with previous research by Currie et al., exploring influencing factors on treatment outcomes when treating trauma survivors with NF (32). Like statements from our participants, Currie and colleagues described how the therapeutic process begins the moment the patient enters the door. The calming atmosphere in the treatment room is the first step in establishing a therapeutic alliance, which is an essential ingredient in successful NF. Our results showed clearly how the bigger office allowed the participants to feel safe and relaxed with the therapist, and thus potentially absorb themselves more in the training.

3) The issue of how to improve the feasibility of NF treatment was addressed by two of the participants, suggesting personalizing the feedback stimuli, i.e. the music and videos. It is known that some participants benefit more from one type of feedback over another (63), and our results show that the participants were very sensitive to the audio-visual feedback, as it could provoke flashbacks and unpleasant feelings. This is in line with findings from a case study by Askovic and Sebern (35), investigating NF treatment for a traumatised refugee, discovering that “memories that had been implicit became explicit”. Since reexperiencing symptoms is an essential part of PTSD (64), the potential trauma-related triggers was a predictable issue, which concerned the NF therapists a lot during the preparation and planning of the NF feasibility study. However, it was difficult and time consuming to map all potential triggering stimuli and therefore the selection of auditory and visual stimuli was a result of a trial-and error approach. Still, we argue that a personalized selection of the NF stimuli promotes the feasibility, as the participants are able to relate to the content and thereby engage fully. By not only tailoring the feedback stimuli, but the conduction of the NF training sessions in general, the participants’ special needs and traits are met, such as the adjustment of the treatment to the severity of the concentration deficits, e.g. designing more simple training setups with shorter sessions (32, 65).

Thus, by having these three essential facilitating components of the NF treatment in mind, a potentially more feasible and acceptable NF treatment for trauma-affected refugees might be possible to carry out.

Strength and limitations

The study holds important strengths. It is the first to investigate the NF questions. This means that a larger number of interviewees completing both “interview A” and “interview B” is needed in future research in order to reach saturation, where further interviews do not produce new knowledge (66). Furthermore, an ‘interview C’ collected after completion of the 12 training sessions may provide more comprehensive and deeper insight into their experiences, and especially to the perceived impact of the NF treatment. Another

limitation involves the objectivity of the researcher. The fact that the first author was the primary researcher of this qualitative study, while also being the NF therapist for many of the participants, increased the risk of the participants giving dishonest answers. It is known that ethnic minorities often are prone to heed the therapists instruction to a greater extent than Danish patients (51), and this might conceivably result in overly positive answers from the interviewees in order to please and be 'good patients'. Vice versa, the familiarity can perhaps have generated confidence and security, resulting in more honest answers. Even though NF treatment is a non-verbal method of treatment, the information before as well as the instructions during the NF training sessions appeared to be of greater influence than expected. Thus, findings of this study have to be seen in light of some limitations in regard to working with interpreters, where the risk of losing or misunderstand essential elements of the conversation is increased (67–69). Dealing with a complex subject such as NF requires sufficient technical understanding as well as mastering special terminology. Our interpreters were not informed in detail about NF, and their lack of understanding might have affected the quality of the interpretation.

Clinical implications

Our results indicate, that by following a few simple, yet essential rules of thumb, the facilitation of a more successful and feasible course of NF treatment is enabled. First, in order to avoid misunderstanding and disappointment it is important to explicitly evaluate the patient's outcome expectations (44) and adjust misunderstanding with clear and thorough information about what symptoms this kind of NF designed to relieve. Similarly, it is crucial that the NF therapist understands the pitfalls of giving instructions of such a complex subject as the NF equipment without "over-simplifying" and to ascertain if the communication have been successful the *teach-back method* (56) might be useful. As the degree of complexity of this information is high, repetition of the instructions might be advantageous, e.g., during the first training sessions. Secondly, this study has successfully discovered valuable knowledge regarding factors enhancing the acceptability as well as the feasibility. This includes focusing on the breathing exercises during the training sessions as well as at home. Furthermore, the prioritizing of a spacious and light NF treatment room is emphasized and most importantly the adjustment of the NF training, arguing to tailor the visual and auditory feedback stimuli to fit the participants' preferences.

Conclusion

The in-depth qualitative interviews in the present study were carried out in order to evaluate the feasibility of NF with trauma-affected refugees. Findings from this study show that facilitation of successful treatment was challenged by the participants' comprehension of the NF treatment and its capabilities, resulting in disappointment as their expectations were not met. This accentuates the importance of thorough, repetitive and understandable instructions in regards to which symptoms the NF treatment protocol is designed to treat as well as the actual capabilities of the NF equipment. Our results indicate that despite the lack of benefit from NF, the participants did find NF to be an acceptable treatment method, recommendable to others. Finally, several important factors enhancing the feasibility and acceptability of NF treatment was discovered: The importance of the breathing exercises, the prioritizing

of a spacious NF treatment room and the personalization of the NF stimuli. However, more research is needed to explore the effectiveness of personalized NF treatment for this population.

Abbreviations

UNHCR: The UN Refugee agency, PTSD: Post traumatic stress disorder; ICD-10: International Classification of Diseases; CTP: Centre for Transcultural Psychiatry; RCT: Randomized controlled trials; NF: Neurofeedback; Hz: Herz; EEG: Electroencephalography; STARTTS: Service for the Treatment and Rehabilitation of Torture and Trauma Survivors; HL: Health Literacy

Declarations

Ethics approval and consent to participate

The NF feasibility study was approved by The Danish National Committee of Health Research Ethics (H-18040354), thus all methods were carried out in accordance with these guidelines and regulations. All participants' interests were considered and protected through the research process. As only participants from the quantitative substudy were eligible interview candidates, a separate consent to the quantitative substudy was already obtained. The prospective participants received a brief verbal introduction to the nature and purpose of the qualitative substudy. If the participant could not speak Danish, the information was translated and given by an interpreter. All participants were subsequently thoroughly informed about ensured confidentiality and anonymity and the voluntary nature before they gave their oral and written informed consent for participation in the qualitative substudy. Furthermore, the participants were informed that they had the right to withdraw from the study at any time without any consequences for their treatment at CTP.

Consent for publication

NA.

Availability of data and materials

The datasets analysed during the current study are not publicly available due to them containing information that could compromise research participant privacy but are available from the corresponding author on reasonable request.

Competing interests

The authors of this paper all declare that they have no competing interest.

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Authors' contributions

SZ and HLA designed the qualitative interview study and analysed the data. Supervised by HLA, SZ wrote the two interview guides and SZ conducted the interviews. SZ, HLA and JC were all involved in the interpretation and discussion of data. SZ wrote the manuscript with editing and revisions suggested by HLA and JC. Both SZ and EV functioned as NF therapists and EV proofread the manuscript. All authors have read and approved the final manuscript.

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Figures

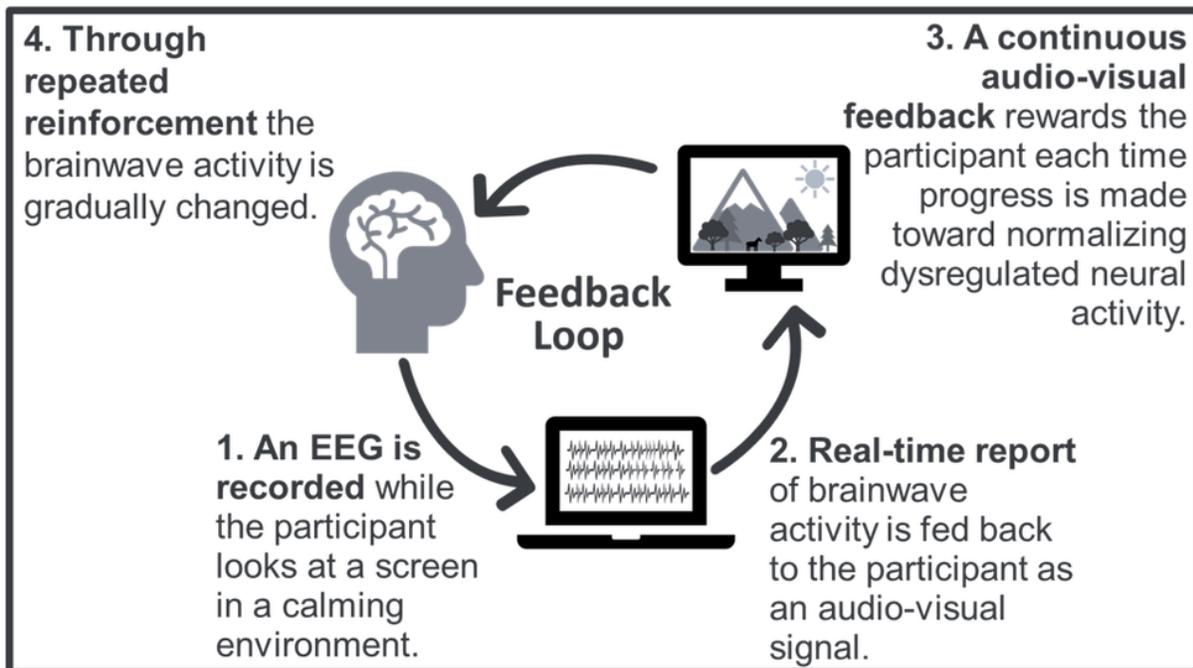


Figure 1

The feedback loop. Brainwave activity are measured and interpreted by a computer, while the participant receives constant audio-visual feedback of the measured neurological activity.

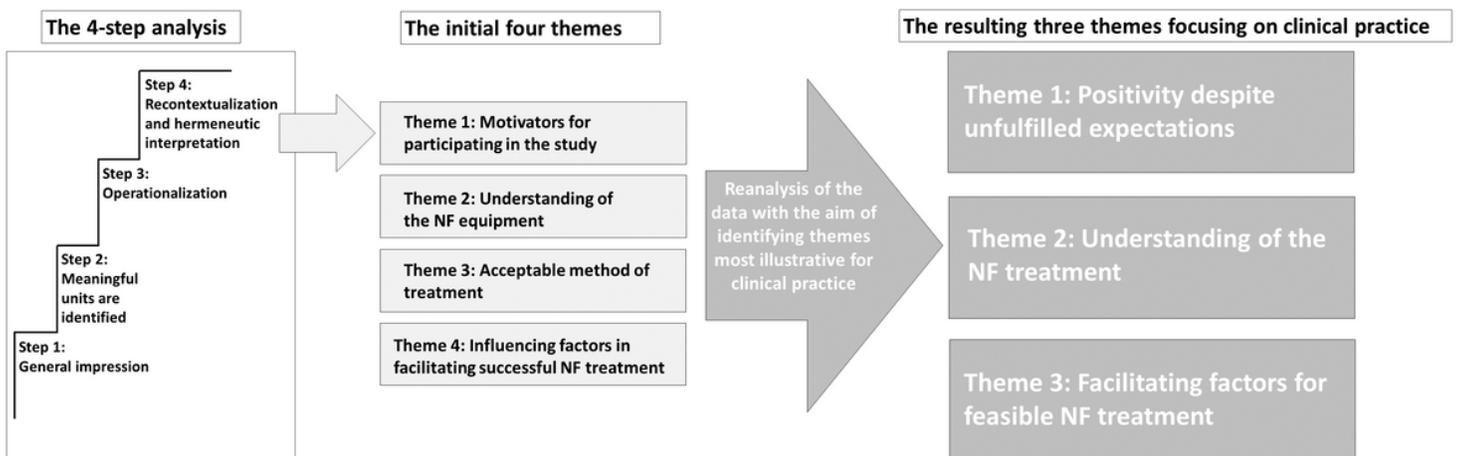


Figure 2

The 4-step analysis and the resulting three themes