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Case Report

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Eye movement desensitization and reprocessing (EMDR) and mediative behavioral therapy for the treatment of suffocation related post-traumatic stress disorder (PTSD) in amyotrophic lateral sclerosis (ALS): A case report

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Abstract

Objective. Eye movement desensitization and reprocessing (EMDR) is an established treatment for post-traumatic stress disorders (PTSD). Some patients diagnosed with amyotrophic lateral sclerosis (ALS) experience PTSD following choking or suffocation in the course of progressive loss of the ability to breathe. Although a loss of breathing functions in ALS is relatively common, there are currently no studies available on treatment for the fear of choking following advanced ALS.

Methods. In this case study, we describe the positive effects of EMDR, an evidence-based form of trauma therapy, in a 48-year-old female, suffering from advanced ALS. As the consequence of ALS, she was not able to speak or breath independently, but could communicate through a speech-generating device. She experienced panic attacks, flashbacks, nightmares, and severe anxiety after her tracheostomy jammed, and she almost suffocated.

Results. Mediative treatment was started by instructing the care staff to respond neutrally with step-by-step instructions following tracheostomy jam, resulting in significantly less panic attacks and flashbacks. EMDR was initiated two weeks later, and resulted in full remittance of the trauma symptomatology.

Significance of the results. The present case study suggests that symptoms of PTSD, namely the strong fear of suffocation, can be successfully treated by means of mediative behavioral therapy combined with EMDR.

Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal adult-onset neurodegenerative disease. ALS has an incidence of 2–3/100.000 and a prevalence of 6–7/100.000 in Europe (Cleveland and Rothstein, 2001; Costa and De Carvalho, 2016). As a consequence of progressive ALS, patients lose their ability to talk, breathe independently, and have difficulty swallowing (Masrori and Van Damme, 2020). In the later stages of the disease, patients are dependent on noninvasive ventilation (Vandenberghe et al., 2013). Patients diagnosed with later stage ALS often fear of dying from suffocation. Although this fear seems realistic, research shows that ALS patients seldomly die from suffocation (Van Leeuwen et al., 2013). Because the fear of dying by suffocation is so common in ALS patients, this issue asks for active psychological treatment. The positive effects of (mediative) behavioral therapy for ventilator-dependent patients were earlier described by Cohen and colleagues (Cohen et al., 2019). In this form of therapy, anxiety is reduced by means of cognitive and behavioral strategies aiming to reduce the fear of suffocation, often helped by care staff in supporting the patient. Results on mediative behavioral therapy are generally promising (Currid et al., 2011).

Eye movement desensitization and reprocessing (EMDR) is a psychotherapy that enables people to heal from the symptoms and emotional distress that are the result of disturbing life experiences (post-traumatic stress disorder, PTSD) (Shapiro and Laliotis, 2011). It uses bilateral stimulation (e.g., taps, tones, or eye movements), which aims to stimulate the information processing system of the brain. More than 30 randomized controlled trials show that EMDR is an effective treatment strategy for PTSD (de Jongh et al., 2019; Matthijssen et al., 2020).

In the present case study, a patient is described who had a near-death experience following a jammed tracheostomy in the course of progressive ALS, and had the post-traumatic fear of dying by suffocation, shown as panic attacks, flashbacks, nightmares, and severe anxiety.

Methods

Subject

Our patient was a 48-year-old woman with a 2-year diagnosis of sporadic ALS. She could communicate by the use of an eye movement-based speech-generating device. She was admitted to the hospital for the placement of a tracheostomy. Seven days following placement she had a lot of salivation, and her tracheostomy got jammed. The device was drained without medical complications, and she was admitted to a specialized facility for rehabilitation with 24/7 ventilation. Following surgery, she was accompanied for 24/7 by a care-companion with experience in ALS care. After admission to the facility, she was having panic attacks, flashbacks, and severe anxiety following the tracheostomy jam.

Assessment

PTSD was assessed by means of the DSM-5 criteria (American Psychiatric Association, 2013).

Treatment: mediative behavioral therapy

In the specialized care facility, a devoted nursing staff team for patients requiring full-time ventilation is present. Because patients on ventilation relatively often experience anxiety, mediative behavioral therapy plans are present for most clients. There are meetings with the care staff and psychologist to discuss the mediative care plans. These plans are indicated by a psychologist (second author JB) in alignment with the wishes of patient and care staff, and incorporate actions to take in case of experienced anxiety. For our patient, this plan incorporated the steps to stay calm as a care member in response to jamming of the tracheostomy, followed by actively naming all the steps of the process of draining the tracheostomy to distract and comfort the patient. The care staff was asked to always carry out this plan in case of jamming of the tracheostomy. The plan was started three weeks following admission and evaluated two weeks later. In these two weeks, a registration list was used to index panic by the nurse and the client on a 0–10 scale, 0 indicating no panic at all and 10 indicating the worst possible panic.

Treatment: EMDR

Following mediative behavioral therapy, EMDR treatment was carried out. The patient had prior knowledge of the EMDR procedure. The Dutch standard EMDR protocol 2019 was used as a basis for the EMDR session with the patient (de Jongh and Ten Broeke, 2019). Because of limited communication possibilities, the following adaptions were made to the protocol:

1. Introduction phase: Because communication was restricted, the desensitization phase was explained to the patient with the question to not answer, but actively envision what was asked. In the desensitization phase, the disturbing event is evaluated rationally. The patient is asked to focus on an image that evokes a negative reaction while simultaneously making eye movements.
2. Assessment phase: In the assessment phase, the traumatic event is assessed. Instead of telling the entire story with details, the patient was asked to globally sketch the traumatic event in a minimal number of sentences, by means of the speech-generating device. The assessment phase was further shortened by assuming a target selection within the "control" domain by not asking for a positive or negative cognition, and credibility of this cognition, but asking: "Do you still have an active image of the event?" and "Do you still feel powerless when you look at the image?".
3. Desensitization phase: As stated in the introduction phase, the patient had to actively envision in response to the asked questions "What comes up?/What are you noticing?". By moving her eyes, she could answer whether she actively envisioned this, followed by "Concentrate on that aspect"/"Stay with that", as stated by the therapist, back to target image was always started after four sets of eye movements.
4. Installation of Positive Cognition: The installation of a Positive Cognition (PC) was skipped because of accumulating tiredness.
5. Body Scan: Instead of asking the patient to scan the entire body for residual tension, all elements of the body (head, arms, legs, chest, stomach, feet, etc.) were separately named by the therapist.
6. Positive closure: In the positive closure phase, to enhance belief or faith in possessing relevant personality traits, the patient is normally asked to posture like someone who is in possession of the personality trait required to handle the situation (such as strong/capable). Instead of asking to posture like someone who is … (possessing this personality trait), the patient was asked to close her eyes and to imagine an earlier event were she felt like someone who is … (possessing this personality trait) (Driessen and Ten Broeke, 2014).

Results

Treatment: mediative behavioral therapy

At the start of the mediative treatment, the patient reported daily panic attacks. In the two weeks following the initiation of the mediative treatment plan, the patient reported four panic attacks in total. Three panic attacks were scored as a 5 out of 10, and one with an 8 out of 10 by the patient. The nursing staff scored two panic attacks with a 5 out of 10, one panic attack with a 4 out of 10, and one with a 3 out of 10.

After the first two weeks of mediative treatment, the patient was asked what could have caused the reduction in panic attacks. She reported that she had the opinion that the care staff understood why she felt tension, and were more confident in treating the situation (removing saliva from the tracheostomy).

Treatment: EMDR

The total duration of the EMDR session was 40 min. In the assessment phase, the patient asked the psychologist (EO) to contact her partner for the entire story regarding the traumatizing event. The psychologist asked whether she still felt powerless, and she agreed. She felt anxiety in her chest and stomach. Without asking for the Subjective Units of Disturbance (SUD),

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the desensitization phase was started. After four sets of eye movements (each of around 30 s), her SUD was 7 out of 10.

Going back to the original image, as now stored in memory (Back to target) led to the image of her with the fear of dying, concentrating on her eyes. After another four sets, the SUD was 5. Back to target resulted in thoughts about leaving her partner behind. After concentrating on the feeling in her stomach and four additional sets, the SUD was 4 out of 10. Concentrating again on this feeling and four additional sets led to a SUD of 2 out of 10. She concentrated on the entire image, and the SUD was 0 out of 10 following four more sets.

A body scan resulted in no more feelings of anxiety. In the positive closure phase, she envisioned herself feeling at peace. And in the second part of this phase, she returned to an image of her being strong. Nine days after the EMDR session the symptomatology was evaluated, and none of the symptoms were present. A month later the PTSD was still in remission.

Discussion

The ALS patient in the present case report showed a positive result of mediative behavioral therapy and EMDR on PTSD symptomatology following suffocation. Mediative therapy reduced the number of panic attacks and symptoms of anxiety. EMDR resulted in remission of flashbacks and night terrors, followed by full remission of the PTSD symptoms nine days after treatment.

While the fear of suffocation is very common in patients with later stage ALS, treatment strategies for this fear have not commonly been described (Vandenberghe et al., 2013). In this case study, combining mediative behavioral therapy and EMDR was effective in reducing traumatic symptoms following suffocation. We applied a shortened EMDR treatment protocol, because of restrictions in communication due to advanced ALS. Both mediative strategies and EMDR resulted in prompt reduction of tension and anxiety.

Earlier studies showed effectiveness of EMDR in populations with restricted autonomy, such as dementia patients (Van der Wielen et al., 2019), patients with intellectual disabilities (Gilderthorp, 2015), or patients with restricted motoric and intellectual capacities (Ahmed, 2018). There is a growing interest in patient groups that do not always have access to therapy, with a broad application of EMDR in case of depression, stress, and anxiety (Guina and Guina, 2018; Scelles and Bulnes, 2021).

There is currently no research available on ALS patients successfully receiving EMDR, therefore this study indicates EMDR as a novel psychological treatment strategy for fear and anxiety in ALS patients.

Mediative treatment strategies, involving behavioral treatment plans made with both the patient, family, and care staff are valuable tools to increase the quality of life in advanced ALS patients. In the present case study, the patient was admitted to a 24/7 rehabilitation and care facility for ventilator patients.

A limitation of the present study was that we did not use standardized scales to assess PTSD symptomatology. Moreover, the diagnosis of PTSD was assessed by the second author who was also involved in the treatment.

To conclude, we found evidence for EMDR and mediative behavioral therapy in the treatment of anxiety and PTSD in advanced ALS. Based on our findings, we hope that other patients with advanced ALS will receive EMDR and mediative behavioral therapy for reducing stress, panic, and anxiety.

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