Do persons with intellectual disability and limited verbal capacities respond to trauma treatment?
Mevissen, Liesbeth; Lievegoed, R.; Seubert, A; de Jongh, A.

Published in:
Journal of Intellectual & Developmental Disability

DOI:
10.3109/13668250.2011.621415

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
BRIEF REPORT

Do persons with intellectual disability and limited verbal capacities respond to trauma treatment?

LIESBETH MEVISSEN¹, REINOUT LIEVEGOED², ANDREW SEUBERT³ & AD DE JONGH⁴

¹Accare – Deventer, the Netherlands, ²Zonnehuizen – Zeist, the Netherlands, ³ClearPath Healing Arts Centre, Mansfield, Pennsylvania, USA, and ⁴Academic Centre for Dentistry Amsterdam (ACTA), University of Amsterdam and Vrije Universiteit, – Amsterdam, the Netherlands

Correspondence: Liesbeth Mevissen, Accare, Diepenveenseweg 169, 7413 AP, Deventer, the Netherlands
E-mail: l.mevissen@accare.nl
Abstract

Background  There is not one case report of successful trauma treatment with the use of an evidence-based treatment method in people with substantially limited verbal capacities. This paper assessed the applicability of eye movement desensitisation and reprocessing (EMDR) in two clients with moderate ID, serious behavioural problems, and histories of negative life events.

Method  The 8-phase protocol of EMDR, a first-line treatment for psychological trauma, was applied.

Results  In both cases, posttraumatic stress disorder (PTSD)-like symptoms decreased in a total of only 6 and 5 sessions, respectively. Gains were maintained at 32 and 10 months’ follow-up.

Conclusions  EMDR seems to be an applicable psychological trauma treatment for persons with limited verbal capacities. Considering the importance of these findings, further and more rigorous research is required.

Keywords: trauma, treatment, EMDR, moderate intellectual disability, posttraumatic stress disorder (PTSD), life events
Introduction

In the general population posttraumatic stress disorder (PTSD) is known as a disorder with high prevalence rates (5%–10%; Kessler, Chiu, Demler, & Waters, 2005) and disruptive effects on a person’s daily life functioning (van der Kolk & McFarlane, 1996). Fortunately, effective treatment methods are available with trauma-focused cognitive behavioural therapy (TFCBT) and eye movement desensitisation and reprocessing (EMDR) having the strongest empirical support (Bisson et al., 2007; Rodenburg, Benjamin, de Roos, Meijer, & Stams, 2009).

People with intellectual disability (ID) have been found to be more likely to experience traumatic events and negative life events than those without intellectual disability (Tsakanikos, Bouras, Costello, & Holt, 2007). There is also tentative evidence for a causal role of life events with regard to psychological problems (Hulbert-Williams & Hastings, 2008). However, a recent review of the literature revealed that (1) there are no reliable and valid instruments for assessing PTSD in this population, (2) prevalence data on PTSD in people with ID are lacking, and (3) there are no evidence-based treatment methods for people with ID who suffer from PTSD (Mevissen & De Jongh, 2010). Because of its importance, PTSD is assigned its own chapter in the *Diagnostic Manual – Intellectual Disability* (DM-ID; Fletcher, Loschen, Stavrakaki, & First, 2007), including recommendations for adapted PTSD symptom descriptions in people with various levels of ID. Thus, PTSD in this population is an underdiagnosed, as well as an undertreated, disorder.

To date, four case reports of PTSD treatment of clients with ID using TFCBT and 13 using EMDR have been found in the literature (Barol & Seubert, 2010; Mevissen, Lievegoed, & De Jongh, 2011). Of them, 14 clients had mild ID and one had moderate ID. Since the latter person, treated with EMDR, was described as very articulate and able to reflect on feelings verbally, the question remains whether this case was representative of this
population. Because of EMDR’s largely nonverbal character, the purpose of the present case report was to extend aforementioned findings and to examine whether EMDR would be an applicable and effective treatment method for clients with substantial limited verbal capacities.

Method
The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all clients who agreed to participate after the procedures were explained. Ethical approval was not obtained from a medical ethical body because none of the participants had been restricted from participating in treatment; moreover, there is no alternative treatment method available for PTSD-like symptoms with a similar evidence base for this group of people. In this case, under Dutch law and regulations, it is not necessary to seek ethical approval.

Participants
Participants were four clients with moderate ID and substantial limited verbal capacities. They were referred for outpatient treatment by their psychiatrist or other mental health professional as it was assumed that there was a relationship between their problem behaviours and a number of traumatic life events to which they had been exposed.

The first author, a clinical psychologist and EMDR practitioner with more than 30 years’ experience with persons with ID and mental health issues, conducted clinical interviews with the participants and their trusted caregivers and examined their records. All participants seemed to experience PTSD-like symptoms, according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR;
American Psychiatric Association, 2000) and DM-ID (Fletcher et al., 2007). Given that these participants had a close relationship with at least one family member (and/or a trusted staff member), they were considered to be eligible for EMDR treatment. The legal representatives were informed about the study and invited to participate. All four agreed with EMDR treatment of their relative, but only two signed an informed consent form giving the researchers permission to include the treatment findings in their study.

Procedure

The first author administered treatment. Treatment and related procedures were explained in detail to the caregivers who supported the participants during the treatment sessions. The participants themselves underwent weekly therapy sessions of one hour each. The total number of sessions was based on their individual needs. The caregivers were asked to observe participant behaviour in daily life and to make notes about observed changes, especially with regard to the complaints for which they had been referred. All sessions were videotaped with written consent. The therapist analysed the tapes with regard to the most significant aspects of the trauma processing. Due to the participants’ cognitive disabilities and poor verbal capacities, complaint-related changes had to be reported by the caregiver at the beginning of each session.

Treatment

EMDR is a protocolised, eight-phase psychotherapeutic approach, developed to resolve symptoms resulting from disturbing and unprocessed life experiences (Shapiro, 2001). Phase I consists of history taking and case formulation, resulting in a treatment plan. In Phase II the client is prepared for the trauma work. Skill building and resource development are typically necessary. Phase III to VII consist of the reprocessing of the traumatic memory. It begins with
a focus on the traumatic memory itself by asking the client to bring up the memory and to concentrate on various aspects of it; specifically, the most distressing image and the dysfunctional negative cognition of oneself in relation to the image, as well as the accompanying emotions and the body disturbance that go along with it. A core feature of the procedure is the performance of eye movements (typically, the therapist moving her fingers back and forth in front of the client, asking the client to track the movements while keeping his head still), while concentrating on the trauma memory (Shapiro, 2001). Following the image and negative cognition, access to the emotional and somatic aspects of the memory takes place. The therapist then asks the client to follow her fingers, while encouraging to “go with” whatever freely arises in his awareness. Repeatedly the client is asked to report emotional, cognitive, somatic, and/or imagistic experiences until internal disturbances reach a SUDs (Subjective Unit of Disturbances scale) of zero and adaptive and positive beliefs are rated strong on a VoC (Validity of Cognition) scale (Shapiro, 2001). Phase VII is dedicated to closing down the session and preparing the client for the interim between sessions. Phase VIII consists of re-evaluation and integration.

EMDR practice is guided by a theory of adaptive information processing (Shapiro, 2007) which asserts that the application of the EMDR procedure induces a physiological condition in which unprocessed memories of traumatic events become linked up with networks that already include adaptive information and skills (Shapiro, 2001). The results of clinical outcome studies are corroborated by a large array of experimental studies showing that eye movements during recall of aversive memories reduce their vividness and emotionality (e.g., Engelhard, van den Hout, & Smeets, 2011; Gunter & Bodner, 2008). During recall, emotional memories become “labile,” (i.e., liable to change) and their reconsolidation is affected by experiences during recall (Baddeley, 1998). Recalling a traumatic memory is assumed to depend on working memory resources that are limited. If
another task is executed during recall, fewer resources will be available for recalling an
episode and the memory will be experienced as less vivid and emotional. Eye movements are
held to serve as such a “secondary” task that taxes working memory (Engelhard et al., 2011;
Gunter & Bodner, 2008). The needs of clinical practice have led to task variations. With
children, for instance, the therapist might put stickers on her fingers to facilitate the child’s
tracking. With even younger children, buzzers can be used to vibrate alternately between their
right and left hand, or the therapist can provide tactile bilateral stimulation by tapping on the
child’s hands or knees (Adler-Tapia & Settle, 2008). Auditory stimulation can also be
employed, such as the use of alternating tones via a headphone or audio speakers placed on
either side of the client.

Instructions as to how to activate the trauma memory, and how to support the client
during the desensitisation and reprocessing phase, are age-related and adjusted to the person’s
mental age, taking into account any associated conditions such as autism (Adler-Tapia &
Settle, 2008; Barol & Seubert, 2010; Greenwald, 1999; Mevissen et al., 2011; Tinker &
Wilson, 1999). In Phase III, for example, children with a mental age between 4 and 8 are
asked to draw the target image instead of describing it verbally. The negative and positive
cognition are omitted with clients younger than 5, and in Phase IV the level of distress is
measured in a concrete, visual way with the use of facial images or spreading hands. The
Story Telling Method (Lovett, 1999) is of great use when applying EMDR to the youngest
children (< 3 years). Typically, parents or caregivers tell the story of the traumatic event. The
story has a positive beginning, followed by the relating of the traumatic event, which includes
the distressing details as to what was seen, heard, felt (emotionally and somatically), thought,
or smelt. Occasionally, photos, drawings, or physical objects are employed to engage the
senses and to activate the trauma memory. The story also includes the way the person
responded, but the ending is always positive, including a positive self-belief.
Results

A description of the two clients, including a summary of the results of their treatment is provided in Table 1.

Case 1

Maria could be described as a young woman living with her family who was sexually abused by two perpetrators. She has moderate ID (WISC-R; IQ = 44) and symptoms of autism. Maria had become restless, had sleep problems, and was often tearful. She displayed aggressive outbursts and obsessive behaviour. Her personal hygiene deteriorated, and she was quite demanding of her mother. These problems started three months after she had been sexually abused. Play therapy was ineffective, and her complaints worsened. An antipsychotic medication (risperidone) was administered, but with no positive results. Maria then had to be placed in a crisis unit, since her parents could no longer manage her behaviours.

Since Maria was neither able to speak nor create drawings about the abuse, the Story Telling Method was employed. In terms of general description, her mother narrated the events, including the forced move to the crisis unit. Maria could not tolerate headphones, buzzers, or eye movements. Consequently, external audio speakers were chosen. In the first session, Maria reacted emotionally, rage slowly changing to anger and ending with sadness. During the second session, she was able to verbalise to some extent what the perpetrators had done to her and could tolerate buzzers in her hands. Complaints decreased overall and visits to her parents’ home were re-established. In the fifth session, Maria created sequential drawings of what had happened. Each of nine drawings was regarded as a separate target
Brief Report: Treatment of trauma in people with ID

(being kissed, in the shower, touching breasts, etc.) and was processed separately. Each target still elicited some emotional disturbance, but they were all fully reprocessed. Finally, a future template was installed; for example, a fearful situation that she typically avoided after the traumatic event was imagined and accompanied by a positive belief. Maria successfully imagined meeting the perpetrators, while telling herself, “Yes, I can!”

After six 1-hour sessions Maria was no longer restless, the obsessive behaviours had disappeared, her sleeping patterns returned to normal, and her positive mood returned. Aggression ceased, and her personal hygiene improved to its former status. Effects of treatment were maintained after four months. Maria’s only remaining difficulty was being alone at home.

During a 32-month follow-up, her mother reported that Maria was still doing very well. In the interim, she had moved voluntarily to her own apartment, with the support of caregivers. Her independence continued to increase. She had a job, and in her leisure time she was taking a course in reading and writing. The only difficulty, according to the mother, was in getting Maria to curb her enthusiastic phone calls to her parents. Importantly, she eventually ran into the perpetrators without becoming upset.

Case 2

Simon is a middle-aged man with moderate ID (WPPSI-R; average developmental level 4.9 years)2 living in a group home. Ten months ago Simon’s mother died. Subsequently, he became aggressive, threatened someone with a knife, and was suspended from work. Caregivers and family members feared he would attack others. He developed an ongoing physical shaking and he began to overeat, actually stuffing food in his mouth. Simon knew Ann, his girlfriend, a woman with mild ID and autism, from childhood. They were in fact colleagues, and Simon was quite possessive of her and his caregivers in general. Yet, he
began to continuously complain about Ann.

The first session was used to initiate preparation for treatment with a trusted family member and caregiver. In taking his history, other traumatic events surfaced. When Simon was in his late adolescence, he experienced several profound losses. His father suddenly died of a heart attack. Simon was left behind at the farmhouse with the other members of the family. Simon and his father had been close. Each day when Simon returned from school, he assisted his father in the cowshed. After his father’s death, the farm work had to be maintained, so Simon became his mother’s helper. During that same period, he changed from school to a workshop. Ann got a job elsewhere, so they met less frequently. Approximately 20 years later, the farmhouse was sold and his mother moved into an apartment, and Simon was placed in a group home. Simon became passive, was often in a bad mood and was very possessive of Ann. Caregivers decided that their relationship needed to be dissolved. About two years after his placement in the group home, Simon received a psychiatric evaluation, yet no diagnosis was established. The only recommendation was to arrange for meaningful activities for Simon. Gradually, he improved and stabilised.

A close family member was present for each EMDR session. It took four 1-hour sessions to treat Simon’s traumatic memories. The first memory targeted in the session was his mother’s death. Simon drew an image representing the memory: Simon himself, his mother, and an empty house. He felt “a pity,” and reported “a lot of” disturbance in his “belly.” This memory was fully processed with using buzzers as a secondary task. However, with regard to the memory of his father’s death, Simon was not able to talk about what had happened, nor could he draw the memory. His facial expression, however, revealed emotional stress, so bilateral stimulation (using buzzers in his hands) was initiated. At the end, to be sure that all aspects of the memory were reprocessed, the therapist narrated the entire story of the father’s death, while administering the buzzers, until there was no distress left. The forced
break-up of his relationship with Ann was treated in a similar manner.

As a result of treatment, Simon became more relaxed. He still became frustrated when teased about Ann by his peers, but his extreme rage responses disappeared. His dependence on Ann and his caregivers decreased, whereas self-reliance increased, and he could now talk about Ann and about his mother more calmly.

Shortly after his fourth treatment session, another overwhelming event occurred. Simon and Ann joined a trip abroad with their peers. They were separated from the group at one point, and subsequently lost their way. Unable to find them, an international search effort was initiated. At the end of the second day, the search team found them and brought them to a police station, where their families could retrieve them. Within a week, an EMDR session was arranged to help Simon reprocess the event and, at a 10-week follow-up, his improved functioning maintained. Simon was doing well at work, and his swearing and threatening behaviours ceased. He was able to simply talk about his thoughts and feelings, and he consulted his caregivers whenever he experienced difficulties.

At a 10-month follow-up, Simon’s caregiver reported that problems in the relationship between Simon and Ann continued at their sheltered workshop, involving aggressive behaviours on both parts. A change of workplace for Simon was set in motion. Ann’s autism and Simon’s cognitive limitations together seemed to create insurmountable obstacles to mutual satisfaction in their relationship, but he could now accept the help of his relatives and caregivers in managing his problems with Ann. Simon no longer showed any signs of disturbance, either with regard to the death of his parents or to the experience of being lost. His growth in independence continued, and he continued to do well in his group home, as well as with his family members.

**Discussion**
These case descriptions suggest that EMDR is a potentially applicable psychotherapeutic treatment method for clients with ID, even if they have substantially limited verbal capacities. The results are congruent with research findings when employing EMDR with people with mild intellectual disability (Barol & Seubert, 2010; Mevissen et al., 2011). Both participants met PTSD criteria as described in the DM-ID, particularly when one considers their trauma histories and the behavioural changes that occured after treatment.

The two clients were unable to express themselves with regard to (some of) the traumatic events, neither in simple words nor in a drawing. In the absence of such communication, it was necessary to use a trusted caregiver’s report regarding what had happened to create a narrative, which then activated the trauma memory. In both clients it was possible to bring back the SUD level comparable to zero, according to the observations made by the family members who accompanied them during treatment. The serious and increasing behavioural problems were resolved after five 1-hour EMDR treatment sessions and were maintained at 10 months’ follow-up, and extreme aggressive outbursts were solved after six without any homework and maintained at the 32-month follow-up. Moreover, in both cases personal functioning improved and the results were maintained at 10- and 32-months’ follow-up, respectively.

The findings highlight the need for further exploration of EMDR’s applicability in people with severe ID and to assess the scope of its utilisation within people with ID and mental health issues. Although there may be concern for the safety of the clients undergoing treatments that may involve emotionally charged materials in this population, our experiences suggest the opposite. None of the clients we treated thus far showed any exacerbation of symptoms due to the treatment.

With regard to the methodological shortcomings of this preliminary study more rigorous research is needed, particularly with regard to the effectiveness and efficacy of
EMDR in people with various levels of ID, for instance by using multiple baseline designs. This also requires the development of a valid and reliable instrument for the assessment of PTSD in people with ID, as well as well-trained, certified EMDR therapists, who also possess expertise in working with this population. To this end, awareness of PTSD and potential triggers in persons with ID is a prerequisite for treatment. The more limited a person’s verbal capacities are, the more difficult assessment will be. Therefore, awareness of this deficit among medical and mental health professionals, family members and caregivers is important. It will alert them more immediately to behavioural changes that follow negative life events and, consequently, increase the possibility of successful treatment.
Author note

No research funding was involved and there was no conflict of interest.
For clarity in this report, the female pronoun is used to denote the therapist and the male pronoun the client.

The level of functioning is reported as described in the participant’s file.
References


Table 1. EMDR treatment of two patients with poor verbal capacities

<table>
<thead>
<tr>
<th>Case</th>
<th>Level of ID &amp; comorbidity</th>
<th>Complaints</th>
<th>Trauma/life events</th>
<th>Number of sessions</th>
<th>Results</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maria</td>
<td>Moderate</td>
<td>Restless</td>
<td>3 months ago sexual abuse by two perpetrators</td>
<td>6</td>
<td>No longer restless</td>
<td>4 months: Results maintained</td>
</tr>
<tr>
<td>(young woman)</td>
<td></td>
<td>Possessive of mother</td>
<td>Outplacement in crisis unit recently (parents could no longer handle behavior problems)</td>
<td></td>
<td>Obsessive behaviour disappeared</td>
<td>32 months: Results maintained with increased self-sufficiency</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sleep problems</td>
<td>Parents divorced years ago</td>
<td></td>
<td>Sleeping pattern normalised</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Aggressive outbursts</td>
<td></td>
<td></td>
<td>Positive mood returned</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tearful</td>
<td></td>
<td></td>
<td>Aggression disappeared</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bad personal hygiene</td>
<td></td>
<td></td>
<td>Personal hygiene normalised</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Obsessive behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6 months: Results maintained</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simon</td>
<td>Moderate</td>
<td>Since 10 months: Aggressive outbursts; e.g., threatening with knife</td>
<td>10 months ago mother died</td>
<td>5</td>
<td>Self-sufficiency increased</td>
<td>10 months: Results maintained</td>
</tr>
<tr>
<td>(middle-aged man)</td>
<td></td>
<td>Complaining</td>
<td>In his late adolescence father died of heart attack</td>
<td></td>
<td>Able to talk about mother in an appropriate way</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shaking</td>
<td>10 years ago outplacement; family’s farm was sold, mother moved</td>
<td></td>
<td>More relaxed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Possessive of caregivers and girlfriend</td>
<td>Courtship broken up, forced by others</td>
<td></td>
<td>Excessive rage disappeared</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eating too much/stuffing food in mouth</td>
<td>After 4 EMDR sessions: Lost his way during trip abroad, was found after 2 days and brought to police station</td>
<td></td>
<td>Asked for help when in trouble</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Able to talk about thoughts and feelings</td>
<td></td>
</tr>
</tbody>
</table>