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Alastair L. Barrowcliff Gemma A. L Evans

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EMDR treatment for PTSD and Intellectual Disability: a case study

Alastair L. Barrowcliff and Gemma A.L. Evans

Dr Alastair L. Barrowcliff is a Consultant Clinical Psychologist, based at Five Boroughs Partnership NHS Foundation Trust, Community Adult Learning Disability Service, Prescott, UK.
Dr Gemma A.L. Evans is a Clinical Psychologist, based at Department of Clinical Psychology, University of Manchester, Manchester, UK.

Abstract

Purpose – *The purpose of this paper is to provide a detailed description of an adapted Eye-Movement Desensitisation and Reprocessing (EMDR) intervention in the treatment of chronic Post-Traumatic Stress Disorder (PTSD) in an individual with moderate-severe Intellectual Disability (ID), blindness, and Mucopolysaccharidosis Hunters Syndrome.*

Design/methodology/approach – *A case study reporting on the implementation of an eight phase EMDR approach adapted for intellectual and sensory requirements. The intervention involved a series of preparatory meetings and four sessions of EMDR.*

Findings – *The intervention was successful in ameliorating most symptoms attributed to a PTSD presentation.*

Research limitations/implications – *The availability of the full breadth of treatment options for PTSD as indicated in National Institute for Health and Care Excellence (2005) is questionable in clinical practice with individuals with ID. Appropriate investment in research determining the most efficacious interventions for this clinical population is required.*

Originality/value – *This case study addresses issues of complexity in respect of the assessment and treatment of trauma in an ID population. It raises a number of important social/research questions in addition to providing a high level of detail in regard to the adaptations required to deliver EMDR for a complex individual whilst retaining fidelity to the standard treatment model.*

Keywords *Trauma, PTSD, Intellectual Disability, Learning disability, EMDR, Mucopolysaccharidosis Hunters Syndrome*

Paper type *Case study*

Introduction

A dilemma that often presents within the clinical setting, is the complex client who does not fit comfortably within the parameters specified for delivery of the established therapeutic interventions, that would otherwise be automatically considered if the service user did not have an Intellectual Disability (ID). In this paper we reflect on a clinical case presenting with Post-Traumatic Stress Disorder (PTSD) treated using an adapted Eye-Movement Desensitisation and Reprocessing (EMDR) intervention. Whilst there is a small but developing literature highlighting the application of EMDR for ID populations, the presenting complexity and the necessary treatment protocol adaptations makes this case study of particular interest.

ID and PTSD

ID is characterised by limitations in intellectual, social, and adaptive functioning, with an onset before adulthood (British Psychological Society, 2000). PTSD is characterised as the experience or witnessing of a traumatic event with subsequent symptoms involving intrusions, avoidance, hyper-arousal and negative alterations in cognitions and mood (American Psychiatric Association, 2013). Proposed adaptations for the recognition of PTSD in clients with ID include: increased breadth of events considered traumatic; increased likelihood of disorganised

agitated and self-injurious behaviour; isolation; re-enactments; perceived “non-compliance” representing avoidance; and ensuring careful consideration of prior cognitive difficulties during the assessment (Tomasulo and Razza, 2007).

Although reviews of the prevalence of PTSD within ID populations are limited and have estimated variable rates (Mevisen and De Jongh, 2010), individuals with ID are more likely to have experienced traumatic and adverse life events (e.g. Hatton and Emerson, 2004; Reiter *et al.*, 2007) and exposure to such events is associated with increased likelihood of mental health difficulties (Martorell *et al.*, 2009). The provision of appropriate psychological interventions to address traumatic experiences in those with ID is therefore an important clinical issue.

Clinical interventions for PTSD

Interventions recommended by the National Institute for Health and Care Excellence (NICE) for the treatment of PTSD (National Institute for Health and Care Excellence, 2005) include Cognitive Behaviour Therapy (CBT) and EMDR. These guidelines are intended to be of relevance to adults and children of all ages who experience PTSD (with no exclusion or caveat highlighted for ID populations).

EMDR involves imagery, cognitive restructuring, exposure, and the characteristic bilateral stimulation typically involving saccadic eye movements (Shapiro, 1999). Due to the limited communication and cognitive demands of the EMDR protocol, EMDR may provide a more intuitively suitable treatment approach for PTSD within adult ID populations relative to CBT.

ID and EMDR

Randomised-controlled trials have supported the efficacy of EMDR in PTSD treatment for adults (e.g. Bisson *et al.*, 2007; Seidler and Wagner, 2006). The literature examining the efficacy of any PTSD treatment for those with ID is limited and only a handful of reported cases have implemented EMDR. Mevisen and De Jongh (2010) reviewed the literature and identified just two studies in which an EMDR protocol had been used with adults with ID and PTSD. Of these studies, Giltaij (2004) reports on two females with mild ID who both demonstrated improvements at the end of treatment, and Tharner (2006) reports on 19 individuals with mild ID, 16 of who showed successful responses to treatment. Both studies, however, are criticised in regard to the lack of information specifying details of assessment, outcome measurement, and specific case details (Mevisen and De Jongh, 2010). Following this review, several further papers have reported on the use of EMDR in ID populations. Barol and Seubert (2010) report six cases in which EMDR was used, all of which reported positive outcomes. However only three cases used EMDR to work directly on the reported primary traumatic events, and these were generally the individuals reported to be “very articulate” (p. 165). Mevisen *et al.* (2011a) report on four cases of EMDR with individuals with mild ID. EMDR was implemented to address multiple traumas and life events and all cases showed improvements in behavioural outcomes which were maintained at follow-ups spanning three months to 2.5 years. Mevisen *et al.* (2011b) report two cases of EMDR with individuals with moderate ID and substantially limited verbal capacities, who both demonstrated positive behavioural outcomes maintained at follow-ups spanning ten to 32 months. Mevisen *et al.* (2012) reported on four cases of EMDR with individuals with severe ID. EMDR was employed using the story telling method (Lovett, 1999) in which the traumatic event was recounted by a caregiver, and all cases demonstrated improvements in behavioural outcomes following treatment. Finally, Dilly (2014) reports a case in which EMDR was used with an individual with mild ID in a forensic setting. Reduced PTSD symptoms were found following a 12 session intervention.

Although this recent literature is increasingly providing support for the successful use of EMDR in ID populations, the protocol adaptations necessary for individuals with ID remain broadly reported. The current paper aims to add to this existing evidence base by presenting a case study of the use of EMDR for PTSD symptoms following a single, life-threatening traumatic incident with a client with moderate to severe IDs, verbal communication difficulties, and a visual impairment. The presentation of a single, in-depth case study has allowed detailed attendance to the EMDR process. The report will focus particularly on the protocol adaptations and clinical

considerations of the treatment approach, in order to inform and facilitate the future consideration of this method by clinicians.

Methods

Case description

The client was a female in her 40s and asked to be named Ethel in the case study. Ethel had diagnoses of moderate-severe Learning Disability, secondary to Mucopolysaccharidosis Hunters Syndrome (“gargoylism”), limited verbal capabilities, and became registered blind in adulthood, a predicted feature associated with the course of this degenerative condition. Ethel spent her childhood in specialist foster care, with a number of unsuccessful placements in early adulthood prior to a long-term (and current) placement effectively with an adult foster family.

Ethel was referred to the local UK-based NHS community learning disabilities service due to on-going distress as a result of a traumatic incident. The traumatic incident of reference was a house fire which occurred at Ethel’s adult foster placement. Ethel recalled being awoken in the early hours of the morning by her carers and carried from the burning, smoke-filled building. She experienced extreme distress at the time of this event and began to engage in self-harm immediately following evacuation (scratching her face and body, biting her hands and arms). Ethel’s distress was further compounded when she was forcibly placed in an ambulance and taken to a local Accident and Emergency department (A&E). At this point she was described as being “hysterical” and because her carers were being treated independently at the scene, it was some time before they were able to attend to her at A&E and provide support and reassurance. The fire occurred approximately 18-months prior to the intervention.

General assessment

One of the challenges typically faced when working with adults with ID is the ability to obtain meaningful reports of internal cognitive and affective states as experienced by the client. This requires, for example, a degree of self-awareness, an ability to recognise internal states as unique events, and an ability to communicate such experiences to a third-party (e.g. Oathamshaw *et al.*, 2013). There is now a healthy literature detailing clinical adaptations for ID populations, and these approaches are applicable to any assessment or intervention concerning internal events and experiences (see, e.g. Taylor *et al.*, 2013). Unfortunately, Ethel was unable to tolerate completion of standardised assessment tools (e.g. Dagnan and Chadwick, 1997; Oathamshaw and Haddock, 2006) to obtain a baseline understanding of her ability to differentiate these facets of experience. She was, however, able to label two basic emotional states (upset and happy) and provide simple descriptions of her experience congruent with frequent re-experiencing of the event.

In regard to the assessment of trauma symptomatology, application of formalised instruments such as the clinician administered PTSD scale (Blake *et al.*, 1995) and standard assessment scales (e.g. Davidson *et al.*, 1997), was not possible due to language complexities and rating scales. Instead, symptom presentation was benchmarked against DSM-IV-TR criteria using the modifications recommended by Tomasulo and Razza (2007; reproduced by Mevissen and De Jongh, 2010). This process confirmed that Ethel met diagnostic criteria for PTSD. The children’s version of the Impact of Events Scale (CRIES-13; Children and War foundation, 2005) was also administered for self-report, although qualitative responses corroborated with third-party information were utilised in response to items rather than the scoring criteria (see Table I). These measures were applied pre- and post-treatment. Multiple applications were avoided due to the protracted time-periods in completing these measures with Ethel.

Procedure

Shapiro (1999) outlines eight phases of EMDR, considered in greater detail below: we highlight areas of adaptation as required in this case.

1. *Client history and screening.* Ethel presented as a poor personal historian in early sessions. Details of the traumatic incident were presented as a structured and fixed narrative stream of

Table 1 Revised Child Impact of Events Scale (CRIES-13) items and interpreted responses pre- and post-EMDR

	<i>Pre-treatment</i>	<i>Post-EMDR</i>
<i>Intrusion sub-scale items</i>		
Do you think about it even when you do not mean to?	"All the time". Qualified by informant	"Changed [...] think about it less". Qualified by informant
Do you have waves of strong feelings about it?	"Scared all the time". Immediately raised arousal and distress when made reference to incidents in interview, with crying and self-harming behaviour displayed	"Definitely less". Able to sit calmly when discussing the incidents and provided narrative without observable distress or significantly elevated arousal. No crying or self-harm
Do pictures about it pop into your mind?	Ethel could not conceptualise this question although it was evident in the clinical interview that this occurred on a highly frequent basis	Remained unable to conceptualise this question although clinical interview indicated that this had not occurred recently
Do other things keep making you think about it?	Ethel continued to live in the home where the initial incident had occurred, resulting in frequent situational reminders with associated constant preoccupation	Environmental circumstances remained but had lost salience as cues (e.g. associated vigilance reduced and sleep improved)
<i>Avoidance sub-scale items</i>		
Do you try to remove it from your memory?	As a consequence of cognitive difficulties, Ethel could not comprehend the purpose of this question, as she wanted to remove it from memory but could not	This question remained a challenge for Ethel, as she no longer had a need to remove it from her memory
Do you stay away from reminders of it?	Ethel avoided fires and the smell of fires, and avoided heat sources (e.g. the stove) but remained in her home	Ethel was able to engage in cooking at home (obviously with support due to physical disabilities) and no longer avoidant. She continued to remain in her home
Do you try not to talk about it?	A significant problem at home was that this was a single preoccupation for Ethel and she would talk about nothing less, causing distress for her and her family who also experienced on-going trauma symptoms	Preoccupation and pressured speech absent regarding events
Do you try not to think about it?	As for earlier items, Ethel's inability to inhibit her preoccupation with the event or to conceptualise thinking suppression resulted in confusion (e.g. "I can't")	Intrusions significantly reduced however Ethel remained confused regarding the nature of this question
<i>Arousal sub-scale items</i>		
Do you have difficulties paying attention or concentrating?	A long-standing feature of her learning disability	This remained a fixed feature, although attention to external stimuli increased as a consequence of reduced preoccupation with internally generated (intrusive) stimuli
Do you startle more easily or feel more nervous than you did before it happened?	Responded affirmatively	Stated that this was reduced. However, note relatively high basal levels of arousal and startle due to declining visual abilities associated with her degenerative condition
Do you get easily irritable?	Reported that Ethel would "hit out", shout and get angry very quickly. She would engage in self-harming behaviours with a high frequency. Low tolerance of others	Tolerance of others significantly improved along with significant reduction in the self-harming behaviours associated with elevated arousal and agitation
Are you alert and watchful even when there is no obvious need to be?	Remained constantly vigilant at home, frequently looking out for the perpetrators of the initial incident returning	No longer watchful for "the boys" (perpetrators)
Do you have sleep problems?	Significant sleep problems, including difficulties going to sleep, staying asleep and disturbing others. However, this was acknowledged as a long-standing issue which predated the incident	Sleep difficulties remained but were considered a long-standing feature of her existing conditions. Ethel no longer disturbed her carer with trauma-related safety concerns

short duration, always accompanied in pre-treatment sessions with elevated distress (e.g. rocking, distress noises, repetitive phrases), hyper-vigilance and self-harm (hand-biting). Her main carer who accompanied her to initial sessions was also unable to tolerate protracted accounts of the event, having also been traumatised by the experience[1]. The daughter of the main carer agreed to support Ethel to subsequent sessions and provided historical details.

Due to the issues of carer trauma, it was evident that little discussion regarding the event was facilitated outside of the clinical setting. Further, as the family continued to reside in the home after the fire, there were constant environmental reminders of the incident. This was observed in Ethel's frequent checking behaviours, including constantly checking on her main carer and frequently looking out of the window for people starting fires in the bins outside her home (the cause of the initial incident). This checking also occurred at night, when Ethel would repeatedly enter her carer's bedroom to check she was safe.

2. *Preparation.* A couple of sessions were required to ensure appropriate adaptations to the delivery of EMDR and compliance with core components. Key areas for focus are detailed below.

Distancing technique – Ethel struggled with the concept of intrusive images in direct questioning, but was able to understand the idea of consciously initiated visual imagery and had experienced sight in previous years. The analogy of moving into the distance away from the traumatic incident was acceptable for Ethel, although linked to a concrete example to enhance understanding (i.e. watching her dog move away in the back of a car). As sessions commenced it became clear that Ethel would rapidly become overwhelmed by a full sensory reliving of the event. It was therefore imperative to ensure competency in the distancing technique, and several weeks of practice were contracted prior to engagement in the full treatment protocol.

Safe place – identification of a safe place was relatively simple for Ethel, although she again required several weeks of imagery practice to support ready application. For many clients with ID, a concrete exemplar can be utilised to support diversion to the safe place (e.g. an object or picture).

Positive and negative cognitions – it was possible to elicit positive and negative cognitions from Ethel through examination of her trauma narrative, although she lacked the ability to spontaneously label cognitive events. This highlights a typical response pattern in adults with ID, where natural referencing of internal cognitions occurs but requires support to enable automatic and (eventual) independent labelling of such experiences as “cognitions” (e.g. see: Taylor *et al.*, 2013). It is considered that supported labelling in this context is appropriate, although when engaging the client in a more specifically CBT orientated model additional training would be required to support the intervention (e.g. elements of “hot thought” recognition and subsequent challenge or reattribution).

3. *Assessment.* Obtaining some method of evaluating change during the application of a specific therapeutic procedure is essential to understanding aspects of treatment efficacy.

The Subjective Units of Distress (SUDs) and Validity of Cognition (VoC) scales are typically used during EMDR to gauge change and inform treatment progression. The SUDs represents a self-reported estimate of current level of disturbance and is rated on a 0-10 (10 = worst) scale. The VoC reflects a self-reported estimate of the level of truth associated with the positive cognition and is rated on a 1-7 (7 = true) scale. The EMDR treatment protocol stipulates discrete points at which the procedure switches from the active reprocessing of trauma memories (when SUDs fall to 0/1) and the embedding of the positive cognition (completed when the VoC reaches 6/7).

Ethel was unable to complete typical SUDs and VoC ratings as she lacked number concept and was unable to indicate “more” or “less” by typical methods of adaptation (e.g. distance between hands or the use of external visual stimuli). The use of objective measures of distress were considered (e.g. psychophysiological measures of skin conductance; Barrowcliff *et al.*, 2004), however, Ethel could not tolerate the utilisation of any such measurement devices given that her trauma presentation involved the application of medical procedures immediately following the incident. Ethel could however report if things were “better” or “worse”, which permitted at least some monitoring of change and was used in conjunction with observation of affect to determine shifts in stage of therapy.

4. *Desensitisation.* During the assessment, Ethel only made self-reported reference to “the fire” as the key memory to work with. Interestingly, Ethel reported a further two key memory sequences associated with the fire (identified as “the ambulance” (sequence 2) where she was isolated from her support and rushed off to hospital and being examined on arrival

at “the hospital” (sequence 3), again without appropriate support being available) once the treatment was underway, much to the surprise of her carer as she had not previously recounted these additional elements.

Ethel was registered blind, therefore pursuit of a moving visual stimulus was not possible, although lateral stimulation was still required (e.g. MacCulloch and Feldman, 1996). Different methods of bilateral stimulation were tried (e.g. Shapiro, 2001), with Ethel expressing a preference for alternating hand-taps.

Observation of discernible levels of distress was necessary in regard to continuation of exposure sets. This was due to Ethel's significant difficulties in engaging in lateral stimulation whilst providing verbal feedback of changes in internal sequences and emotional responses. Such significant multiple task loading is likely to be a common area of difficulty in clients with ID. This highlights the importance of understanding the idiosyncratic elements of distress presentation in this clinical cohort, to ensure such difficulties do not become inhibitors to therapeutic delivery.

At the end of each exposure set, Ethel was asked to describe residual internal images. It was apparent that shifts in the recall of the trauma sequence had occurred although details remained limited. Eight sets of exposure ranging between 15 and 30 seconds in duration were applied in each of four sessions prior to installation of the positive cognition.

5. *Installation.* The installation phase involves implementing the positive cognition with the memory target and is evaluated using the VoC scale. As indicated previously, use of a number scale was too difficult for Ethel, such that verbal cues of “better” (or “worse”) were applied along with observation. It is also of note that the difference in scales between the SUDs (0-10) and the VoC (1-7) harbours potential for confusion in this clinical cohort, such that congruence between scales would be recommended for ID populations.

6. *Body scan.* The body scan phase involves identifying any residual physiological sensations associated with the memory and indicates a need for further processing. Ethel was able to indicate experience of internal states, and indeed had a propensity towards internal focus, although this was limited to pointing to areas of sensation with evaluative comments (“good” or “bad”) rather than a reliance on verbalised description. Visual formats with ID populations may be considered to support this process where expressive language is limited, such as use of a drawn body outline marking areas of experienced sensation.

7. *Closure.* The closure phase involves implementation of the identified self-control techniques and debriefing. This was concluded as a shared homework task with her carer's daughter, as the carer remained unable to discuss the incident and continued to present with an unresolved trauma response.

8. *Re-evaluation.* The re-evaluation phase involves reviewing symptomology and identifying any additional target events to be processed. As indicated, whilst the carer was aware of the overarching traumatic incident, engagement in the EMDR process revealed additional discrete trauma events which had not previously been identified. These additional events were then considered as discrete sequences that had different associated cognitions and initial fears (e.g. the fire being “I am going to die”; being in the ambulance “I am trapped and alone”).

Results

Significant improvements were indicated following only four sessions of active EMDR, comprised of eight sets of exposure in each session. Table I demonstrates the significant improvement in trauma-related symptoms as revealed by the CRIES-13. Observations also supported considerable improvements in presentation. In the first session Ethel could barely tolerate being in the therapy room, and showed clear signs of elevated distress when the traumatic incident was discussed. In the final sessions, she presented with a relaxed demeanour and absence of negative affect when discussing the trauma sequences. Mapping against adapted DSM-IV-TR assessment criteria for PTSD (Mevisen and De Jongh, 2010) also indicated a significant transformation, with: a shift from 5 to 1 intrusion criteria symptoms; a shift from 5 to 0 avoidance criteria symptoms; and a return to pre-event levels of irritability,

concentration levels, absent hyper-vigilance and reduced generalisation of startle response. Post-intervention, Ethel was no longer considered to meet diagnostic criteria for PTSD.

Ethel declined the opportunity for follow-up sessions (in the context of the problem being resolved). The offer to contact services for further support if symptoms were to re-emerge had not been initiated by 12-months post-intervention, and this was corroborated by a review of her broader health file, supporting continued amelioration of trauma-specific symptoms.

Discussion and conclusions

This case study outlines the implementation of an EMDR treatment protocol for PTSD within ID. Whilst there is an emerging number of case studies and small case series detailing the efficacy of EMDR in the treatment of PTSD within ID populations, the description of treatment modifications have been broad and generally insufficiently detailed in regard to how it may be applied to this cohort effectively. The current study provides considerable detail regarding the challenges and necessary adaptations faced when working with trauma within this clinical population. The study demonstrates however that these challenges need not restrict access to generally efficacious interventions for complex presentations when supporting service users with learning disabilities.

This particular case demonstrates the utility of the EMDR methodology in the treatment of PTSD with adults with an ID. EMDR may indeed offer an advantageous approach over other recognised interventions, given the low level requirements on cognitive reattribution and behavioural exposure to reminders of the traumatic incident. The present study has demonstrated that EMDR treatment delivery with associated modifications can produce positive results and impact significantly on the life experience of the individual. Moreover, in line with other published case studies (e.g. Mevissen *et al.*, 2011b), the presented intervention was extremely effective in alleviating symptom presentation within relatively few treatment sessions, further demonstrating the clinical utility of the approach.

In regard to the identification and recognition of PTSD in adults with ID, in clinical practice there is a high propensity for the misattribution of symptoms due to communication issues (e.g. Mevissen *et al.*, 2011a) or diagnostic overshadowing (e.g. Reiss *et al.*, 1982). Whilst studies have provided varied estimates of PTSD prevalence in ID populations (see Mevissen and De Jongh, 2010, for review), it is typically accepted that as a vulnerable population, people with ID are more exposed to elevated risk variables over the course of their lives (Hatton and Emerson, 2004; Reiter *et al.*, 2007). These factors raise important questions around the expected and observed prevalence of PTSD in ID, and highlight the importance of the availability and provision of appropriate trauma-focused interventions for this clinical group. Furthermore, the limited literature regarding the use of EMDR within ID raises the wider question of how PTSD is effectively treated for this clinical group within the UK at the present time, particularly given the inclusive nature of the NICE guidelines. There is clearly a need for further evaluation of PTSD treatments in ID populations, such as the establishment of a randomised-controlled trial of interventions for this complex population. It will be important to recognise however that NICE recommended trauma-focused interventions require adaptations within this population. Therefore, they may not be expected to have equivalent rates of outcome as reported for non-ID populations, and some flexibility in treatment protocols may be needed.

In summary, we have presented a case study to demonstrate the successful implementation of EMDR to treat PTSD within a female adult with ID and visual impairment. It is considered a general failing that NICE guidance broadly endorses trauma-focused interventions across children and adults, however provides no consideration of the modifications necessary for adult ID populations. The outlined challenges and protocol adaptations presented here have attempted to address this failing, and provide considerations for clinicians working with such clinical populations to ensure inclusive access to interventions for complex presentations.

Note

1. Ethel's main carer had previously accessed trauma-focused psychological therapy within an adult mental health setting. However, she continued to experience distress, potentially as a result of Ethel's own distress and trauma-related behaviours.

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About the authors

Dr Alastair L. Barrowcliff is a Consultant Clinical Psychologist and Clinical Lead working with adults with learning disabilities in an NHS Foundation Trust in the North West of England. Areas of research interest include trauma, psychosis and adaptation of psychological therapies to support adults with intellectual disabilities. Dr Alastair L. Barrowcliff is the corresponding author and can be contacted at: alastair.barrowcliff@5bp.nhs.uk

Dr Gemma A.L. Evans is a Clinical Psychologist and completed training at the University of Manchester. Clinical and research interests include health psychology and neuropsychology, particularly neurodegenerative and neurodevelopmental disorders.

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