

Challenges in diagnosing Posttraumatic stress disorder in dementia: A case report

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ABSTRACT

Background: Assessment of Posttraumatic Stress Disorder (PTSD) symptoms in individuals with dementia is difficult due to diagnostic challenges like an incomplete self-report, interference of neuropsychiatric symptoms and overlapping comorbid psychiatric symptoms.

Objective: These diagnostic challenges are articulated here and an in-depth evaluation of assessment of PTSD in dementia is given.

Method: A qualitative case design was used including an 88 years old woman, living in a nursing home, with moderate-severe dementia and suspected PTSD. The TRAuma and DEmentia(TRADE)-interview, a semi-structured tool to diagnose PTSD in dementia, was assessed independently by two psychologists, followed by a debriefing in which the outcomes were discussed with the use of informant measures (Neuropsychiatric Inventory-Nursing Home (NPI-NH), the Gerontological Personality Disorders Scale (GPS), Levels of Personality Functioning Scale-Brief Form 2.0 (LPFS-BF 2.0) and Personality Inventory DSM-5-Brief Form (PID5-BF).

Results: TRADE-interview indicated PTSD triggered by a cycling accident with agitation as a neuropsychiatric symptom. Personality assessment indicated features of a cluster C personality disorder (PD) with core features of negative affectivity and detachment. In the debriefing psychologists reported three challenges: attributing symptoms to the past traumatic event, interference of neuropsychiatric symptoms and overlap in symptoms between PTSD and PDs.

Conclusions: Distinguishing PTSD symptoms in those with dementia from neuropsychiatric and PD symptoms requires careful evaluation of all symptoms present. The TRADE-interview can be helpful, but sometimes additional resourcefulness and good clinical considerations are advised.

Introduction

Traumatic stress, especially when present in early childhood, has been found to increase the likelihood of experiencing psychiatric illness

in both mid-life and late-life, of which of Posttraumatic Stress Disorder (PTSD) is the most prevalent (Iqbal et al., 2022; Riedl et al., 2019). PTSD is an independent risk factor for cognitive decline and all-cause dementia (Gunak et al., 2021) and its comorbidity in dementia is estimated

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to be 4.7–7.8 % (Sobczak et al., 2021). Worldwide, the number of people with dementia is skyrocketing; indeed the number of people with dementia will almost double every 20 years to about 115.4 million in 2050 (Prince et al., 2013; Patterson, 2018). Recognizing PTSD symptoms in dementia may contribute to prognosis, as it can inform us how care should be provided (using a trauma informed approach) and can give an indication for treatment (Couzner et al., 2022). Psychotherapies, for example Eye Movement Desensitization and Reprocessing (EMDR) and exposure therapy, can also be efficacious in this group (Driessen et al., 2023; Ruisch et al., 2023).

Diagnosing PTSD in individuals with dementia has several challenges. First, people with dementia often cannot provide a valid life report, underreport psychological symptoms, and have difficulty self-reporting (Martinez-Clavera et al., 2017). This may complicate attributing current symptoms to potentially traumatic events (PTEs) (Curcio et al., 2019), especially in people without a previous documented history of PTSD or so-called 'delayed onset' PTSD (Andrews et al., 2007). In delayed-onset PTSD, people are initially able to cope successfully, but symptoms develop over time. Possible triggers may be loss experiences and cognitive decline.

Second, the presentation of PTSD symptoms in dementia are often difficult to recognize and are then regarded as neuropsychiatric symptoms related to neurodegeneration (Ritchie et al., 2022). For instance, flashbacks could be interpreted as hallucinations, hyper-vigilance as paranoia, and hyper-reactivity as agitation.

In addition, other disorders are often comorbid with PTSD, such as depression, substance use and personality disorders (PDs) (Baltjes et al., 2023). There may also be symptom overlap between PTSD and these disorders, for example problems in affect regulation are present both in PTSD and borderline PDs (Felding et al., 2021). Thus, comorbid disorders should also be considered in diagnosing PTSD in dementia.

Despite, several publications have pointed out diagnostic challenges in assessment of PTSD in dementia (Martinez-Clavera et al., 2017; van Dongen et al., 2022), there are no previous studies which give an in-depth evaluation of this assessment. Recently, the TRAuma and DEmentia (TRADE)-interview was developed to diagnose PTSD in people with dementia (Havermans et al., 2023). The current case report reflects on the diagnostic challenges that may arise, and gives a deeper evaluation of the assessment procedure, using the TRADE-interview.

Methods

A qualitative case design was chosen to generate an in-depth understanding of the complexity of PTSD assessment in people with dementia (using the Case Report (CARE) reporting guidelines) (Gagnier et al., 2013). To achieve this, psychologists who were working at Zuyderland Care nursing home and Mondriaan mental health center (the Netherlands) were approached to give a debriefing after psychological assessment in a case in which there was possible PTSD. Because no extra data were taken, and care was as usual, medical ethical evaluation was not requested. Retrospectively, participant and involved informant gave both signed consents to use their given information for publication.

Case introduction

An 88-year-old Caucasian woman was included after her involved elderly care physician in the nursing home indicated the need for psychological assessment because of her behavior (sadness, resistant to care, dependent behavior) possibly related to previous traumatic events. The woman had been living in a Dutch nursing home for the last three months due to progression of dementia and interfering somatic comorbidity.

Her life report showed that she had been widowed in January 1989. Her husband died suddenly after a four-year illness at relatively young age. The death of her husband was very difficult for her. She had three children on which she had relied heavily after since. In 2019 she was

diagnosed with dementia by a clinical geriatrician (DSM-5: Major Neurocognitive Disorder due to multiple etiologies currently with moderate severity). She has had chronic pain for 30 years after a serious traffic accident in which she was involved with her bicycle and got heavily injured (she was hit by a car), on which she focused more since her admission to the nursing home. Her medical history reported COVID-19, hypothyroidism, chronic kidney failure, and a mastectomy of both breasts. When her children were teenagers, she was treated by a psychiatrist for five years for depression (severity unknown). Her children said that this treatment consisted of medication and a short conversation with the psychiatrist once every two months. She reportedly found this 'a terrible experience' and she stopped treatment. Two years later she was successfully treated for grief at a Mental Health Center for 2 months. Thereafter she felt well for a longer time (length unknown). According to her children, this has helped her at that time.

Since the woman was admitted, nurses noted that, whenever she experienced a lot of pain, she expressed feelings of hopelessness and powerlessness. This happened most frequently when she was alone in her room without distractions. Every dull moment she started talking about the pain. According to the nurses and her children, she required a lot of care and attention and made a strong appeal to them, especially her son. Her family attributed this 'dependent' behavior to her personality. At those moments she perseverated about the cycling accident and her pain. Often in the morning, the pain was perceived with such intensity that nurses found it hard to motivate the woman to get out of bed. She would endorse the pain severity on a scale of 1–10 as a '10+'. However, nurses reported that this intensity was never 'reflected in her facial expressions'.

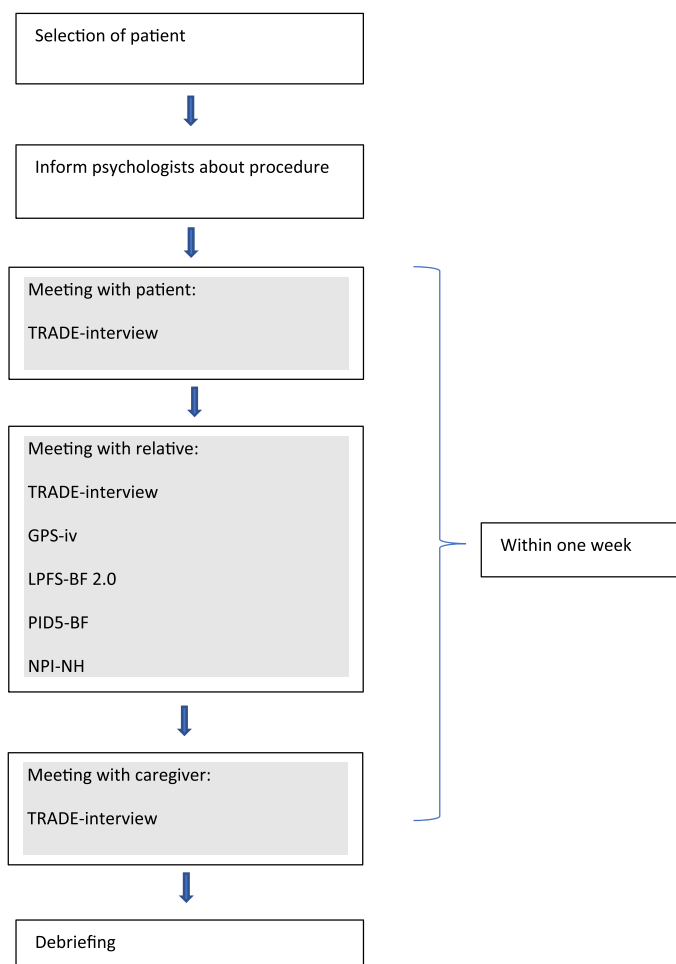
According to her children, the focus on pain complaints had increased simultaneously with her cognitive decline. The psychologist at the nursing home suggested that this might be due to an increased focus on the past and currently fewer distracting activities. Therefore, the psychologist decided to do a life-review, a treatment technique, in which memories are reviewed (Maercker and Bachem, 2013). After this treatment the woman still often recalled negative memories but could recall joyful moments in conversations as well.

Since the woman made limited gains in life review treatment, and continued to report physical pain and dependent behavior, an in-depth assessment was taken to assist in diagnosis and treatment planning. As Fig. 1 shows the procedure. To motivate an in-depth discussion about the diagnostic challenges two independent psychologists (not previously involved in treatment and care of the participant) were involved in the diagnostic procedure; they first independently assessed the findings of the participant in order to subsequently arrive at an undivided consensus PTSD diagnosis, during a debriefing (see Appendix 1). To reduce information bias, the TRADE-interview was taken simultaneously and rated independently.

Measures

The *TRADE-interview* is a semi-structured interview designed to diagnose PTSD, and its severity, in people with dementia. It consists of a self-report, informant and observational questionnaire on PTSD symptoms in the past month (Havermans et al., 2023). PTSD is established if at least one sub-criterion is met in the self-report, informant or observational part on the DSM-5 main criteria A (a stressor), B (intrusion symptoms) and E (alterations in arousal and reactivity). The DSM-5 main criteria C and D do not need to be met, based on expert consensus (literature has shown that these are often absent or difficult to distinguish from neuropsychiatric symptoms) (Havermans et al., 2023). Duration of the symptom must be longer than one month and cannot be explained otherwise (Criteria F, G & H DSM-5) (APA, 2013).

The *Neuropsychiatric Inventory Nursing Home (NPI-NH)* version (Cummings, 2009) identifies neuropsychiatric symptoms and psychopathology in people with dementia based on information from nurses. Research on other translations of the NPI-NH indicates good internal



Legend:

Gerontological Personality disorders Scale (GPS-iv)

Levels of Personality Functioning Scale-Brief Form 2.0 (LPFS-BF 2.0)

Neuropsychiatric Inventory Nursing Home (NPI-NH)

Personality Inventory for Diagnostic and Statistical Manual of Mental Disorders (DSM-5) Brief Form (PID5-BF)

TRAuma and DEmentia-interview (TRADE-interview)

Fig. 1. Procedure of the study

Gerontological Personality disorders Scale (GPS-iv)

Levels of Personality Functioning Scale-Brief Form 2.0 (LPFS-BF 2.0)

Neuropsychiatric Inventory Nursing Home (NPI-NH)

Personality Inventory for Diagnostic and Statistical Manual of Mental Disorders (DSM-5) Brief Form (PID5-BF)

TRAuma and DEmentia-interview (TRADE-interview).

consistency (Selbaek et al., 2008).

The informant version of the *Gerontological Personality disorders Scale- informant version* (GPS-iv); (van Alphen, 2006) which maps habitual behaviors and biographical information was used to establish the presence or absence of PDs. The GPS-iv is based on the current DSM-5 diagnostic manual of mental disorders with a categorical classification approach. It is a reliable and valid screening tool for PDs in (Dutch) geriatric medicine outpatients, with fair to excellent diagnostic accuracy (Meuwissen-van Pol et al., 2020).

Complementary to the GPS-screening instrument, the *Levels of Personality Functioning Scale-Brief Form 2.0* (LPFS-BF 2.0) and *PID-5 – Brief*

Form (PID-5-BF) were assessed due to the dimensional and more intricate approach to measure levels of respectively personality functioning and maladaptive personality traits. The LPFS-BF 2.0 measures personality functioning based on the DSM-5's Alternative Model for Personality Disorders (AMPD) (Weekers et al., 2019). An informant version has been developed, with adequate reliability, validity and good internal consistency in older adults in the U.S. (Stone et al., 2020). The *PID-5-BF* is an informant personality trait assessment scale that assesses five personality trait domains: negative affect, detachment, antagonism, disinhibition and psychoticism (Rossi et al., 2014). There is support for the questionnaire's reliability and factor structure (Anderson et al., 2018).

Results

Psychological assessments took place in January 2022 and debriefing in February 2022. All three children were equally and well involved, but her son was best available. As he was living nearby, he was the primary informal care giver and he knew her story well. Together with her other children it was decided that he would be the best informant. A nurse filled in the observational scales on the TRADE-interview and rated NPI-NH.

The results on the TRADE-interview are shown in Table 1. The traumatic events reported were the cycling accident and sudden death of her husband. Only the cycling accident fulfills the criterion of DSM-5 traumatic event (criterion A). Recurrent memories, flashbacks and nightmares about the accident were rated in criterion B. Avoidance was rated because she has never wanted to ride her bike again (criterion C). She fulfilled criterion D because of reported anger, sadness, and feelings of despair. Irritable affect and sleep disturbances (accompanied by complaining about pain) were present (criterion E). Symptoms lasted more than one month (criterion F) and created distress (criterion G). Overall, symptoms got worse with loss of cognitive functioning, dementia partially attributed to the current severity (Criterion H). In sum, the outcome was indicative for PTSD.

Table 1
Summary of the TRADE-Interview.

DSM-5 Criteria PTSD	Presence and severity of the criterion										
	NO	YES									
Criterion A: The person was exposed to death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence.	0	1	2	3	4	5	6	7	8	9	10
Criterion B: The presence of one (or more) intrusive symptom(s) associated with the traumatic event(s) that started after the traumatic event(s) occurred.	0	1	2	3	4	5	6	7	8	9	10
Criterion C: Persistent avoidance of stimuli associated with the traumatic event(s) that began after the traumatic event(s) occurred.	0	1	2	3	4	5	6	7	8	9	10
Criterion D: Negative changes in cognitions and mood, related to the traumatic event(s), that started or worsened after the traumatic event(s) occurred.	0	1	2	3	4	5	6	7	8	9	10
Criterion E: Marked changes in arousal and reactivity, related to the traumatic event(s), that started or worsened after the traumatic event(s) occurred.	0	1	2	3	4	5	6	7	8	9	10

Note. Bold = The criterion is present with this rated severity. Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5); Posttraumatic Stress Disorder (PTSD); TRAuma and DEmentia (TRADE)-interview.

The results on NPI-NH are shown in Table 2. Agitation was most severe; the patient regularly became upset during moments of care and resisted washing and dressing. Depressive symptoms were sad mood and crying. The participant showed disinhibited behavior by regularly talking to strangers and inappropriately disclosing personal issues. Irritability was rated because of dysphoric mood swings.

On the GPS-iv, the participant scored 3 points (unclear) on the HAB subscale and 6 points (positive) on the BIO subscale, indicating a cluster C PD (items rated: often concerned about her health, hopes that others will solve her problems, fears losing those who care for her, and finds it difficult to stand up for herself).

LPFS-BF 2.0 indicates moderate impairment in personality functioning with a total score on LPFS-BF 2.0 of 22 (mean = 2). Sum scores were 12 on the self-functioning scale (mean = 2) and 10 on the interpersonal scale (mean = 2).

On the PID-5-BF (see Table 3), no heightened average domain scores were found (not higher than 2), although moderate indication for maladaptive personality traits were found on negative affectivity (1.6) and detachment (1.8). The total score of the PID-5-BF was 31 (maximum score = 75) and the overall average score was 1.24.

In sum based on the measurements and clinical assessment the psychologists established a PD with features of negative affectivity and detachment (cluster C PD) was present.

Debriefing of the assessment procedure

There was agreement on 31 items (84 %) of the TRADE-interview and initial disagreement of the two psychologists on six items (16 %):

Self-report: Item A2: It was unclear whether the woman witnessed the passing away of her husband herself and how he passed away. Item D1: Conflicting answers were given about having negative thoughts about herself or the world. She said ‘no’, but reported worries such as ‘why me?’ and ‘what have I done wrong?’. Item E2 (sleep disturbances) was attributed to pain by one psychologist, but not by the other one. As pain could not be objectively verified, consensus was to rate the criterion as present.

Informant: Item B2: Despite conflicting answers, a ‘no’ was rated as distressing dreams have been present in the past, however not in the past month. Item D1: ‘No’ was rated as negative thoughts had always been present, also before the PTE.

Observations: Item E1 and E2: Irritability was concluded to be present however the attribution to the event remained unsure as irritability was also described as a ‘characteristic’ of her.

The psychologists formulated three main diagnostic challenges: 1) potential PTSD symptoms were difficult to attribute to a past PTE (criterion A) with the incomplete life report, and possible other explanations were difficult to exclude, for example with irritability (criterion E1) and disturbed sleep (criterion E2); 2) interference of neuropsychiatric symptoms led to doubts and inconsistencies in the scoring of the TRADE-interview (e.g. criterion H); 3) overlap in PTSD and PDs

Table 2
Results of the NPI-NH.

NPI-NH domain	Present	Severity
Delusions	No	–
Hallucinations	No	–
Agitation/aggression	Yes	Moderate
Depression/dysphoria	Yes	Mild
Anxiety	No	–
Euphoria	No	–
Apathy/indifference	No	–
Disinhibited behavior	Yes	Mild
Irritability/lability	Yes	Mild
Aimless repetitive behavior	No	–
Nocturnal restlessness/sleep disorder	No	–
Appetite/eating behavior change	No	–

Neuropsychiatric Inventory Nursing Home Version (NPI-NH).

Table 3

Results of the PID-5-BF.

Personality Trait Domain	PID-5 BF items	Total Raw Domain Score	Average Domain Score
Negative Affect	8, 9, 10, 11, 15	8	1.6
Detachment	4, 13, 14, 16, 18	9	1.8
Antagonism	17, 19, 20, 22, 25	4	0.8
Disinhibition	1, 2, 3, 5, 6	6	1.2
Psychoticism	7, 12, 21, 23, 24	5	1.0

Personality Inventory for DSM-5–Brief Form (PID-5-BF).

symptoms (for example unexplained avoidance behavior and irritable affect) led to uncertainty in rating.

The psychologist also gave some suggestions for improvement. First, adding clarifying questions beside the TRADE-questions can help the person with dementia in finding answers. Second, in case of contradictory answers from the three sources, it can be helpful to add objective measures to facilitate assessment (such as monitoring sleep). Third, as some questions may remain unanswered. It should be better to score these items as ‘unknown’. This option is currently not included in the TRADE-interview.

Discussion

This case report demonstrated the challenges in diagnosis and assessment of PTSD in individuals with dementia. PTSD was established by the TRADE-interview in this older woman who was residing in a nursing home. Endorsed neuropsychiatric symptoms were agitation, depression, disinhibited behavior, and irritability and a PD with features of negative affectivity and detachment (cluster C PD) was present.

The debriefing of the assessment procedure showed the TRADE-interview to be applicable, but information from the three sources sometimes contradicted each other, resulting in 16 % disagreement between the raters. This illustrates limitations of an unreliable self-report and relying on informant and observer information in diagnostics, as the first diagnostic challenge. Objective measurements, such as monitoring sleep by doing nightly checks) could then possibly be worth adding. Clinical practice shows that family members are sometimes unaware of the past PTE or its details. People experiencing shame tend to hide, deny, and keep the occurrence as well as the details of the PTE a secret for as long as possible (Shi et al., 2021). In dementia, re-experiences are often difficult to hide, but may present inconsistently (for example one day one may tell the story in detail and next day she or he denies). Trauma awareness among those who use the TRADE-interview is relevant to the given answers. Besides, the clinical manifestation of PTSD may differ in dementia; most people do not have sufficient symptoms for a diagnosis (van Dongen et al., 2022) and other symptoms can be present (e.g., screaming, wandering). Thus, attributing possible PTSD symptoms to a past event must be carefully considered.

A second diagnostic challenge is differentiating neuropsychiatric symptoms associated with dementia, or neurodegeneration, with symptoms of PTSD. Reported symptoms of agitation, depression, disinhibition, and irritability on the NPI-NH may be regarded as appropriate for dementia but may also be regarded as unrecognized symptoms of PTSD. Neuropsychiatric symptoms can be explained by many factors and using a bio-psychosocial approach in evaluating these symptoms is recommended. Patient-related factors in this approach include type of dementia (e.g., aggression in frontotemporal dementia), severity of dementia, coping strategies, and physical complaints (Black et al., 2019). Environmental factors, such as the expertise of nurses, building characteristics (noise, light), and social support, may also contribute to neuropsychiatric symptoms (Zuidema et al., 2010). For example,

disturbed sleep was associated with pain in the current case. Pain flashbacks (re-experiencing of pain felt during the PTE), are present in 49 % of PTSD patients, the patient’s pain might be regarded as such (Macdonald et al., 2018). Presence of PTE’s in the past should cue the clinician to consider PTSD.

The third diagnostic challenge in the current case is the interference of comorbid PDs in recognizing PTSD symptoms due to symptom overlap. Indeed, characteristics of PTSD can be indicated by higher scores on the multidimensional personality trait model (James et al., 2015; Krueger et al., 2012). The fact that PDs and PTSD often co-occur has even led to the formulation of complex PTSD (cPTSD) in the 11th Edition of the International Classification of Diseases (ICD-11) (Ford, 2021). For example, avoidance behavior and affect dysregulation, as demonstrated in the case, may be present in both cPTSD and PDs. We suggest that in people with dementia, specifications about the avoidance behavior may be difficult to determine and should be carefully considered using all information available (including a biographic life report if possible) to distinct between these two diagnoses (Havermans et al., 2023). It is described that when both diagnostic criteria of PTSD and PD are met, only PTSD should be assigned unless PD diagnosis contributes clinically useful information that is not sufficiently covered by PTSD (Felding et al., 2021). The added value of using validated tools to diagnose PDs in older adults with dementia is reflected in the reported conflicting results on the GPS-iv and LPFS-BF and PID-5-BF. We suggest that using validated tool would diminish conflicting results.

The strength of this report is the in-depth approach on the complexity of assessment of PTSD symptoms and its interference with other symptoms in individuals with dementia in a real-life setting. But to improve empirical evidence on assessment of PTSD in dementia the TRADE-interview needs further validation for the appropriate norm group.

This in-depth evaluation of PTSD assessment using the TRADE-interview in an older woman illustrates that distinguishing PTSD symptoms in dementia from neuropsychiatric symptoms and PD symptoms requires careful evaluation of all symptoms present. It helps to bring awareness of a possible association of present symptoms with a previous PTE and adding informant information and behavioral observations. Adding clinical diagnostic instruments can be helpful. But linking symptoms to a previous PTE may remain difficult. Difficulties in assessment of PTSD may be due to contradictory answers of information sources, unanswered questions and symptom overlap with other psychiatric disorders which may also be associated with trauma (e.g. depression). Clinicians should then be resourceful in determination of PTSD symptoms. Objective measures (e.g. monitoring sleep) can be used in case of inconsistencies. It is important to note that when doubt of a definitive diagnosis, recognizing a possible PTSD in people with dementia is already clinically relevant.

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CRedit authorship contribution statement

Sjacko Sobczak: Writing – review & editing. **Maaïke van Korde-noordt:** Writing – original draft, Resources, Investigation. **Renske Uiterwijk:** Writing – original draft, Data curation. **Joan M. Cook:** Writing – review & editing, Supervision. **Demi C.D. Havermans:** Writing – review & editing. **Larissa Vossen:** Writing – original draft, Investigation. **Inez Ramakers:** Supervision. **Miranda Olf:** Writing – original draft, Supervision, Methodology. **Sebastiaan P.J. van Alphen:** Writing – review & editing, Supervision, Methodology.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Sjacko Sobczak reports was provided by Maastricht University. Sjacko Sobczak reports a relationship with Maastricht University that includes: employment. Sjacko Sobczak has patent pending to none.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.psycr.2024.100207](https://doi.org/10.1016/j.psycr.2024.100207).

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