PTSD in older adults and people with dementia

Jessica Everdina Ruisch

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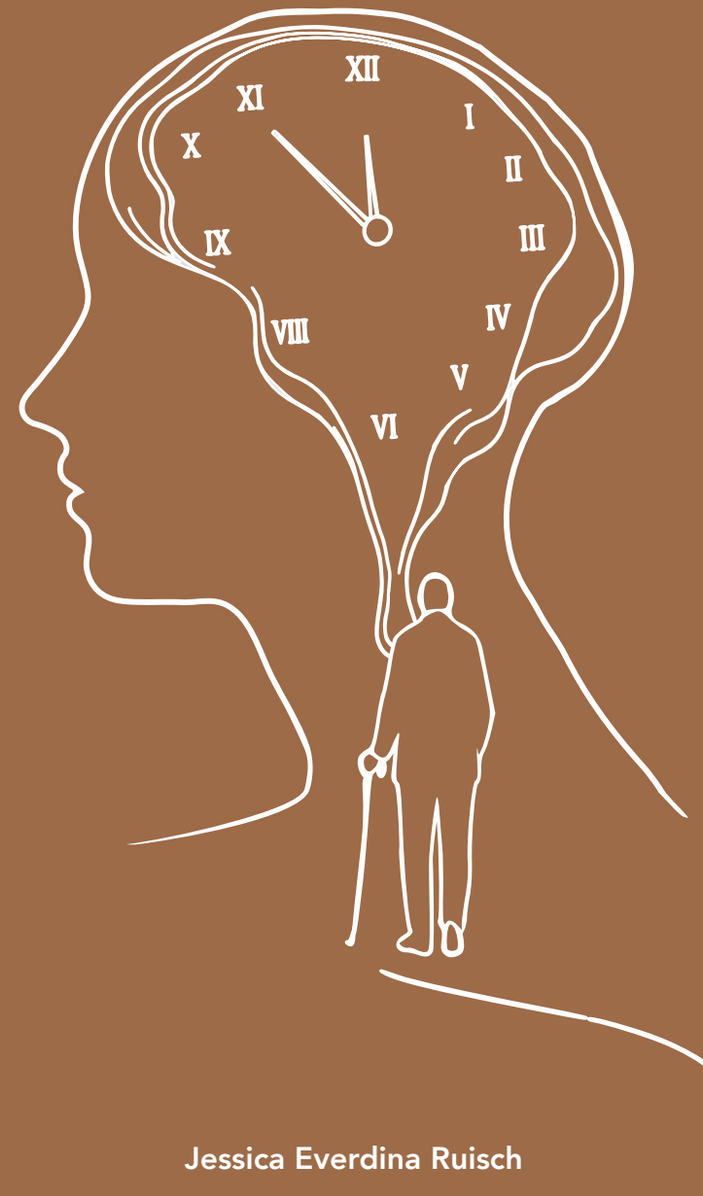
Implications for geriatric care



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Sevagram

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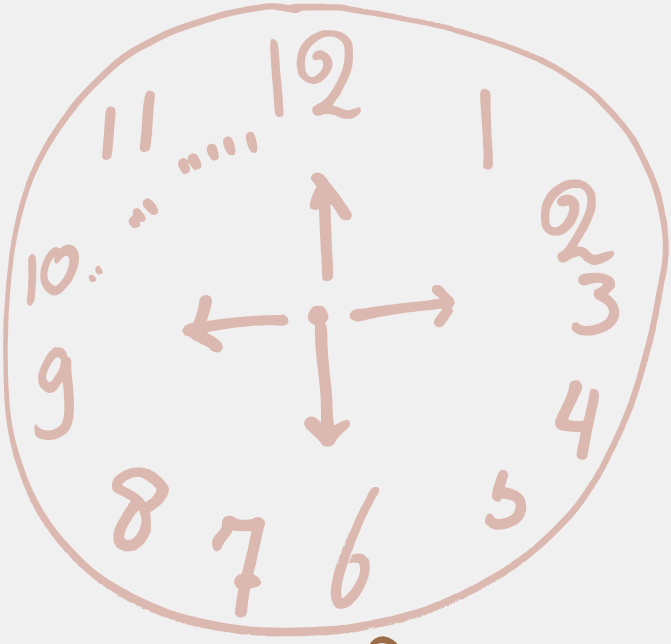
Abbreviations

ACE	Adverse Childhood Experience
ACEs	Adverse Childhood Experiences
BRS	Brief Resilience Scale
CTBS	Childhood Trauma Burden Score
CURA	'Concentreren', 'Uitstellen', 'Reflecteren' en 'Actie ondernemen (NL) Translated to: 'Concentrate', 'postpone', 'reflect' and 'take action'
DSM	Diagnostic and Statistical Manual of Mental Disorders
EMDR	Eye Movement Desentisation and Reprocessing
GFI	Geriatric Frailty Index
METC	Medical Ethical Testing Committee
NPS	Neuropsychiatric symptoms
PDs	Personality disorders
PSS-SR	Post-traumatic Stress Symptom Self-report
PTE	Potentially Traumatic Event
PTSD	Post-traumatic stress disorder
PTSS	Posttraumatische stressstoornis (NL)
TIC	Trauma Informed Care
TRADE	TRAuma and DEmentia
QoL	Quality of Life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Chapter 1

General introduction

General introduction

Clinical practice shows that many people with dementia in geriatric care have experienced an adverse or traumatic life event. These events may have occurred throughout the course of life, from early childhood to older adult life. Some are a one-time occurrence; others recur throughout life. Although some of these experiences occurred many decades ago, the memories haven't necessarily faded away. One of the major psychological disorders that is a consequence of events like these is post-traumatic stress disorder (PTSD). PTSD can occur in older adults and may be present in people with dementia; however, research in this population remains scarce. Given the ageing population and the increasing incidence of dementia (1, 2) research into PTSD in older adults and individuals with dementia is a high priority. Many healthcare professionals may recognize scenarios such as the following:

> **Clinical case**: *'Mrs L is an 84-year-old woman living on the psychogeriatric ward. She was diagnosed with dementia three years ago. She walks around the ward the whole day, tiring herself out but unable to take a rest. The nursing professionals only manage to distract her with activities for short intervals, after which she stands up and walks around again. It is tiring for her, she has lost a lot of weight, and it appears to reduce her quality of life, additionally the care burden for nursing professionals is high. Elaborate examinations find no somatic cause. Medication is prescribed, initially haloperidol is tried but the effect was insufficient, and she experienced side effects such as tremors. Other forms of medication like lorazepam made her somnolent. Further psychological tests showed mild depressive symptoms and a potentially traumatic event (PTE). She had experienced a car accident in her thirties and has feared driving since the accident.' – case based on personal experience*

ACE, PTE, trauma and PTSD

Negative events during life can potentially have adverse consequences for psychological well-being. Especially when these events occur during childhood, such events may influence how a person develops and builds relationships; these experiences are commonly referred to as adverse childhood experiences (ACEs) (3). ACEs encompass a broad range of experiences, from abuse and neglect to household dysfunction and exposure to violence that occur during childhood. A systematic review and meta-analysis found a prevalence of people experiencing one or more ACEs of approximately 42.2% in Europe (4). Studies in the Netherlands have found a similar prevalence of 45.3% of children reporting an ACE (5).

A PTE is any event that can potentially be or become traumatic. The term PTE can refer to specific forms of ACEs that particularly affect an individual's sense of personal integrity and safety. But the difference is that a PTE, can also refer to a situation that occurs after childhood. Examples of PTE are physical or sexual abuse, severe neglect, or exposure to life-threatening situations. An event is considered a trauma when the emotional or psychological impact cannot be coped with completely, a trauma can have long-lasting negative effects on a person. An example of these long-lasting effects that is seen most is PTSD, but trauma is also indirectly associated with other psychiatric conditions, including depression, substance abuse and personality disorders (PDs) (6-8).

The perspective of a PTE, for example an ACE, is especially relevant for older adults and individuals with dementia. Events that occurred in the past can still become a trauma, particularly when cognitive decline reduces coping capacity or the move to a long-term care facility reactivates traumatic memories (9). For example, an older adult with dementia who experienced a car accident such as Mrs L, may be afraid when she sees a busy road or when she crosses this road when walking outside. These examples illustrate how seemingly remote experiences, could potentially become clinically significant across the lifespan. Of the people who experience a PTE, 7-11.1% develop PTSD (6-8). Factors such as female gender, lower level of education, presence of preexisting psychopathology, severity of the PTE (sexual assault, physical abuse) and lower perceived social support after the PTE are examples of known risk factors for the development of PTSD (10). At the same time it is hypothesized that resilience protects from the development of PTSD (11). Resilience is defined as the ability for people to adapt positively to adversity. It consists of both psychosocial and biological aspects and it is often seen as the sum between risk and protective factors such as high psychological wellbeing (12, 13).

Impact of PTSD in older people and people with dementia

The psychological impact of trauma and more specifically PTSD is likely underrecognized in older people. Van Zelst et al. found a point prevalence of PTSD of only 0.9% in older people without dementia (14). Additionally, a comorbidity rate of 4.7-7.8% is suggested of PTSD with dementia, but this is presumably an underestimation due to the lack of a diagnostic tool in this population (15).

Beyond its psychological consequences, post-traumatic stress disorder (PTSD) also affects somatic, functional, and social domains. This underscores the importance of studying and recognizing PTSD and its broad implications in older people and people with dementia. Luckily more insights are emerging on these broad and late life effects of PTSD.

> **Clinical case:** *'Mrs A is a 70-year-old woman with dementia. She daily complains of pain in her hips and genital region, often during the care process. Nursing professionals have discussed this during the weekly visits of the physician and have done regular screenings for bladder infection as possible cause. Sometimes bacteriuria was found and pragmatically treated, other times the results were negative. But the pain symptoms don't evidently decrease. A physical therapist examined her hip joints and pain medication has been prescribed which had minimal effect but did not completely treat her pain. An occupation therapist and a behavioural expert have been involved to assess the care process and gave practical advice to the nursing professionals. One advice was to coach Mrs. A and give her more control in the care process, this has had relatively good effects on the decrease of pain symptoms. In the last multidisciplinary meeting, her daughter shared a past sexual trauma that Mrs A has experienced in early adulthood, could this be related?' – case based on personal experience*

The case above illustrates an anonymized practice-based case, it shows many symptoms possibly related to a PTE. But in people with dementia PTSD symptoms may be difficult to recognize due to the different presentation compared to adults, and the possible overlap with neuropsychological symptoms of dementia. The next section discusses the known impact of PTSD on different domains in older people and people with dementia. This and the described case mark the importance of a broad clinical perspective when caring for older people and people with dementia and PTSD.

Somatic conditions related to PTSD

Many associations are observed between PTSD and somatic disadvantages such as accelerated metabolic and physiological ageing (16). For example, a relation between PTSD and pain is described in multiple studies (17). Additionally, treatment of PTSD is associated with positive effects on heart rate, blood pressure and hypertension (18).

Psychological conditions related to PTSD

It is well known that PTSD is associated with a high burden of psychological comorbidities. PTSD has, for example, been related to a higher prevalence of anxiety disorders, PDs and depression in the general population (19). A review by Baltjes et al. shows this is also seen in older adults with a comorbidity rate of depression of 14.7-62.5% (20). Interestingly, a previous study by Reynolds et al. finds decreased odds of psychiatric comorbidity in older adults with PTSD compared to adults without PTSD (21). This could be a consequence of lower reports of psychiatric disorders in older adults (11.6% >60; 27%-34% 18-59)

(22). Below the relationship with personality and cognition is highlighted more broadly.

The relationship with personality: PTSD is associated with high comorbidity rates of PDs. A review by Baltjes et al. finds a comorbidity rate of 22-26% in older adults over the age of 60 years (20). Other studies find similar comorbidity rates specifically for borderline personality disorder, 22-24% (23). Fox et al. find a comorbidity rate of borderline PDs of 28% in adults aged 60 years and older with PTSD. Additionally, comorbidity rates of antisocial PDs are seen of 4% and of schizotypal PDs of 18.4% in people over the age of 60 years (24). Moreover, the presence of both disorders is associated with a poorer quality of life (QoL) (25). Treatment outcomes of PTSD in people with PDs appear to show less symptom improvement compared to people without PDs (26). Showing the importance of recognizing and addressing both disorders.

The relationship with cognition: PTSD has additionally been associated with cognitive decline in specific cognitive domains as well as in the form of the overarching diagnosis of dementia. PTSD has been associated with accelerated cognitive decline in domains of attention and memory performance. Additionally, studies on PTSD and executive functioning show conflicting results (27). These cognitive changes may contribute to the increased risk of dementia observed in individuals with PTSD, even after controlling for confounders such as medication use, educational attainment, and comorbid conditions (28, 29). All dementia subtypes are potentially associated with PTSD, an analysis by Yaffe et al. finds a highest adjusted hazard ratio for PTSD in people with frontotemporal dementia (HR 2.19) and the lowest for vascular dementia (HR 1.69) (30). Multiple hypotheses exist possibly explaining the relation between PTSD and dementia based on pathological-, neuroimaging- and risk behaviour studies, such as it being a consequence of increased cortisol levels due to stress that negatively impact cognitive functions over time (31). Changes in brain structures have been linked to PTSD and possibly cognitive decline or dementia (32) and a higher risk for metabolic syndrome is seen, which additionally is associated with reduced cortical thickness and dementia (33). Although results in literature are conflicting as a review by Guo et al. does not find sufficient evidence for a specific biomarker explaining an increased risk for cognitive impairment in people with PTSD (34). Thus overall – there seems to be a bidirectional link between PTSD and cognitive decline. Given this association, it is striking how limited research is in people with both PTSD and dementia.

Quality of life in relation to PTSD

PTSD and the consequences and comorbidities described above can affect the QoL, the clinical case of Mrs A highlights the diverse ways in which this can

potentially occur in people with dementia. Not surprisingly, PTSD is related to a poorer health related QoL when compared to people without PTSD (35). Van Zelst et al. specifically studied the consequences in an elderly population, finding that PTSD-symptoms have multiple influences such as an impact on disability and well-being, resulting in more days in bed and more use of healthcare in older people (14). Treatment of PTSD in older people has shown to improve QoL (36). In dementia care QoL is an important and broadly used outcome measure as there is no cure available for dementia (37).

Additionally, higher frailty scores are related to lower QoL scores (38-40). There is also a known association between PTSD and functional outcomes such as frailty. Frailty is common in the older population (41). A recent study in 257 older people in Greece, with a mean age of 75.4 years show that recent traumatic events, not specifically PTSD, in the last years, increases frailty (42). Treatment of PTSD in older adults can improve frailty scores as well as QoL scores (36). Studies including both PTSD, QoL and frailty in people with dementia are important as both PTSD, dementia and frailty are known to affect the QoL, but to the best of our knowledge these studies are not available.

Clinical presentation of PTSD in older adults and people with dementia

> **Clinical case:** *'Mr. T is a 84-year-old man with a mild-moderate dementia. He has recently moved to the long-term care facility. He is friendly and enjoys company of other residents during the day. But in the evening, he is reluctant to go to bed and nursing professionals struggle to convince him to go to bed. At night he is anxious. He often shouts out for the nursing professionals for help. They tell him he is safe here, but that doesn't reassure him for a long period of time. With the minimal presence of nursing staff at night it is hard for them to timely respond to his calls for help. In the informant history his wife mentions he wasn't this anxious when living at home with her, but he did experience nightmares occasionally. Consultation by psychologist leads to Mr. T sharing his fear for the night, because when in bed he thinks about his time in a prison camp on Java during WOII. When he falls asleep, he is awakened by nightmares of these same events. Changes in mood and cognition are not registered or are related to his dementia diagnosis. Because of this Mr. T does not meet the diagnostic criteria of PTSD, but he does have clear symptoms of his past traumatic event such as avoidance and sleep disturbances' – case based on personal experience*

PTSD exerts a diverse impact across the lifespan and as shown above, affects not only adults but also older people. However, lifetime prevalence of PTSD in older adults is reported lower than in younger adults (23.83% in 16-34; 2.44% in age 75+ years) (8). One factor contributing to this lower prevalence of PTSD in people with dementia, could be a differences in clinical symptom presentation. This could lead to the diagnostic criteria of PTSD not being met (43). Additionally, these symptoms are potentially misinterpreted as neuropsychiatric symptoms (NPS) due to neurodegeneration (43-45).

NPS are non-cognitive symptoms of dementia. Common examples of NPS occurring in people with dementia are depression, apathy, and anxiety with a 5-year prevalence of 77%, 71% and 62% respectively (46). NPS are present in 97% of people with dementia along the course of the disease (46, 47). As mentioned above these NPS not only heighten the care burden for nursing professionals, it also significantly influences the QoL of people with dementia (48, 49). People with dementia and PTSD can possibly show similar symptoms as the NPS described above, risking the misinterpretation of these symptoms (44). Mr. T described in the previous case is anxious and he frequently shouts for help. A review of case reports by Van Dongen et al. confirms a different symptom presentation of PTSD in people with dementia when compared to the DSM-5 criteria: avoidance is seldomly reported and wandering/roaming around and screaming is seen more frequently (50).

But why do these symptoms start in late life? Research shows that as a consequence of dementia and ageing (less social support and negative health changes), people experience more PTSD symptoms, the memories of the PTE may appear more realistic and symptoms can be more difficult to inhibit (51, 52). Dementia can also increase sensitivity and reactivity to a PTE, making it harder to avoid triggers and regulate emotions when presented with triggers of the trauma (9, 50). Additionally, living in a long-term care facility can result in the confrontation with new trauma related triggers such as being in busier areas more often and not being able to leave the ward. For Mr. T, being alone at night, without his partner, could possibly be the trigger of the increase in anxiety and nightmares.

Besides the consequences of these symptoms on the person with dementia the presence of (new) PTSD symptoms also affect the nursing professionals. The nursing professionals provide geriatric care for people with dementia and are also faced with these symptoms. This possibly makes it harder to provide the needed care and help someone when experiencing symptoms such as screaming and wandering, as seen in case above. NPS, like anxiety or irritability, are known to cause high levels of distress in nursing professionals

(53) highlighting the importance of considering the effect of PTSD symptoms on the nursing professionals as well.

Diagnostic challenges of PTSD in older adults and people with dementia

As illustrated in the cases, diagnosing PTSD in people with multiple comorbidities both somatic and psychological is not straightforward. Validated diagnostic tools to access PTSD in the older adult population are limited possibly another factor contributing to it PTSD being underdiagnosed in people with dementia (54). To improve diagnostics of PTSD in people with dementia the TRAuma and DEmentia (TRADE)-interview was developed (55). This interview contains questions for the person with dementia, the nursing professional, and an informant (such as a family member or friend). It combines information on the presence of PTEs and the symptoms related to trauma such as intrusive symptoms (recurring memories, nightmares and flashbacks), and changes in arousal and reactivity (irritability or sleeping problems). These symptoms do not only affect a person with dementia but also the formal and informal caregivers close to this person. This emphasizes the need to understand and recognize the symptoms so treatment options can be considered.

Treatment of PTSD in older adults and people with dementia

Although many validated treatment forms for PTSD exist, older adults receive low rates of treatment with <25% receiving pharmacotherapy and 0% receiving psychotherapy for PTSD (43). This is possibly a consequence of the limited number of studies performed in older adults. Although studies of PTSD treatment in older adults are limited, the studies that have been done show for example; improvement in frailty and QoL after EMDR (36) and significant clinical improvement of the clinical administered PTSD-scale after prolonged exposure (56, 57). Research of PTSD treatment in people with dementia is even more limited. To the best of our knowledge only case reports exist describing treatment of PTSD in people with dementia. For example, case reports describe pharmacological interventions (58, 59), or forms of psychotherapy such as EMDR, prolonged exposure and cognitive behavioural therapy (60-62). Emphasizing the underrepresentation of this growing population and the shortcomings in the provided treatment options.

Knowledge gaps in PTSD in older adults and people with dementia

The described cases of Mrs. L, Mrs A. and Mr. T are three of many clinical cases reflecting the diversity of trauma and clinical presentation of PTSD in older people and people with dementia, also highlighted in recent literature (43, 50). This different clinical presentation makes diagnostics and recognition

of PTSD in people with dementia a challenge for healthcare professionals. Additionally, due to the diverse and broad clinical impact, the implications for geriatric care involve many different care professionals. Nursing professionals have an intensive involvement with their clients and care burden for the nursing professionals can be increased by symptoms possibly related to trauma. Better recognition of PTE in people with dementia could lead to more understanding and where needed support for nursing professionals. When a person is diagnosed with PTSD the treatment options are broad but studies in older adults are limited, it has been shown that frailty and QoL can potentially improve upon treatment in older adults (36). Psychologists could benefit from further research to increase evidence on different forms of psychotherapy. These treatments are possibly feasible in people with dementia as well, but to date only described in case reports in this population (58, 59) (60-62). In addition to the practical knowledge gaps found in clinical care there are also knowledge gaps in scientific research. These identified gaps, against a background of an ageing population and increasing prevalence of dementia (1), clearly point to the need for studies on PTSD in populations of older people and people with dementia to fully address the implications for geriatric care.

Context of this thesis

The knowledge gaps and cases described above point to the broad impact of PTEs and PTSD on this population and highlight the effects on the individual but also on people across many disciplines involved in geriatric care. In this thesis, geriatric care refers to all forms of specialized healthcare for older adults, including care at home and care in long-term care facilities. These facilities most commonly include nursing or care homes but can also entail psychiatric care facilities.

To take a first step in the improvement of care for older adults and people with dementia and PTSD we should focus on this broad clinical context with the main research question 'What are the implications of PTSD in older adults, particularly those with dementia, for geriatric care?'. Accordingly, to answer this main research question the following sub-questions will be addressed in this thesis:

1. Do ACEs and / or PTSD symptoms impact cognitive performance in older adults?
2. What are feasible treatment options for PTSD in people with a diagnosis of dementia?
3. What is the impact of PTSD on quality of life in people with dementia in geriatric care?

4. What is the impact of caring for people with trauma and dementia on nursing professionals in geriatric care?

Dissertation aims and outline

While memory deficits are a core symptom of dementia it is not possible to choose which memories are forgotten. The current thesis will focus on PTSD in older adults and people with dementia providing a first step in answering the research questions above.

To answer the first research questions this thesis will analyse adverse childhood experiences in relation to late life cognitive performance in people >60 years of age without dementia in **chapter 2**.

For the second research question **chapter 3** will provide a structured literature review of the possible treatment forms of PTSD in people with dementia. Next, in **chapter 4**, a case report will be presented that highlights the importance of recognizing PTSD in a person with dementia and it will describe the feasibility of EMDR.

The third research question is addressed in **chapter 5. Chapter 5** summarizes the protocol of the TRAuma and DEmentia (TRADE)-study, the foundation of a multicentre cross sectional and prospective study looking at the diagnosis and treatment of PTSD in people with dementia living in long-term care facilities. **Chapter 6** examines the relation of PTSD symptoms and PTSD mediated by frailty on QoL using the TRADE-study database.

For the final research question **chapter 7** presents the results of a qualitative study aimed to explore the increased care burden by exploring the moral distress nursing professionals face when caring for people with dementia and trauma.

Lastly, **chapter 8** consists of a general discussion presenting the overall findings of this thesis in relation to the clinical implications and following steps for future research are highlighted.

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Chapter 2

The association of childhood adversity and post-traumatic stress symptoms with cognition in older adults: a cross-sectional study

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Abstract

Aim and objectives: Adverse childhood experiences (ACEs) and post-traumatic stress symptoms can have long-term consequences such as cognitive impairment. This study aimed to examine this association in older adults, ≥60 years.

Methods: This cross-sectional study included healthy controls (n = 63) and individuals with personality disorders (PD, n = 46) from the 'PhArmacotherapy aND pOlypharmacy in oldeR Adults' study. ACEs were assessed using the childhood traumatic burden score (CTBS), post-traumatic stress symptoms using the Posttraumatic Symptom Scale Self-Report (PSS-SR) and cognition using a compact test battery including memory and executive functioning. Multiple linear regression controlled for confounding effects of age, gender, education and PD.

Results: The results of this study indicate that ACEs do not influence memory or executive functioning in this population. On the contrary, higher PSS-SR scores are associated with lower scores of executive functioning. Factors such as higher age, female gender, presence of PD and lower level of education are associated with poorer test outcomes.

Conclusions: ACEs are not associated with impairment in memory and executive functioning, but post-traumatic stress symptoms are negatively related to executive functioning.

Clinical implications: Clinicians working with older adults should consider routine assessment of trauma symptomatology, particularly in cases of unexplained executive functioning deficits.

Introduction

Adverse childhood experiences (ACEs) are highly prevalent, with a meta-analysis of 206 studies estimating that 6 in 10 individuals report experiencing at least one ACE (1). ACE is a term used to describe a stressful event that can have negative effects on the well-being of a child (2). ACEs may include, among others, an experience such as household dysfunction, abuse or neglect (emotional, sexual and/or physical) (2). ACEs have negative consequences on multiple aspects of psychological and physical domains such as more ACEs leading to more behavioural problems in children (3, 4) and the presence of chronic health conditions in adults (2-5). ACEs are also known to influence long-term health outcomes such as increasing the risk of acquiring dementia and the presence of personality disorders (PDs) (6-10). The global population is aging rapidly, with the proportion of people aged 60 and over increasing from 12% in 2015 to an expected 22% by 2050. (11). The prevalence of cognitive disorders such as dementia is also rising. These disorders significantly increase the caregiver burden and decrease quality of life (12, 13). Improving insight into ACE in relation to cognitive functioning in older people with comorbidities, such as personality disorders, is valuable. This because it could potentially benefit personalized care and increase cognitive resilience in the future, if this factor is modifiable.

There is a growing but varied body of evidence suggesting a negative association between ACEs and cognitive functioning (14-18). Research indicates that children exposed to trauma have greater cognitive deficits compared to children in healthy control groups (17). Specific types of childhood trauma appear to have distinct long-term effects. Psychological abuse during childhood has been linked to poorer outcomes in working memory capacity, verbal recall and attention ability in adulthood (14); physical neglect has been associated with impaired memory performance; and emotional abuse with deficits in spatial working memory (15). On the contrary, studies in holocaust survivors show less cognitive deficits (MMSE <24/30) in holocaust survivors aged 85-90, but no difference over the age of 90 (19). Golier et al. find the presence of PTSD in holocaust survivors (mean age 68.6 years) to be related to poorer cognitive functioning in memory performance but not the survival of the holocaust itself (20). However, previous mentioned findings are based on studies in younger and middle-aged adults or specific types of ACE, and research on the long-term cognitive consequences of diverse ACEs in adults over the age of 60 remains limited. One study measuring verbal fluency in older adults reports a lower risk of cognitive impairment after being exposed to physical, mental or sexual abuse as a child (18). But when analysing recent adverse events no significant effect on cognitive performance is found to be present (18). Whereas other studies find that in older adults, with a mean age of 83, physical neglect during

childhood is associated with lower scores on global cognition (a mean score of 10 neuropsychological tests on different cognitive domains), but this study does not differentiate between different cognitive domains or current post-traumatic stress symptoms (16). These inconsistencies point to the need for further research focused specifically on cognitive performance in older adults with a history of ACEs.

Psychological trauma, including ACEs, may have multiple long-term consequences such as depression, anxiety and PTSD (21, 22). Individuals diagnosed with PTSD exhibit greater global cognitive decline compared to those without PTSD (23, 24). Besides studying the diagnosis of PTSD, it is also possible to study post-traumatic stress symptoms. Post-traumatic stress symptoms are symptoms such as unwanted or upsetting memories, nightmares and losing interest in activities (25). Emerging research suggests that these symptoms negatively affect cognitive functioning. Moreover, Poff et al. (2024) found that higher levels of post-traumatic stress symptoms are associated with poorer self-reported memory and overall cognitive function (26). These findings suggest that post-traumatic stress symptoms may be an important mechanism linking early trauma to cognitive decline in later life. Moreover, PTSD and trauma exposure are highly prevalent among individuals with PDs, a group known to have experienced more ACEs than the general population (9, 10). In fact, 22–26% of people with PTSD are estimated to have a PD, and PDs themselves have been associated with cognitive impairments (27). Despite these interconnections, older nonveteran populations especially those with complex psychiatric profiles remain underrepresented in trauma research.

To our knowledge, no previous research has investigated the combined effects of ACEs and current post-traumatic stress symptoms on cognitive performance in older adults. We hypothesize that older participants with more ACEs perform worse than participants with less ACEs on a test battery examining memory and executive functioning. Additionally, we hypothesize that post-traumatic stress symptoms at time of testing are of negative influence on test performance. Given the established associations between ACEs, PTSD, PDs, and cognitive impairments, the current study controls for the presence of PDs to better isolate the effects of trauma and current stress symptoms on cognitive outcomes.

Methods

This study follows an observational comparative cross-sectional research design and is a subsection of the PANDORA study. The main results of the PANDORA study have been described elsewhere (28, 29). The PANDORA study specifically includes participants with PDs and healthy controls (HC) so we included PD presence as confounders in the analysis (28, 29).

Setting

Data for this study was collected between 2020 and 2023 in the Netherlands.

Participants

The current study includes both males and female participants which are included from the PANDORA study. The participants consist of HC (n= 63) and participants with a PD (n= 46) from the general population. Inclusion criteria for the participants with PD are 1) 60 years or older (2) presence of a PD diagnosis based on the DSM-5. Participants are excluded in case of (1) a diagnosis of dementia (2) physical handicaps interfering with the execution of the cognitive tasks and (3) hospitalization. Eligibility to participate is checked by their therapist. The HCs are recruited via posters, flyers and online advertisement. Their eligibility is checked by the researcher and inclusion criteria are (1) 60 years or older and (2) not receiving care for a psychiatric disorder. In the current paper we include the participants from the PANDORA dataset who have: (1) completed a combined PSS-SR questionnaire and/or trauma burden scale (CTBS) (2) performed at least one of the cognitive tests (n=109).

Ethical consideration

The study protocol complies with the Declaration of Helsinki and has been granted approval from the Medical Ethics Committee of Zuyderland Medical care (METCZ20180104). Prior to participating, participants are fully informed and written consent is collected. The researchers handle all data in accordance with the Dutch Data Protection Act.

Measures

All the measurements are taken on one day in approximately one hour at the Clinical Centre of Excellence for Older Adults with Personality Disorders, Mondriaan Mental Health Center. Both the PD and the HC group receive the same tests. Additionally, the HC group receive the biographic information questionnaire were demographic information (e.g. Diagnostic and Statistical Manual of Mental Disorders-5 (DSM 5) classification code, gender, date of birth, marital status, current somatic complaints and therapy in mental health care) is collected. Level of education is reported according to Dutch 'standaard

onderwijsindeling (SOI) 2016' which is based on the international standard classification of education (ISCED 2011). For the PD group this information is collected from the electronic health record (2017; Quarant®).

The Childhood Traumatic Events Scale (CTES) is used to examine ACEs (28, 30-32). The CTES assesses different domains of childhood exposure to trauma before the age of 17, namely: death of close friend or family member, problems in household, traumatic sexual experiences, being a victim of violence, experienced severe illness or injuries and other important experiences. The questionnaire asks whether the person experienced the aforementioned events. Additionally, participants are instructed to rate how traumatic the experience was at that time (Likert scale 1= not at all; 7= a lot). The sum of these scores provides the Childhood Traumatic Burden Score (CTBS). Resulting in a score ranging from 0 to 42. The higher the CTBS, the higher the traumatic burden has been (Lai et al., 2016).

Posttraumatic Symptom Scale Self-Report (PSS-SR) is used to measure current post-traumatic stress symptoms. The PSS-SR is a self-report questionnaire based on the DMS-IV designed by Foa and colleagues (1993), assessing 22 post-traumatic stress symptoms. The PSS-SR is a validated questionnaire in a population of participants aged 18-65 (33). Participants are instructed to note how often these symptoms have been present in the last week using a Likert scale (0= never; 1= once a week; 2= two till four times a week; 3= at least five times a week). Total PSS-SR score is calculated as the sum of these scores. Resulting in a highest possible score of 66 and lowest possible score of 0; higher scores indicating a higher frequency of current PTSD complaints.

Cognitive functioning is examined using three tasks. A short test battery is used adjusted to be applicable in older adults, which requires approximately 20 minutes to complete, including: Memory and executive functioning. Table 1 provides a summary of the assessment tools used.

Verbal memory
Verbal memory is measured using the 12 Word Learning Task (WLT) with immediate and delayed recall. The WLT consists of a list of 12 written words in Dutch (34). The words are shown one by one on a computer screen. After all the 12 words are presented, the participant verbally recalls as many words as possible. The list is repeated three times, each round the same words in the same order are presented. The sum of remembered words after each trial (WLT immediate) is calculated resulting in a maximum score of 36. For the WLT recall the total amount of remembered words is noted after fifteen minutes

(WLT recall) with a maximum score of 12. A higher score reflects better memory performance.

Executive functioning

Executive functioning is assessed using the shortened version of the Concept Shift Task (CST); only part C of the original CST was used, which assesses cognitive flexibility (35). Participants are instructed to cross out the digits and letters alternately in numerical and alphabetical order on paper. A practice round is included to familiarize the participant with the task. The time needed in seconds to complete the CST (CST-time) and the number of errors (CST-errors) is noted. The dependent variable used is a combined z-score of CST-time and a negative of CST-error, with a higher z-score reflecting better performance (36, 37).

Additionally, executive functioning is examined using a computerized version of the Tower of London (TOL) (38). The task consists of six rounds in which the correct answer is either two, three or four steps. A practice round is included to familiarize the participant with the task. The number of total correct answers (TOL-correct) is noted. Additionally, the mean time needed in milliseconds (ms) is recorded (TOL-time). The dependent variable used is a combined z-score, subtracting TOL-time z-score from the TOL-correct z-score, with a higher combined z-score reflecting better performance.

Table 1. Overview of the assessment tools

Cognitive domain	Specification	Test name (abbreviation)
Memory	Immediate recall	12 Word Learning Task (WLT)
	Delayed recall	12 Word Learning Task (WLT)
Executive functioning		Concept Shift Task (CST)
		Tower of London (TOL)

Data analysis

Analyses are conducted in JASP (0.18.3). The data is analysed using multiple linear regression models. Model assumptions (normality, linearity, homoscedasticity, and independence) were verified. Regarding multicollinearity CTBS scores and other confounders are only moderately correlated. To test the primary hypothesis, the PSS-SR or the CTBS score was included as the predictor, with cognitive test performance as the dependent variables. Age, gender, level of education and presence of PDs were entered as covariates to control for general effects (39-41) (figure 1). Because this was a retrospective study, an a priori power calculation was not performed. Instead, results are reported with

confidence intervals to convey the precision of the estimates. Missing data was not imputed; a complete case analysis was performed. Significance was set at $p<0.05$. Exploratory post-hoc analysis were performed to assess the potential differential effects of distinct ACE categories on cognitive performance.

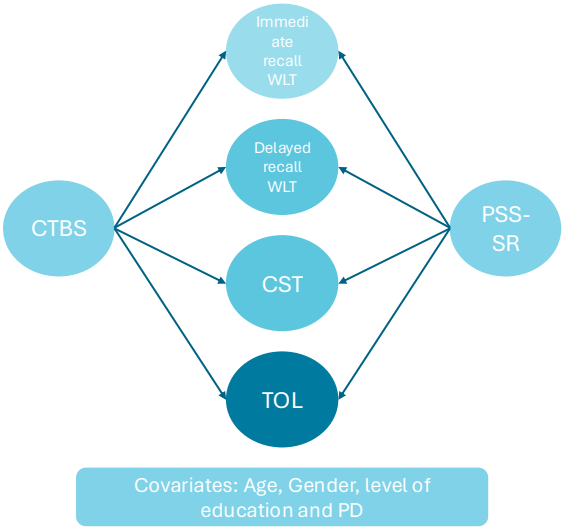

Figure 1. Overview of the different linear regression models performed
Caption: CST = Concept shift task, CTBS = childhood trauma burden score, PD = personality disorders, PSS-SR = Posttraumatic Symptom Scale Self Report, TOL = Tower of Londen, WLT = word learning task

Results

Sample characteristics

The mean (SD) age of the study population was 68.14 (5.93) years. Other sample characteristics are shown in table 2. Overall, the most frequently reported ACEs in the investigated population were death of a family member (n=62). Whereas violence and sexual abuse were seen least frequently (n=20 and n=20); with most cases of violence and sexual abuse in people in the PD group (n=12 and n=14 respectively).

Table 2. Sample characteristics (n=109)

		Percentage (n)
Gender	Male	52.7% (n=58)
	Female	46.4% (n=51)
Level of education	Low	13.6% (n=15)
	Middle	34.5% (n=38)
	High	49.1% (n=54)
	Missing	2.2% (n=1)
Personality disorder		41.8% (n=46)
Type of trauma (CTES)	Violence	18.2% (n=20)
	Sexual trauma	18.2% (n=20)
	Disease	30% (n=33)
	Death family	56.4% (n=62)
	Problems family	22.7% (n=25)
	Other trauma	43.6% (n=48)
		Mean (SD)
Childhood Traumatic Burden Score (CTBS)		8.385 (8.658)
Post-traumatic stress symptoms (PSS-SR)		13.358 (13.709)

Caption: CTES = childhood traumatic events scale, SD = standard deviation

Memory: No effect of childhood traumatic burden score

Multiple regression analysis examined the extent to which CTBS, level of education, age, gender and PD predicted memory performance (see Figure 2A). The regression models for immediate recall (n=107) (F (6,100) = 5.728, p <.001); and delayed recall (n=107) (F (6,100) = 3.512, p=.003); were significant and explained respectively 25.6% and 17.4% of the variance in test performance. When controlling for age, gender, education and PD, CTBS score did not predict performance on the immediate recall (B=0.002, SE=0.058, CI = -0.113 - 0.117, p = .977).

For delayed recall the regression model was also significant, F (6,100) p=.003, and explained approximately 17.4% of the variance in test performance, R^2=.174. When controlling for age, gender, education and PD, CTBS score did not predict the delayed recall (B=0.020, SE-0.029, CI= -0.038 – 0.078, p = 0.496).

When examining the confounders, PD significantly predicted the performance of immediate recall (p = 0.013); people without a PD had on average higher scores. PD significantly predicted the performance on delayed recall (p = 0.05); people without a PD scored better. Moreover, age predicted both immediate (p =.001) and delayed recall (p = 0.001). Older age was negatively associated to test performance. In the regression model in which gender was a covariate, gender was a significant predictor of immediate recall (p = 0.009). Where being female was positively associated with the performance on immediate recall. The other confounders were not significant and are shown in supplement 1 together with the B, SE and CI of the significant confounders.

Exploratory follow-up analysis regarding the type of trauma revealed that the trauma type 'other' significantly predicted the delayed recall in the regression model (B= 1.332, SE=0.618, p= 0.034). The other trauma types were not significant. No significant results were found in the exploratory analysis of the immediate recall (all p's > 0.280).

Executive functioning (CST): No effect of childhood traumatic burden score

The multiple regression analysis revealed a significant association for executive functioning (CST) and CTBS score, (n=107) $F(6,100)$ =2.943, p = .011. It explained approximately 15.0% of the variance in executive functioning (CST) performance, R^2=0.150. When controlling for age, gender, education and PD, CTBS score did not predict performance on the executive functioning (CST) test (B=-0.011, SE = 0.019, CI= -0.049 – 0.028, p = .579; n=109; see Figure 3A).

When examining the confounders in the regression model, education was a significant predictor of executive functioning (CST) for both middle level of education (p=0.027) and high level of education (p=0.012). This finding suggests that, compared to low education, middle and high on average, performed better on executive functioning (CST), holding other variables constant. The other confounders were not significant and are shown in supplement 1 together with the B, SE and CI of the significant confounders.

Exploratory follow-up analysis regarding type of trauma revealed that trauma type 'disease' was negatively associated with executive functioning (CST) test performance (B=0.763, SE= 0.353, p = 0.033).

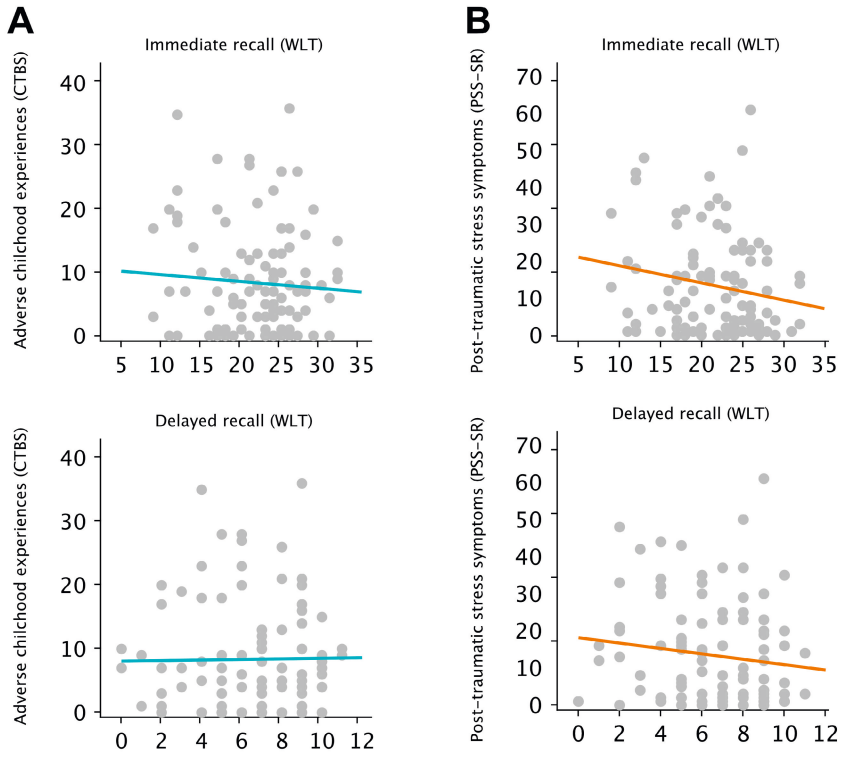

Figure 2. Scatterplots of the CTBS (panel A) or PSS-SR (panel B) score and the memory performance scores, not corrected for confounders.
Caption: Childhood Trauma Burden Score (CTBS); *Posttraumatic Symptom Scale Self-Report (PSS-SR);* 12 Word Learning Task *(WLT)*

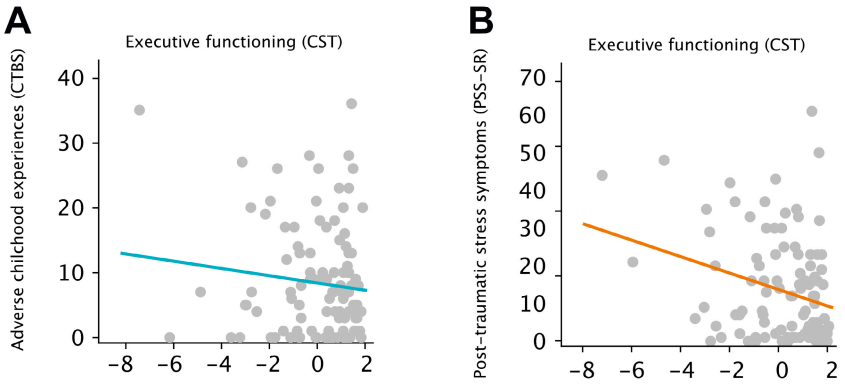

Figure 3. Scatterplots of the CTBS (panel A) or PSS-SR (panel B) score and the executive functioning (CST) performance scores, not corrected for confounders.
Caption: Concept Shift Task (CST); Childhood Trauma Burden Score (CTBS); Posttraumatic Symptom Scale Self-Report (PSS-SR)

Executive functioning (TOL): No effect of childhood traumatic burden score

The regression model was significant for executive functioning and CTBS score, (n=86) $F(6,79) = 6.162$, p=<0.001, and explained approximately 31.9% of the variance in test performance, R^2=0.319. When controlling for age, gender, education and PD, CTBS score did not predict performance on executive functioning (TOL) (B=0.009, SE = 0.017, CI= -0.025 – 0.043, p = 0.590, see Figure 4A).

When examining the confounders in the regression model, PD predicted executive functioning where people in the HC group performed better compared to people with PD (p = .028). Moreover, both middle level of education (p = 0.020) and high level of education (p = 0.017) predicted executive functioning. A lower level of education was related to lower test scores. The other confounders were not significant and are shown in supplement 1 together with the B, SE and CI of the significant confounders.

Exploratory follow-up analysis regarding type of trauma revealed no trauma type significantly effected executive functioning (TOL) (all p's >.205).

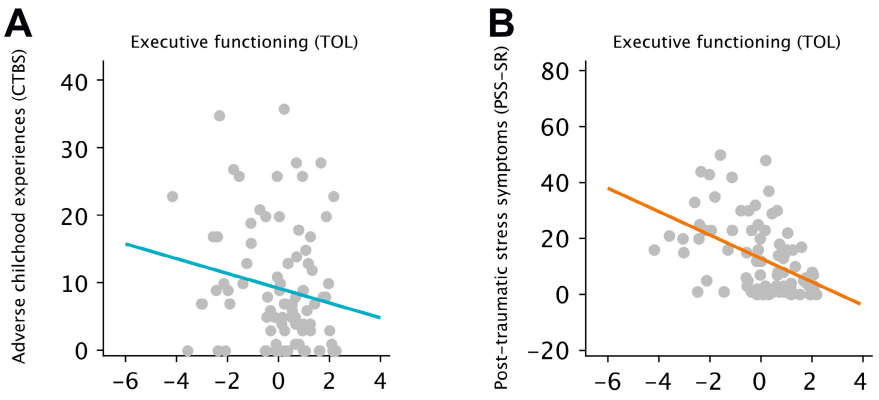

Figure 4. Scatterplots of the CTBS (panel A) or PSS-SR (panel B) score and the executive functioning performance scores, not corrected for confounders.
Caption: Childhood Trauma Burden Score (CTBS); *Posttraumatic Symptom Scale Self-Report (PSS-SR); Tower of Londen (TOL*

Memory: No effect of current post-traumatic stress symptoms

The multiple regression model with PSS-SR for both immediate recall and delayed recall was significant, (immediate: (n=104) F (6,97) = 5.149, p <.001; Delayed: (n=104) F (6,97) =3.353, p = 0.005), explaining 24.2% and 17.2%

respectively of the variance in test performance. PSS-SR did not predict performance on immediate recall (*B* = -0.024, SE=0.048, CI = -0.121 - 0.072, *p* = 0.615) or on delayed recall (*B* = -0.014, SE=0.025, CI = -0.063 - 0.035, *p* = 0.583) when controlling for age, gender, education and PD (see Figure 2B).

When examining the control variables in the regression model, lower age was a significant predictor of better performance on both immediate (*p* =0.001) and delayed recall (*p* = 0.02). Where increasing age was negatively associated to test performance. Gender predicted immediate recall (*p* = 0.018). Where being female was positively associated to the outcome of the immediate recall. The other confounders were not significant and are shown in supplement 1 together with the B, SE and CI of the significant confounders.

Executive functioning (CST): Current post-traumatic stress symptoms negatively affect performance

The multiple regression model with PSS-SR and *executive functioning (CST)* test performance was significant (n=104) F (6.97) = 4.319, *p* <0.001, explaining 21.1% of the variance in test performance, R^2=.211. PSS-SR predicted performance of on the *executive functioning (CST)* task (*B*=-0.042, SE = 0.016, CI= -0.074 – -0.011, *p* = 0.009). This result indicates that higher self-reported posttraumatic stress symptoms were associated with lower performance on the *executive functioning (CST)* task, even after controlling for age, gender, education and PD (see Figure 3B).

Age was a significant predictor in the regression model where lower age performed better on *executive functioning (CST)* (*p*=0.014). Additionally, compared to low education, middle and high on average, performed better on *executive functioning (CST),* holding other variables constant. The other confounders were not significant and are shown in supplement 1 together with the B, SE and CI of the significant confounders.

Executive functioning (TOL): Current post-traumatic stress symptoms negatively affect performance

A multiple regression model with PSS-SR and TOL performance was significant (n=84) *F* (6,77) = 7.954 = *p* <0.001, explaining 38.3% of the variance in test performance, R^2=.383. PSS-SR predicted executive functioning (TOL) (*B*=-0.040., SE = 0.014, CI= -0.068- -0.012, *p* = 0.005; n=84). This finding indicates that higher self-reported posttraumatic stress symptoms were associated with lower performance on the executive functioning (TOL) task, after controlling for age, gender, education and PD see Figure 4B.

The confounder level of education predicted executive functioning (TOL): people with a middle level of education ($p = 0.007$) and higher level of education ($p = 0.008$) performed better. The other confounders were not significant and are shown in supplement 1 together with the B, SE and CI of the significant confounders.

Discussion

The aim of the current study was to examine the association of ACEs and post-traumatic stress symptoms with cognitive performance in older adults. Overall, the CTBS score was not significantly associated with memory or executive functioning in this group of older adults. But post-hoc analysis did indicate that people who have experienced 'disease/illness' during childhood scored significantly lower on the executive functioning (CST) test. A higher PSS-SR score was associated with lower scores of executive functioning but did not affect memory performance.

In contrast to previous studies, mentioned before, we do not find an association between CTBS and cognitive performance. To illustrate, Dodaj et al. (14) found that a history of childhood maltreatment in females is associated with greater difficulties in working memory capacity and executive functioning in adulthood. The discrepancy between those findings and ours may be explained by differences in sample characteristics. Specifically, our study focused on all forms of childhood adversity, included an older population (>60) and both males and females (52.7% male), whereas Dodaj et al. (14) focused exclusively on females across a broader age range (age 16-67) examining only childhood maltreatment. Majer et al. (15) found significant associations of childhood trauma scores on memory but not on executive functioning or attention in people with a mean age of 51.51 and a sample of 85% females. Additionally, all these studies do not include resilience or positive childhood experiences which are known to influence the long-term consequences of ACEs (42, 43). Ritchie et al. (2011) did include protective factors (impression parents did their best, happy childhood, normal education) possibly reflecting resilience, and found females with loss of a parent as ACE show poorer verbal retrieval in adults aged >65 (18). Severe abuse was found to be related to a lower risk of cognitive impairment (18). This highlights the importance of including protective factors, positive childhood experiences or resilience in future trauma related studies.

In the post-hoc analysis we found a statistically significant negative influence of the ACE 'disease/illness' in relation to executive functioning (CST) in older adults. This is in line with previous studies, demonstrating that poor cognitive

performance is related to specific types of trauma such as being sent to a foster home, or being maltreated by schoolmates (18). It could be hypothesized that this significant result is a consequence of, for example, medical conditions (such as pulmonary disorders) that affect cognition (44-46). As the current study includes different categorization of ACEs a direct comparison is not possible. No association was found in relation to specific ACEs with memory or executive functioning (TOL) in the current study. One possible explanation for the absence of an observed association is the presence of protective factors, the recovery of memory and executive functioning over time, or the limitation of a small sample size. Evidence from older populations also suggest that the cognitive effects of specific trauma types may become less pronounced with age. Ritchie et al hypothesized that the long-term consequences of childhood trauma may either attenuate over time or manifest as pathological aging processes such as mild cognitive impairment (MCI) or dementia, people diagnosed with MCI or dementia are not represented in the current study (18).

The association of post-traumatic stress symptoms and a poorer performance on executive functioning (CST) tests is in accordance with another study in middle-aged women (47). A meta-analysis also describes this association when looking at PTSD diagnosis compared to people with a trauma history without PTSD, but this study does not take symptom severity into account (48). Additionally, cognitive deficits have been described in older adults with PTSD in the domain of memory and executive functioning (24, 48). The post-hoc relationship found specifically between childhood illness and poorer executive functioning (CST) performance could reflect either early neurodevelopmental disruptions or ongoing medical vulnerabilities affecting executive functioning in later life.

We do not find an association between PSS-SR score and memory, measured with immediate or delayed recall, in older adults, contradicting other studies where post-traumatic stress symptoms, or their consequences, have been found to impair immediate and delayed recall in active-duty service men (mean age 36.26) (49). A possible cause for this difference could be the study population of Disner et al consisting of younger people at an outpatient neuropsychological clinic for unspecified anxiety (36%), depressive disorder (14%), PTSD (13%) or comorbid PTSD + depression (9%). Potentially indicating that performance on memory is partially effected by the presence of underlying disorders, such as PTSD, in older adults. Previous studies do find a significant relation between presence of PTSD diagnosis and poorer memory performance in older (mean age 68.6) holocaust survivors compared to holocaust survivors without PTSD or control subjects, but PTSD symptoms are not included in this study (20). Future research should disentangle these temporal and causal pathways.

Level of education was consistently associated with better cognitive performance, especially in executive functioning (TOL and CST). The strong predictive value of education suggests a possible cognitive reserve effect, aligning with literature showing that educational level is protective against cognitive decline (50, 51) and that education moderates the impact of depression on aging-related cognitive decline (52). The influence of PDs on cognitive functioning appears inconsistently across domains and predictors. While PD was significantly associated with memory and executive functioning in some models, its effect was not consistent across analyses. This may reflect the shared variance between PD symptoms and chronic post-traumatic stress, potentially masking PD's individual contribution when current symptom burden is accounted for. Both level of education and presence of mental illness, as well as gender are positive predictors for outcomes on resilience scales (42). Future studies should consider resilience in a broader context when studying longterm effects of ACEs.

This study has several limitations. First, selection bias may be present due to the inclusion of a specific sample of older adults, either receiving treatment for PDs or classified as healthy controls. As a result, very old adults, those with other psychiatric disorders, or individuals with significant cognitive impairment (e.g., MCI or dementia) are underrepresented, potentially underestimating the impact of ACEs or post-traumatic stress symptoms on cognition. Additionally, the healthy control group was relatively well-educated, which may have influenced group differences. Second, the brief cognitive test battery limits comparability with more comprehensive assessments. For example, aspects such as word recognition or attentional interference were not measured. The adjustments on the scales for cognitive performance have not been validated on a larger scale. Third, we use the summed CTBS score from the CTES. This questionnaire has been used in multiple previous studies, also in older populations but reliabilities of this questionnaire in this population are not known. The PSS-SR questionnaire had been validated but it is based on the DSM-IV possible excluding the full range of symptoms as assessed in the DSM-5. Also, the small sample size in a cross-sectional study is a limiting factor considering the presence of longitudinal studies with a larger sample size of older adults (53, 54), yet to our knowledge the current study is the first to look at both ACE and post-traumatic stress symptoms in association with memory and executive functioning in this population. Finally, as we included ACEs and current post-traumatic stress symptoms, we missed trauma's that happened in adulthood which could potentially also influence the results (55). We do hypothesize these traumas, if present, are related to the post-traumatic stress symptoms score to a certain extent.

Conclusion

The results of the current study indicate that ACEs alone do not influence memory or executive functioning in this population. The significant impact of post-traumatic stress symptoms, particularly on executive function, suggests that current psychological symptom burden, not past trauma, may be a more proximal driver of cognitive outcomes in older adults. Thus, improving insight into ACE alone appears insufficient when identifying modifiable risk factors of cognitive decline to improve personalized care. Additionally, these results confirm the impact of mental health on cognitive performance. They highlight the potential importance of assessing trauma symptomatology, particularly in cases of isolated executive functioning deficits. Future studies on risk factors for cognitive decline should focus on post-traumatic stress symptoms as a potentially modifiable factor in the course of cognitive decline in older people.

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Supplements

Supplement 1. Full regression results of all confounders for the CTBS and PSS-SR analysis.

Predictor	Dependent variables	PD	Age	Gender
CTBS	Immediate recall	*B* = -2.933 SE = 1.155 CI = -5.223 - -0.642 *p* = 0.013	*B* = -0.273 SE = 0.080 CI = -0.432 - -0.114 *p* = .001	*B* = 2.637 SE = 0.993 CI = 0.668 – 4.607 *p* = 0.009
	Delayed recall	*B* = -1.162 SE = 0.585 CI = -2.322 - -0.002 *p* = 0.05	*B* = -0.123 SE = 0.041 CI = -0.203 - -0.042 *p* = 0.001	*B* = 0.936 SE = 0.503 CI = -0.063 - 1.933 *p* = 0.066
	CST	*B* = -0.152 SE = 0.338 CI = -0.922 – 0.619 *p* = 0.697	*B* =-0.052 SE = 0.027 CI = -0.105- 0.001 *p* = 0.056	*B* = 0.374 SE = 0.334 CI = -0.288- 1.036 *p* = 0.265
	TOL	*B* = -0.803 SE = 0.359 CI = -1.517 – -0.089 *p* = .028	*B* = -0.038 SE = 0.024 CI = -0.086– 0.010 *p* = 0.122	*B* = -0.302 SE = 0.283 CI = -0.864 – 0.261 *p* = 0.289
PSS-SR	Memory immediate	*B* = -2.229 SE = 1.454 CI = -5.114 - 0.656 *p* = 0.128	B = -0.279 SE = 0.083 CI = -0.443 - -0.115 *p* = 0.001	*B* = 2.442 SE = 1.015 CI = 0.427 – 4.456 *p* = 0.018
	Memory delayed	*B* = -0.652 SE = 0.740 CI = -2.120 - 0.816 *p* = 0.380	*B* = -0.135 SE = 0.042 CI = -0.218 – 0.052 *p* = 0.02	*B* = 0.942 SE = 0.526 CI = -0.083– 1.976 *p* = 0.071
	CST	*B* = 0.653 SE = 0.475 CI = -0.290 – 1.596 *p* = 0.172	*B* = -0.068 SE = 0.027 CI = -0.121- -0.014 *p* = 0.014	*B* = 0.442 SE = 0.332 CI = -0.216- 1.101 *p* = 0.186
	TOL	*B* = 0.091 SE = 0.425 CI = -0.756 – 0.938 *p* = 0.831	B = -0.043 SE = 0.023 CI = -0.089– 0.003 *p* = 0.065	*B* = -0.331 SE = 0.276 CI = -0.880– 0.218 *p* = 0.233

Caption: B= coefficient, CI = confidence interval, CST = Concept shift task, CTBS = Childhood Traumatic Burden Score, PD = Personality disorder, PSS-SR = post-traumatic stress symptoms, SE = standard error, TOL = Tower of London

	Education	
	Middle	High
	B = 0.672 SE = 1.583 CI = -2.468- 3.813 *p* = 0.672	*B* = -0.927 SE = 1.740 CI = -4.379- 2.524 *p* = 0.595
	B = -0.291 SE = 0.801 CI = -1.881- 1.299 *p* = 0.717	*B* = -0.576 SE = 0.881 CI = -2.324- 1.172 *p* = 0.515
	B = -1.197 SE = 0.532 CI = -2.253- -0.141 *p* = 0.027	*B* = -1.491 SE = 0.585 CI = -2.651- -0.331 *p* = 0.012
	B = -1.152 SE = 0.485 CI = -2.117 - -0.187 *p* = 0.020	*B* = -1.283 SE = 0.525 CI = -2.328 – -0.238 *p* = 0.017
	B =0.844 SE = 1.591 CI = -2.313 – 4.002 *p* = 0.597	*B* = -0.883 SE = 1.751 CI = -4.359 – 2.593 *p* = 0.615
	B = -0.202 SE = 0.809 CI = -1.809- 1.404 *p* = 0.803	*B* = -0.610 SE = 0.891 CI = -2.378 – 1.159 *p* = 0.496
	B = -1.170 SE = 0.520 CI = -2.202- -0.138 *p* = 0.027	*B* = -1.534 SE = 0.573 CI = -2.670- -0.397 *p* = 0.009
	B = -1.295 SE = 0.469 CI = -2.228– -0.361 *p* = 0.007	*B* = -1.379 SE = 0.506 CI = -2.388 - -0.371 *p* = 0.008


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Chapter 3

Treatment of post-traumatic stress disorder in people with dementia: a structured literature review

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Abstract

Aim and objectives: Posttraumatic stress disorder (PTSD) is associated with cognitive dysfunctions and is an independent risk factor for dementia. A recent study has found that the prevalence of PTSD in people with dementia is 4.7-7.8%. However, little is known about the effectiveness of PTSD treatment for people with dementia. The primary aim of the current study is to review previous studies on the treatment of PTSD in people with dementia.

Methods: A structured literature review was performed using a 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' analysis in PubMed, Embase, PsycINFO and CINAHL. Two independent researchers screened titles and abstracts. The inclusion criteria were: PTSD symptoms present, diagnosis of dementia, PTSD treatment form described and effects of the treatment mentioned. Articles that matched these criteria were included and content and quality were analyzed.

Results: We included nine articles, all case reports, with a total of eleven cases. The discussed treatment options are eye movement desensitization and reprocessing (EMDR) (n=3), prolonged exposure (n=1), cognitive behavioral therapy (n=1) and pharmacological treatment (n=4). All articles reported a positive effect of the intervention on several monitored symptoms. Evidence for positive effects and feasibility of EMDR was most reliable, it was applied in two articles of sufficient quality published in 2018 and 2019. EMDR 'on-the-spot' was described with positive effect in one article in which three cases were discussed. The quality of included papers ranged from insufficient to sufficient.

Conclusion: This review shows that people with PTSD and dementia can benefit from PTSD treatment. EMDR, prolonged exposure, acceptance and commitment therapy and pharmacological treatment are applicable in this population. EMDR treatment is most described in this population (n=5), shows positive results and the studies are of sufficient quality (n=3). Further research in the form of a randomized controlled trial is required to study the effectivity of different treatment interventions in this population.

Introduction

Posttraumatic stress disorder (PTSD) is a psychiatric condition that may develop after exposure to a traumatic event (1). Main symptoms of PTSD are onset of intrusive symptoms after a traumatic event, hyperarousal, changes in mood or cognition and avoidance of trauma associated triggers (2). The life time prevalence in the general population of PTSD is 7-8% (3). People with PTSD experience a high burden of disease with a higher risk of suicide attempts and anxiety compared to people without PTSD (4). There is also a high caregiver burden related to the increased symptom severity in PTSD (5, 6). Effective treatments for PTSD can improve quality of life (7-9).

In people with dementia, the combination of neurodegeneration and decreased cognitive reserve may increase the reactivation of traumatic memories and thereby elicit PTSD symptoms (10, 11). Although research on the prevalence of PTSD in people with dementia is scarce, a recent literature review described a prevalence of 4.7-7.8%, based on three studies in veterans (12). It appears that in people with dementia, PTSD is difficult to recognize and a trauma history is often not documented (13). In addition, people with dementia and PTSD can show a variety of symptoms often associated with neuropsychiatric symptoms of dementia and not as symptoms of PTSD (14). Examples are verbal agitation, physical aggression, flashbacks, fear and nightmares (15, 16). For neuropsychiatric symptoms seen in people with dementia the treatment options reported are broad with low grades of evidence (17). A thorough investigation of the possible cause of the symptoms is required as the symptoms are often mistreated (18, 19). We believe recognizing PTSD in this population can provide more effective treatment options. Currently caregivers are often not trained to recognize PTSD symptoms in people with dementia due to lack of available literature and diagnostic tools (12). To adequately reduce the symptoms of PTSD it is important to diagnose and adequately treat PTSD. This review focusses on the treatment options for PTSD in people with dementia.

Several treatment options exist for PTSD in adults and elderly people without dementia. For example, substantial empirical evidence exists for the effectiveness of Eye Movement Desensitization and Reprocessing (EMDR) and (trauma focused) cognitive behavioural therapy (CBT) in reducing PTSD symptoms (9, 20-22). Studies focusing on older people with dementia are scare. The purpose of this literature review is to systematically summarize the available literature on the treatment of PTSD in people with dementia.

Methods

Data sources and search

This review used a structured design. The literature search was conducted according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines in PubMed, Embase, PsycINFO and CINAHL. The search strategy consisted of terms related to; dementia and posttraumatic stress disorder (PTSD) or trauma history. The complete search strategy is provided in Supplement 1.

Study selection

Publications until January 2022 were included in the search. Titles and abstracts were screened by two researchers and selected based on the following inclusion criteria: (1) inclusion of people with PTSD symptoms; (2) inclusion people with the diagnosis of dementia; (3) the treatment form applied in the study must be described adequately; (4) the effect of the treatment form applied must be reported; (5) the study must have used one of the following designs: clinical trial, cohort study, cross sectional study or case report.

The search was executed in January 2022 including articles up to January 2022. When there was doubt about an inclusion a third researcher was consulted, complete consensus was achieved. Studies were screened based on title and abstract, relevant full text studies were read and the reference list was screened to include possible missed studies.

Data extraction and quality assessment

Data was extracted by the first and second author by using a standardized data collection table (table 2). The tool for evaluating the methodological quality of case reports and case series by Murad (2018) was used to assess quality of the included case reports by the first author and checked by a second author (23). The papers quality was then described as sufficient, dubious or insufficient. Where sufficient papers score positive on more than 50% of the criteria, dubious score positive on 50% of the criteria and insufficient scores positive on less than 50% of the criteria.

Results

The results will be sectioned per treatment method. We will first describe the background of the treatment addressed in the articles. Second, the results described in the papers will be summarized and their quality described. The systematic searches yielded a total of 5087 papers (4074 after removal of

duplicates). 4018 of these articles were excluded based on title and abstract. 56 articles were selected for screening of the full text. Seven out of these met the inclusion criteria. The screening of the reference lists resulted in the inclusion of two additional articles. This resulted in a total of nine articles (figure 1).

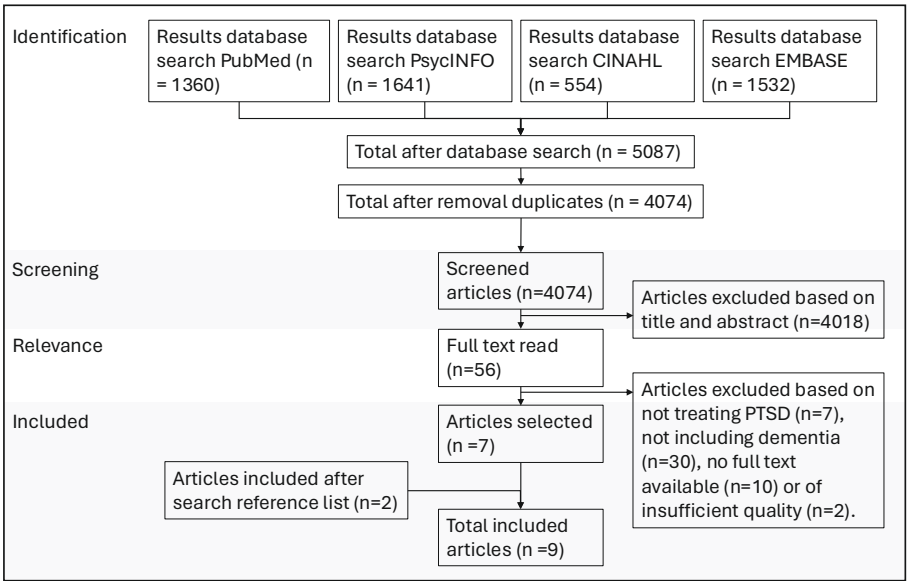

Figure 1: PRISMA flowchart showing selection of articles

All included articles (n=9) were case reports, in which a combined total of eleven cases were discussed. Of the nine case reports six were of sufficient quality (table 1). Eight case reports discussed one patient per paper and one case report discussed three patients. All without the use of control interventions. In three case reports a combination of two treatment forms were used (24-26). Two cases were treated with EMDR (27), (28), and three cases with a modified form of EMDR, EMDR 'on-the-spot' (24). In addition, four cases were treated with, each a different form of, pharmacological treatment (25, 29-31), one case received prolonged exposure therapy (26) and one cognitive behavioural therapy (32). The way diagnosis of PTSD was assessed, form of dementia and comorbidities differed between cases. Table 2 shows the main study characteristics.

Eye Movement Desensitization and Reprocessing (EMDR)

Eye movement desensitization and reprocessing (EMDR) is a protocolized psychological treatment method aimed to reduce the distress related to an experienced traumatic life event. It requires a person to recall the traumatic event and select the most distressing part of this event that is accompanied

with dysfunctional thoughts and feelings. While visualizing and discussing this moment a distracting stimulus is applied. The participant must follow the therapist finger movements from right to left. This uses the working memory and decreases the ability to feel the emotions connected to the traumatic event. Giving the body the ability to connect a different emotional and physical meaning to the event; rescripting (33-35).

Our literature search resulted in two case reports that described EMDR in two people with PTSD and dementia (27, 28). Van der Wielen (2019) described a woman of 69 with a mild stage of Alzheimer's dementia and trauma related stress symptoms. She suffered from intrusive trauma related memories about her mother's institutionalized palliative care phase paired with emotional outbursts and feelings of guilt. She received one session of EMDR conform standard care, but with the presence of her husband during the therapy session. The authors concluded that EMDR according to protocol is applicable for people with mild Alzheimer dementia (table 2). The quality of this paper is sufficient with a relatively long follow-up of 13 months (table 1)

Ahmed (2018) described a case of a Caucasian woman of 83 years old with mild Parkinson dementia who had experienced multiple traumatic life events. She had a history of depression and neuropathic pain. She underwent 6 weekly EMDR according to standard protocol. She reported less complaints of tension related to the traumatic memory, less avoidance and felt more resilient. Her depression and fear increased which she reported to be a consequence of decline of the M. Parkinson. The authors concluded that EMDR is a realistic treatment option for the treatment of people with dementia who suffer from traumatic memories but requires more research (table 2). The quality of this case report is sufficient with a follow-up of nine months and adequate description of the intervention (table 1).

EMDR 'on-the-spot'

EMDR 'on-the-spot' is a version of EMDR where, when the person shows the mentioned symptoms, therapy is executed by bilateral tapping on shoulders or knees and using simple words whilst they were reliving the traumatic experience (whereas in EMDR a person is asked to actively think of this experience) (24). Amano (2014) described three cases in a case series, involving three Asian nursing home residents. All three cases experienced challenging behaviour often associated with neuropsychiatric symptoms of dementia such as physical aggression, screaming, restlessness, agitation, wandering and sleeping disorders. Due to trauma in the past, they were thought to have PTSD, but a formal diagnosis was not made. In these cases, a personalized and more simplified form of EMDR, which they named EMDR 'on-the-spot', was used as

people included could not follow instruction of the therapist due to the severity of the dementia. The EMDR 'on-the-spot' sessions were held four to six times. All three cases showed a significant improvement of symptoms (less anger, less reliving of the trauma, more smiling) in the caregiver reports (table 2). The quality of this paper is dubious as the outcome was evaluated using only patient files and clinical observation (table 1).

Prolonged exposure

Prolonged exposure is a form of trauma-focused Cognitive behavioural therapy (CBT) (36). It combines exposure in thoughts and in practice in such a way that the traumatic memory can be processed. The focus is on repetitive and long reliving in which avoidance is brought to a minimum (37, 38). Prolonged exposure requires 8-15 sessions each of 60-90minutes, it is a validated form of psychotherapy for PTSD (36).

One article was found that used prolonged exposure for the treatment of PTSD in a person with dementia (26) (n=1). Duax et al described a 65-year-old male veteran with PTSD and early staged Lewy Body dementia. He had symptoms of agitation, apathy, sleeping disorders, nightmares and cognitive problems. PTSD was diagnosed following clinical interviews and a detailed history with his wife. The standard protocol for prolonged exposure was adjusted to better fit the needs of the patient; some sessions lasted longer, sessions were recorded for re-watching by the patient and the partner was present to guide the patient in the first five sessions. After the 14 sessions of prolonged exposure, additional therapy sessions were held every two weeks for six months to monitor progress and/or decline. The content of these sessions was diverse, among others, behavioural activation and exposure, risk assessment and monitoring, discussions of caregiver burden. After the treatment the Clinician-Administered PTSD Scale for DSM-IV showed a positive effect of treatment on the PTSD symptoms as did the self-reports. The positive effect was still present six months after treatment (table 2). This case report is of sufficient quality with good ascertainment of the treatment outcomes (table 1).

Multiple psychological interventions

We found one case report that used multiple forms of interventions not included in the other case reports (32). They combined cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), psychoeducation and formation of a memory book.

CBT is based on the theory that a person's problems are maintained by potentially modifiable cognitions and behaviour. It is a form of psychotherapy that teaches to think differently about a stressful event in such a way that it does

not raise intense emotions (39). Contrary, in ACT, the goal is not to analyse and change your cognitions, but rather to accept them for what they are and instead to focus on personal values and goals. The goal is that as a consequence, internal experiences will have less influence on emotion and behaviour(40). Jacobs and Dinoff discussed the case of a 90-year-old Caucasian male, with sufficient vascular dementia, somatoform disorder and PTSD symptoms after WWII trauma. The patient experienced a fear of dying, gastrointestinal symptoms, feelings of depression, lack of energy and agitation. He was also aggressive. The patient received multiple therapy sessions divided in three phases using multiple forms of therapy; CBT, ACT and psychoeducation combined with a memory book.

In the study by Jacobs and Dinoff, phase I consisted of a geropsychological evaluation with a behavioural analysis and therapy sessions. In the therapy sessions which both the patient and his wife were involved for six months and specific issues such as the fear of abandonment by his wife, were addressed. Following this, primary improvements of mood, agitation and anxiety were seen. Phase II consisted of CBT and ACT. The CBT was adjusted to accommodate the vascular dementia. Sessions were slower than usual, visual aids were used, and information was repeated more often. Regardless it did not appear possible for him to challenge his own thoughts sufficiently for the CBT to have effect. Therefore, ACT started, and it was possible for the patient to experience creative hopelessness and he felt grief for his situation. He no longer wanted to go home and accepted living in the nursing home, but the distress and fear of dying remained. Phase III consisted of psychoeducation and 'treatment' of the dementia in the form of a memory book. The memory book and psychoeducation helped the participant when he was agitated resulting in a decrease in lorazepam use (32) (table 2). The paper by Jacobs and Dinoff is of sufficient quality with a short follow-up term but detailed case description (table 1.)

Pharmacological treatment

The symptoms of PTSD can also be targeted with pharmacological treatment. Clinical practice shows that people with PTSD and dementia are often administered with anti-psychotics (41). PTSD is not a registered indication for treatment with anti-psychotics and often anti-psychotics have a high risk of adverse events and side-effects requiring caution in their administration for off label use (42). Specific serotonergic agents have been proven to be effective in treatment of PTSD, but not superior to trauma focused-psychotherapy forms (21, 43).

We found four case studies in which pharmacological treatment was given in people with PTSD and dementia (25, 29-31) (n=4). Chopra (2011) described an 85-year-old Caucasian male with PTSD and mild to moderate dementia. He has PTSD as a consequence of WWII trauma. At onset of the study, he had been receiving treatment with citalopram 40mg 1dd1 in the past two years which was continued during the course of the study. The patient suffered from sleeping disorders and nightmares and first prazosin 1mg was started, which was increased to 3mg during a course of 5 weeks with no effect. Due to side effects, orthostatic hypotension causing falls, the prazosin was stopped. Consequently, memantine was titrated to 10mg 2dd1 without side effects (table 2). This paper is of dubious quality with no challenge-rechallenge phenomenon, but a relatively good measurement of outcomes using a structured but not validated measuring tool (table 1).

Hamilton, Workman Jr, Hargrave and colleagues and Severson & McCartney performed studies dating further back (25, 30, 44). One of the case reports describes a Caucasian male of 94 years old with moderate Alzheimer dementia and combat related post-traumatic stress symptoms. The patient is treated with trazodone combined with haloperidol and lorazepam. A good effect of the combination therapy with improvement of sleep and no more nighttime agitation is described (44)

The case report of Hargrave (1993) describes a Caucasian male of 70 years old with multi-infarct dementia and PTSD without trauma description. He was treated with trazodone and buspirone. It shows a positive effect of the treatment with decreased combativeness, decreased yelling and resolved flashbacks and nightmares (30).

The case report of Severson and McCartney describes a Caucasian female of 82 years old with Alzheimer's dementia who suffers from PTSD after sexual trauma. She was treated with trazodone and sertraline. The person became calmer and showed less rushing through the hallways (25) (table 2). These papers are all of insufficient quality due to the short description of treatment outcomes without use of measuring tools (table 1).

Table 1: Quality assessment of included studies according to Murad et al, 2018

		Ahmed, 2018	**Amano, 2014**	**Chopra, 2011**
Selection	1. represent(s) the whole experience of the investigator (center/) or selection method unclear	N= 1 method unclear	N=3 method unclear	N=1 method unclear
Ascertainment	2. Was the exposure adequately ascertained?	Yes	Yes	Yes
	3. Was the outcome adequately ascertained?	Yes	Moderate	Yes
Causality	4. Were other alternative causes that may explain the observation ruled out?	Not ruled out but mentioned	No	Not ruled out but mentioned
	5. Was there a challenge/ rechallenge phenomenon?	n.a.	n.a.	No
	6. Was there a dose–response effect?	n.a	n.a.	No
	7. Was follow-up long enough for outcomes to occur?	Yes, 9 months	Yes, 6 months	Yes, 9 months
Reporting	8. Is the case(s) described with sufficient details	Yes	Yes	Yes
Overal score	Yes = 1 No = 0	4/6 Sufficient	3/6 Dubious	4/8 Dubious

Duax, 2013	**Hamilton, 1998**	**Hargrave, 1993**	**Jacobs, 2012**	**Severson, 1997**	**Van der Wielen, 2019**
N= 1 method unclear	N=1 Method unclear	N= 1 method unclear	N= 1 method unclear	N= 1 method unclear	N=1 method unclear
Yes	Yes	Yes	Yes	Yes	Yes
Yes	Moderate	Moderate	Yes	Moderate	Yes
Not ruled out but mentioned	No	No	Not ruled out but mentioned	No	Not ruled out but mentioned
n.a.	No	No	n.a.	No	n.a.
n.a.	No	No	n.a.	No	n.a.
Yes, 6 months	No, 2 months	No	No, 1 month	No, 3 week	Yes, 13 months
Yes	Yes	Yes	Yes	Yes	Yes
4/6 Sufficient	3/8 Insufficient	3/8 In sufficient	4/6 Sufficient	3/8 In sufficient	4/6 Sufficient

Table 2. Overview of included studies (all case reports) and specifications per case

Case report	Case	Form of dementia	PTSD diagnosis (trauma related to)	Comorbidities
Ahmed, 2018	1	Mild parkinson dementia	History of traumatic events (sexual abuse, family death, burglary)	Depression, neuropathic pain and 'extensive comorbidities'
Amano et al, 2014	1	Early onset Alzheimer dementia now severe	PTSD like symptoms (abusive childhood)	None mentioned
	2	Moderate vascular dementia	PTSD like symptoms (WWII, burglary, fire)	Asthma, cerebrovascular disease, lower limb paralysis
	3	Severe alzheimer dementia	PTSD like symptoms (WWII)	Diabetes, hypertension and hyperlipidemia

Age/ gender/ ethnicity	Treatment form	Follow up (months)	Measurement tool	Treatment effect
83/f Caucasian	EMDR	9	HADS and qualitative experience of participant	Subjective improvement of PTSD symptoms and resilience/ Increase of depression and fear
67/f Asian	EMDR on the spot	6	data is extracted from patient files from clinical observations	Chronic jeering and cursing decreased, smiled more, wandering remained but silently or singing songs
85/m Asian	EMDR on the spot	6	data is extracted from patient files from clinical observations	Decrease of restlessness, almost ceased moments of falling into a painful state of mind for hours, no reexperiencing of trauma.
83/m Asian	EMDR on the spot with Yokukansan granular extract (Chinese supplement) and two forms of sleeping medication	6	data is extracted from patient files from clinical observations	Calmed down and smiled more, bilateral tapping gave a sense of security.

Table 2. Overview of included studies (all case reports) and specifications per case *(continued)*

Case report	Case	Form of dementia	PTSD diagnosis (trauma related to)	Comorbidities
Chopra et al 2011	1	Mild to moderate dementia	PTSD (WWII)	Depression (for which citalopram)
Duax et al, 2013	1	Early lewy body dementia / parkinson plus syndrome	PTSD (Vietnam war)	Depression (for which 200mg sertraline / 10mg donepezil), anxiety, somatic preoccupation and suspiciousness
Hamilton & Workman 1998	1	Alzheimer dementia, moderate	Combat related post-traumatic stress symptoms	Delirium due to urinary tract infection and dehydration, near blindness
Hargrave et al, 1993	1	Multi infarct dementia	PTSD	Cerebrovascular accident
Jacobs & Dinoff, 2012	1	Moderate vascular dementia	PTSD symptoms (WWII)	Depression, anxiety, undifferentiated somatization disorder
Severson & McCartney, 1997	1	Alzheimers dementia	PTSD (Recent sexual trauma)	Glaucoma, arthritis

Age/ gender/ ethnicity	Treatment form	Follow up (months)	Measurement tool	Treatment effect
85/m Caucasian	Memantine	9	self-report and informant report consistently using a PTSD-CI tool	Self-reported improvement of PTSD symptoms. Staff reported no significant change. Improved cognition
65/m Not mentioned	Prolonged exposure	6	PCL-C, also BDI-II for depression	Improvement of PTSD symptoms. Reduction of depressive symptoms. Decline in cognition
94/m Caucasian	Haloperidol 2mg, trazodone 200mg, lorazepam 0.5mg	2	Not stated	Improvement of sleep and no nighttime aggitation
70/m Caucasian	Trazodone 400mg, buspirone 15mg	2	Not stated	Decreased combativeness and repetitive yelling. Flashbacks and nightmares re-solved.
90/m Caucasian	Therapy sessions, CBT/ACT, psychoeducation (memory book)	1	SLUMS, GDS, self and informant report	Improved SLUMS/GDS, better QoL reported, less anxious, less somatic symptoms. No effect CBT.
82/f Caucasian	Trazodone 25g, sertraline 25mg and later 50mg	-	Not stated	Calmer, no more running down the hallway

Table 2. Overview of included studies (all case reports) and specifications per case *(continued)*

Case report	Case	Form of dementia	PTSD diagnosis (trauma related to)	Comorbidities
Van der Wielen et al, 2019	1	Mild stage Alzheimer dementia.	Trauma history (family)	None mentioned

Caption: *ACT= Acceptance and Commitment therapy, BDI-II = Beck depression inventory - II; BPSD= Behavioral and Psychological Symptoms of Dementia; CBT= cognitive behavioural therapy; EMDR = eye movement desensitization and reprocessing; GDS: Geriatric Depression Scale, HADS-A = Hospital anxiety and depression scale – Anxiety subscale; PCL-C = PTSD checklist - civilian; PTSD = post-traumatic stress disorder, SLUMS: Saint Louis University Mental Status Examination, QoL = Quality of life; WWII= World war two.*

	Age/ gender/ ethnicity	Treatment form	Follow up (months)	Measurement tool	Treatment effect
	69/f Caucasian	EMDR	13	Interviews, BDS-II and HADS-A	Decrease of guilt and flashbacks based on interviews No difference on BDS-II and HADS-A

Discussion

This review shows that studies of the treatment of PTSD in people with dementia are rare and only identified a few studies in the form of case reports. The quality of the nine case reports varies. There were three case reports all discussing pharmacological intervention, of insufficient quality (25, 30, 44), two dubious studies discussing EMDR 'on-the-spot' (24) and memantine (29) and four case reports of sufficient quality (27, 32, 45, 46). Of which two describing EMDR (27, 46), one applying prolonged exposure (45) and a fourth describing a combination of therapies (32).

The quality of case reports describing EMDR were sufficient, a clear case description was given (table 1) (24, 27, 46). EMDR is an approved intervention for PTSD and described in practice guidelines (33-35). All three studies that describe EMDR in people with dementia, describe it as a feasible intervention. The case reports show positive effects on the symptoms measured or described such as less flashbacks, more accepting of the past and less restlessness (24, 27, 46). Positive effects of EMDR on neuropsychiatric symptoms often associated with challenging behaviour of dementia can reflect the alternative clinical presentation of PTSD in people with dementia, showing symptoms such as screaming (16). These case reports indicate that EMDR might be also feasible and effective for reducing PTSD symptoms in people with dementia. In the case report of Amano et al the intervention was combined with pharmacological intervention (24). As a consequence, the effect of the EMDR alone cannot be established, but these results are transferable to common practice, where patients often also receive pharmacological treatment.

Four papers discus pharmacological treatment, but the quality of these papers is dubious (29) or insufficient (25, 30, 31). Chopra (2011) show a careful positive effect of memantine in addition to citalopram on PTSD symptoms and cognitive decline in people with mild-moderate dementia, but a challenge-rechallenge and dose response effect is not ascertained. Further studies on pharmacological interventions for PTSD, such as an open label trial by Ramaswamy, also shows a positive effect of memantine in 26 veterans with PTSD and mild cognitive disorders, but this study excluded people with dementia (47). Future research could be beneficial to explore the effects of memantine in people with PTSD and dementia. The other three included case reports all administered trazodone in combination with another form of medication such as haloperidol with lorazepam, buspirone or sertraline. They reported positive effects with the patients improved sleep, yelling less, being calmer and smiling more (25, 30, 44). The paper of Bruneau described treatment with antipsychotic medication in two cases of PTSD with dementia. In one case it was ceased due to side effects

and in a second case it was effective, but the specific type of anti-psychotic is not mentioned (48). The quality of found literature provide insufficient reliable evidence for the pharmacological treatment of PTSD in people with dementia.

Prolonged exposure is described in one case report with positive effects on PTSD symptoms, even after six months. The quality of the paper is sufficient but due to the combination of pharmacological treatment, the positive results cannot be directly linked to the prolonged exposure. Prolonged exposure is a well-researched form of therapy proven successful for the treatment of PTSD (49). The current case report shows us that prolonged exposure can also be applied in people with dementia. Nonetheless, there is insufficient evidence of the positive effect of prolonged exposure in people with dementia.

Jacobs and Dinoff describe an elaborate combination of therapy forms; CBT, ACT and psychoeducation combined with a memory book (32). CBT is an approved form of PTSD treatment in people without dementia (50). The case described showed the complexity of CBT, due to the combination of PTSD with dementia and this part of the treatment was unsuccessful. ACT managed to give the patient insight into his limitations and the effects of memory book were not described. This case report of sufficient quality describes expected challenges in the use of CBT in people with dementia, there is too little evidence to exclude CBT in this population all together.

Overall, the studies include patients with different forms of dementia with varying severity. We found no description regarding the objective assessment of severity of dementia. The severity of dementia plays an important part in clinical practice as certain neuropsychiatric symptoms are more prevalent in certain stages of the dementia (51). Five cases describe Alzheimer dementia, three describe vascular dementia, two describe a form of Lewy body or Parkinson dementia and in one case the aetiology in not mentioned. There is no literature describing the influence of different forms of dementia on trauma processing and/or PTSD. PTSD increases the risk of dementia in general, but so far studies have not found PTSD to accelerate certain aetiologies of dementia (52). Four females and seven males are included in the case reports. Six males had combat and/or war related traumas, in one of the cases the cause of trauma was not mentioned. Two of the females experienced sexual trauma and two experienced violence during their childhood. Woman have a higher risk of developing PTSD due to gender roles, predisposition and hormonal influences (53).

Besides the variation in diagnosis of dementia, in five case reports a clear diagnostic description and/or tool for diagnosing PTSD in people with dementia is missing. In multiple cases there was no formal diagnosis of PTSD but the descriptive diagnosis of 'PTSD symptoms' (24, 32, 44) or 'history of traumatic

events' (27, 46). Of the included studies Ahmed, 2018, Jacobs and Dinoff 2012 and van der Wielen, 2019 did not use tools for the specific evaluation of PTSD symptoms but tools aimed at fear, depression and/or cognition to measure treatment outcome. Amano extracted data from patient files and clinical observations which are not further specified. Chopra and Duax do use a structured tool; the PTSD – cognitive impaired tool, which is a structured but not yet a validated tool. The PTSD checklist – civilian is used by Duax.

This study contributes to the existing knowledge and marks the need for further research, but there are limitations. The scientific evidence of this review is limited due to the absence of any controlled and/or randomized studies. Most of the included case reports have a sufficient level of quality, but the sole inclusion of case reports may lead to publication bias with mainly positive results. Selection bias is increased as the method of inclusion is not clear in any of the case reports. In addition, although the results are assessed with objective questionnaires, only few are specifically aimed at measuring PTSD symptoms. Thus, an objective comparison of the effects between the case reports is not feasible. In five of the nine case reports the formal diagnosis of PTSD has been formed (25, 26, 29, 30, 32). Relevant comorbidities are described in all but two case reports (24, 25).

Conclusion

The case reports in this structured literature review show us PTSD treatment in people with dementia can be effective to reduce symptoms possibly related to PTSD. EMDR, prolonged exposure, ACT and pharmacological interventions are feasible interventions in this population, even in cases of severe dementia. The case reports show most hopeful results of EMDR. The clinical implications of the included studies are limited due the demographic variables such as type of dementia and severity, absence of validated diagnostic tools for PTSD and validated PTSD symptom evaluation tools, making the quality baseline comparison for treatment effects limited.
The treatment of PTSD in people with dementia starts with recognizing PTSD in this population. To recognize PTSD it is important to differentiate PTSD from symptoms often associated with neuropsychiatric symptoms of dementia, for this a structured diagnostic tool of PTSD for people with dementia could be beneficial (54). Besides this, more research is required to study the effectiveness of different treatment interventions in this population using a standardized measuring tool for PTSD symptoms. Based on this review randomized controlled trials to analyse the effect of EMDR in people with dementia and PTSD are most hopeful but so far, evidence is limited due to the low number of studies in this population.

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Supplements

Supplement 1: Complete search strategy

PubMed

S1: (dement* OR Cognitive* OR Alzheimer OR Korsakoff OR Lewy body OR dementia [MeSH] OR cognitive dysfunction[MeSH]) [title/abstract]
S2: (PTSD OR Post Traumatic* OR sexual abuse OR battered child syndrome OR combat disorder OR sexual trauma OR PTSS OR Stress disorders [MeSH] OR Traumatic [MeSH]) [title/abstract]
S3: S1 AND S2

27/01/2022 → 1360 hits

PsycINFO

S1: AB (dement* OR Cognitive* OR Alzheimer OR Korsakoff OR Lewy body)
S2: AB (PTSD OR Post Traumatic* OR sexual abuse OR battered child syndrome OR combat disorder OR sexual trauma OR PTSS)
S3: S1 AND S2

27/01/2022 → 1641 hits

CINAHL

S1: AB (dement* OR Cognitive* OR Alzheimer OR Korsakoff OR Lewy body)
S2: AB (PTSD OR Post Traumatic* OR sexual abuse OR battered child syndrome OR combat disorder OR sexual trauma OR PTSS)
S3: S1 AND S2

27/01/2022 → 554 hits

Embase

S1: (dement* OR Cognitive* OR Alzheimer OR Korsakoff OR Lewy body) .ab .ti
S2: (PTSD OR Post Traumatic* OR sexual abuse OR battered child syndrome OR combat disorder OR sexual trauma OR PTSS) .ab .ti
S3: S1 AND S2

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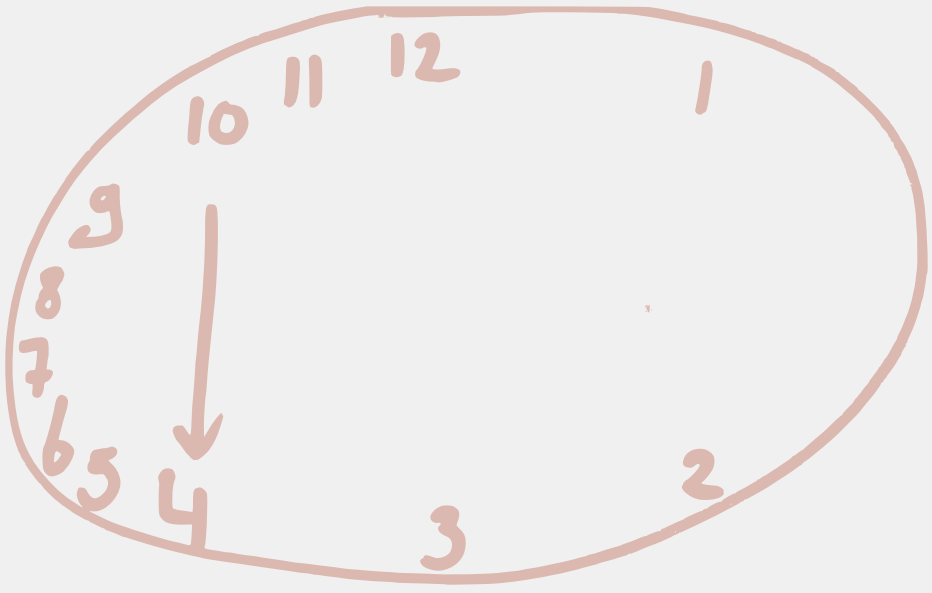
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Chapter 4

Feasibility of EMDR in a person with dementia and PTSD: a case report

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Abstract

Aim and objectives: Post-traumatic stress disorder (PTSD) is an independent risk factor for dementia. Case reports of poor-moderate quality indicate the feasibility of Eye Movement Desensitization and Reprocessing (EMDR) sessions in this population but lack a detailed description of the treatment and its challenges.

This report aimed to provide a detailed description of the feasibility and challenges of EMDR for a person with dementia to assist in the first step toward recognizing and treating PTSD in people with dementia.

Methods: In this case study, we describe an 89-year-old nursing home resident with mild–moderate dementia and trauma related symptoms. EMDR treatment was indicated, and four sessions, according to a standard child/youth protocol, were applied. Debriefing questionnaires were completed by a psychologist after each EMDR session. To monitor the effect of the EMDR therapy, a structured interview exploring PTSD symptoms (TRADE- TRAuma and DEmentia interview) was conducted between the treatment sessions.

Results: The debriefing questionnaires showed that EMDR was well tolerated and experienced as pleasant, but some challenges occurred; During the EMDR sessions she (1) was easily distracted, (2) requested multiple breaks, and (3) required the use of shorter sentences, with a more directive approach. PTSD symptoms of recurring memories and negative thoughts were reduced.

Conclusion: This case report provides a detailed description showing the feasibility of EMDR therapy for a person with PTSD and dementia. It appeared necessary to adjust the EMDR standard child/youth protocol to a further simplified form, due to the reduced concentration and endurance.

Introduction

Post-traumatic stress disorder (PTSD) is described as a disorder that develops in response to actual or threatened death, serious injury, or sexual violation (1). It results in a wide variety of symptoms divisible into categories of intrusion, avoidance, negative changes in cognition and mood and changes in arousal and reactivity (1). For older adults' treatment of PTSD can positively impact quality of life (2). The prevalence of PTSD in older adults with dementia is estimated at 4.7% to 7.8% (3). The lower prevalence of PTSD in older adults could be related to the presentations with more somatic symptoms of PTSD rather than relating emotional struggles to past traumatic experiences (4). The underdiagnosis of older people with dementia may also be caused by a difference in symptom expression (5). These symptoms are often labelled as neuropsychiatric symptoms of dementia (5). The 'TRAuma and DEmentia (TRADE) – interview' has been developed, aiming to improve diagnoses of PTSD in people with dementia. It is awaiting validation (6). Older people receive PTSD treatment less often than other populations (7). With the population ageing and the complexity of care increasing we believe it is of importance to further develop treatment options in this population. We hypothesized that adequate treatment can improve the quality of life of people with PTSD and comorbid dementia.

Eye Movement Desensitization and Reprocessing (EMDR) is a psychotherapeutic approach proven effective for older people with PTSD (2, 8, 9). Case reports of moderate quality do indicate the feasibility of EMDR in adjusted forms for this population, but reports have lacked a detailed descriptions of the procedure used, their applicability, the actual applied treatment, and their measured effects (10-13). The case report of Amano et al. describes three cases of people with severe dementia in which EMDR on-the-spot was performed for PTSD-like symptoms; there was no formal diagnosis of PTSD, and the dementia was severe (11). Van der Wielen et al. described a case of a person with moderate Alzheimer's dementia in which only one EMDR session was performed. The participant was not diagnosed with PTSD (13). Finally, Ahmed et al also described a case with features of PTSD but no formal diagnosis of PTSD; this patient also presented with extensive comorbidities, including depression and anxiety (12). However, to our knowledge, no studies have investigated the applicability of EMDR, described in combination with its challenges for people with PTSD and mild-moderate dementia.

Thus, in this case report we explore the challenges and applicability of EMDR treatment for a person with mild-moderate dementia and PTSD, living in a long-term care facility. We describe the case's specific effects in detail. We aim to describe this case elaborately to assist psychologists and physicians toward

treating PTSD with EMDR for people with dementia. Hoping it will assist them in providing therapy in the older adult populations with dementia who have experienced past trauma.

Methods

Study design

This is a retrospective case report (n = 1) (14).

Informed consent

The person with dementia and her legal representative provided informed consent for the EMDR as care-as-usual. After the treatments, they provided informed consent for the collection of anonymized data for the retrospective publication of results.

Intervention

The intervention observed in this study was EMDR performed according to the standard Dutch child and youth protocol in a person with PTSD and dementia living in a long-term care facility (15). The Dutch EMDR protocol is based on the eight-step protocol by Shapiro and Solomon (2001), with some tightening and new tools in the instructions for therapists (9). The child and youth protocol is the same as the regular Dutch EMDR protocol, but its sentences are simplified, the instructions are shorter, and it suggests drawing an image (15). We chose to use this protocol for this person because people with dementia may have a decline in cognitive skills such as memory, complex attention, and language (1). Additionally, in the Dutch protocol, for example, multiple steps have been elaborated on to provide more support for therapists, such as the determination of the target selection and the negative cognition (16). The negative and positive cognitions are related to beliefs someone has formed towards themselves, after the trauma (17). When the negative cognition (NC) reflects powerlessness, the following steps of positive cognition (PC) and validity of cognition (VoC) are skipped to directly move to the establishment of the emotion. This change is made as the steps of PC and VoC determination are seen as a distraction that leads to the PC often being something like "I can face this" (18). In the back-to-target phase, the Dutch protocol recommends going back to the image formed at the session's start, whereas the international protocol refers the person to the original experience (19). Installing a safe space is not a standard step in the Dutch protocol, but described as optional (19).

The person in this report received EMDR therapy from an EMDR-certified psychologist. EMDR consists of eight phases including history taking,

preparation, assessment, desensitization, installation, body scan, closure, and re-evaluation. In the first part of treatment history taking and preparation, sessions start with psychoeducation, case conceptualization, and the determination of a treatment focus. Following this, EMDR sessions are planned and performed. The number of sessions was not pre-determined. In the EMDR sessions, the Subjective Units of disturbance (SUD) scale was used to assess her level of emotion related to the selected target image in the desensitization phase. This scale ranges from 0-10. The score 0 refers to no distress at all, and 10 indicates an unbearable level of disturbance. This score is given by the participant and can be used by the therapist to evaluate the effect of EMDR (17). To analyse the treatment feasibility, a debriefing questionnaire was completed by the psychologist who facilitated the EMDR sessions (Figure 1). The sessions were discussed in a group of psychologists trained in EMDR.

Outcome measure

We explored the challenges and facilitators faced by the psychologist in performing the EMDR. Additionally, we aimed to analyse the impact of EMDR on this person with PTSD and dementia. For this we used the TRADE-interview, which awaits validation (6). It aims to assess the severity and presence of trauma-related symptoms. The TRADE-interview consists of three components: Questions related to trauma and trauma-related symptoms are included for the person with dementia, for the informal care giver, and for the nursing staff at the location the person is staying. The TRADE-interview was conducted by a different psychologist not performing the EMDR.

Debriefing questionnaire
1. What went well during the administration of the EMDR therapy?
2. What were challenges during the administration of the EMDR therapy?
3. How may these challenges possibly be explained?
4. Are these challenges expected to occur in other people with dementia receiving EMDR?
5. What could possibly be done to overcome these challenges?

Figure 1. Debriefing questionnaire to evaluate the Eye Movement Desensitization and Reprocessing (EMDR) sessions.

Case description

Demographic information

The person described in this case report was an 89-year-old Caucasian woman from the Netherlands. She had been living in a nursing home for 2 years due to

somatic impairments and progressive cognitive impairments due to dementia. Her son saw her isolating herself and having recurrent memories of her past trauma and wondered about using EMDR. Sobczak et al. further described the background and characteristics of this specific case, which were used to ascertain the diagnosis and for the case conceptualisation (20).

Diagnostic assessment
A psychologist indicated the possible value of EMDR treatment for this case, based on the prior PTSD diagnosis as described in the DSM-5 (1). The traumatic event for her was a bicycle accident that occurred 30 years prior. This resulted in chronic pain which was at first insufficiently treated. When she finally received treatment for the pain symptoms, the medical treatment did not have effect. The chronic pain symptoms hindered her self-reliance and independence. She developed a tendency to isolate herself when in pain. When in pain, the memory of the bicycle accident "haunted" her. A lot of repetitive negative thoughts came to her mind at these moments, for instance why nobody saw the accident, why she did not seek help earlier, and why doctors could not help her to reduce the pain. This was accompanied by a negative self-image, she felt guilt, was annoyed easily, and had trouble sleeping. She sometimes said the future appeared hopeless if her chronic pain would continue like this. With the help of EMDR, she hoped that the pain would decrease, and that she would feel better. In the Results section (3.1), phases 1 and 2 of the EMDR protocol are described.

Therapeutic intervention: Evaluation of the EMDR treatment sessions

In total, she had four EMDR sessions. Therefore, four debriefing questionnaires from the psychologist were available to evaluate feasibility (Figure 1, Table 1). In between the sessions, five planned EMDR meetings were cancelled due to her absence, not feeling well, being in too much pain, or feeling too tired. One TRADE-interview was cancelled. Figure 2 shows the course of the therapies and measurements over time. The group of psychologists discussed the course of the sessions and concluded that the maximum effect had been reached after the fourth session, as at that point the memory of her trauma was unrelated to the woman's negative associations. The effects of the sessions and debriefing questionnaires are discussed next.

Table 1. An overview of the results from the debriefing questionnaires held after the Eye Movement Desensitization and Reprocessing (EMDR) sessions.

Feasibility of EMDR • Motivated, cooperative and easily guided • Only needing a short and simple explanation before starting • Remembering the details from previous sessions	**Positive effects of EMDR** • The focus shifted from helplessness to gratefulness during sessions • Being less focused on the pain during sessions • Relaxation was noticeable for the therapist during sessions • Experiencing control over the pain • Noticing a positive effect and feeling amazed by it • Linking the sessions with having less pain • Looking forward to the next session
Hurdles during EMDR • Easily distracted and preoccupied with other things during the sessions • Understanding the explanation written in the EMDR protocol • Staying focused on a certain image • Staying focused when asked detailed questions • Discrepancy between what the person receiving EMDR says and what the therapist sees • Closing the eyes when following the finger movement	**Negative effects of EMDR** • Needing to pause during the session, due to overload/tiredness/illness • Physical complaints after the session, due to illness/overload/effects of session • Getting tired during the session

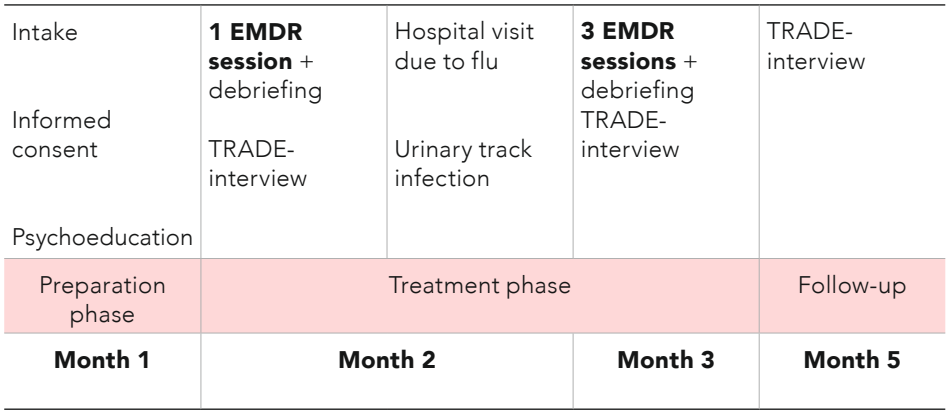

Figure 2. An overview of the course of the eye movement desensitization and reprocessing therapy (EMDR) sessions, debriefing questionnaires and TRAuma and DEmentia (TRADE)-interviews.

Results

We describe the results per session and based on the outcome of the debriefing questionnaire in combination with the outcomes of the TRADE-interviews. Her son - also her the legal representative - was contacted before the sessions to provide psychoeducation.

History taking and preparation phase (T0; Figure 2), occurred 1 month before the first processing session of EMDR. This was aimed at exploring the relationship between symptoms experienced and important traumatic memories. It also included taking the patients history and giving psychoeducation to her. It was difficult for her to understand the explanation fully, so the explanation was simplified. During the TRADE-interview, she mentioned not having experienced a trauma; her son did describe a trauma, however – the biking accident. She felt guilty that she had waited long to seek help for her pain symptoms, she was annoyed easily, and had trouble sleeping due to the pain. During the psychoeducation she could relate these complaints to the accident. A treatment plan was made. The negative cognition (NC) "I am so helpless, why me" was formed, according to the protocol the positive cognition automatically was 'I can face this'. The beach was chosen as an image that could help her relax.

Session one: Assessment- and desensitisation phase (T1; Figure 2), was focused on forming a target image of the bicycle accident. In the meeting she spontaneously described the image of herself lying on the ground and not being able to get up, but it was difficult for her to focus on this specific image. By drawing this image, used in the 'back to target' step in the desensitization phase of the protocol, she was able to focus on the image being processed. She was motivated for the session but did not fully recall the previous explanation of the EMDR in session zero. The repetition of the preparation and assessment phase took around 30 minutes, after which the desensitization phase could start. Whilst tracking the finger movements in the desensitization phase, she often closed her eyes and needed a repetition of short and clear instructions. She had difficulty understanding and giving an SUD score. However, after the repetition of simple explanations, she started with a SUD of 8 and ended the session with a SUD of 3 after 30 minutes of the desensitization phase. The feeling of not being in control prevailed. During this session, she did not report any physical complaints besides the pain. According to her, the pain remained the same, but it was not connected to the target memory. Her body language appeared more relaxed. In the closing phase, the formal caregivers were advised to repeat the positive phrase "I matter", and to offer relaxation exercises like visualizing a beach to aid in the connection with a more positive network. She was grateful that she was finally receiving help and was motivated to schedule the following sessions.

Session two: Re-evaluation and desensitisation (T2; Figure 2), took place 1 month after the first session because multiple sessions were cancelled in between due to hospital admission and difficulties in planning sessions. In the re-evaluation phase, she could not recall the details of the previous session, but she did remember that the therapist performed the EMDR therapy one month ago. The second session started with desensitization of the same image that she had formed in session one, where she was lying on the ground after the accident and could not get up. She could easily recall this image. The most unpleasant part for her was the feeling of helplessness, and this was discussed in depth during the session. She was motivated, and she could recall the previous EMDR instructions. Tracking the finger movements in the desensitization phase appeared more difficult than the previous session, and she requested more breaks. Associations remained regarding the pain and the thought of "why me?". She started with an SUD of 6 and ended the session with an SUD of 7.

At the start of the session, she was very focused on the pain she felt. The desensitization phase took around 30 minutes. During the closing phase, her focus shifted to the feeling of gratitude for the help she was receiving, but she was very tired. Her body language appeared relaxed, and calmer compared to the start of the session. Later, it transpired that during this session she had a urinary tract infection. She was suffering from physical complaints such as dizziness, palpitations, and nausea that had started a few weeks prior. The PC was not installed because of the tension surrounding the target image. Furthermore, the body scan was not performed, in the body scan a person is asked to focus on the sensations one feels in their body which are a consequence of the trauma memory (17). In this case it was expected that it would focus her on the pain. In the closing phase, the formal caregivers were again advised to repeat the positive phrase "I matter" and to aid in relaxation exercises like visualizing the beach to induce positive feelings.

Session three: Installation and body scan (T3; Figure 2), took place 1 week after the second session. Her bladder infection had been treated. The EMDR session started with the previous image, but as the tension no longer appeared to be present, the PC "I can face this" could be installed. Additionally, the body scan revealed no tension. The second target consisted of an image of herself lying in the hospital, where the doctors were at her bedside and could not find the cause of her pain. She regularly emphasized the feeling of helplessness and pain. She knew what the session entailed and was willing to cooperate. Tracking the finger movements in the desensitization phase remained difficult but possible with repeated instructions and pace adjustments. The image started with a SUD of 7 and ended with a SUD of 4. The effective EMDR time was again around 30 minutes. The feeling of helplessness and pain transitioned into a feeling of

gratefulness and love, she mentioned that she was happy to finally get help. There were no physical complaints during the EMDR session other than the known-pain symptoms.

After the session, she did experience dizziness and palpitations. Which made her angry and scared. She did not want to be left alone. After an hour, these complaints went away spontaneously. After the session, the formal caregivers were advised to repeat the positive phrase "I matter" and to help in facilitating the relaxation exercises (e.g., beach visualization).

Session four (T4; Figure 2), the final session, took place 1 week after the third session. The EMDR session started with the image of herself lying in the hospital with the doctors at the bedside, but it was hard for her to form this image. During the desensitization phase, she struggled to concentrate and could not keep her eyes open for the finger tracking, yet she responded well to instructions. It took around 30 minutes. At the start of the session, she had a lot of pain and described a SUD of 10. During the session, the SUD came down to 3. No tension was observed. She said she felt more control over the pain. The feelings of powerlessness and helplessness prevailed but were not connected to the target image or other images formed regarding the trauma memory when they went back to target. For that reason, the PC "I can handle this" was installed, and no tension was observed in the body scan. In the closing phase, the formal caregivers were advised to repeat the positive phrase "I matter" and to help facilitate the relaxation exercises (e.g., beach visualization).

Follow-up

Two months after the final EMDR session, a final TRADE-interview took place in which the woman and informant indicated that she no longer had recurring memories of the trauma. She also indicated no negative thoughts and feelings about herself (e.g., helplessness, anger, guilt, shame), whereas at the initial TRADE-interview, she said she had these negative thoughts and feelings (Supplement 1).

Adverse and unanticipated events

At the end of the second month, after the first EMDR session, the woman suffered from chest pains for which she was examined in a hospital. The pains were related to the flu. A week after this, she also had a urinary tract infection (Figure 2). The symptoms were thought to be unrelated to the EMDR treatment, but they did influence the course of treatment. Two sessions were shortened due to pain or tiredness. Overall, she noticed positive effects, as did the nursing staff, who mentioned this to the psychologist performing the EMDR.

Discussion

This case report investigated the feasibility of EMDR according to a standard child and youth protocol for a woman with dementia. We also highlighted possible challenges faced when facilitating EMDR for people with PTSD and dementia living in care facilities.

Recognizing and indicating the possible benefit of trauma-related treatment is the first step towards considering EMDR as a treatment option. In this case, the request for help did not come from the woman herself, but it came from her son. This highlights the value of people in the environment, of a person with dementia, in recognizing the impact of unprocessed adverse life events. For people such as caregivers and relatives to be able to signal past trauma, trauma-related symptoms need to be recognized. Studies of people with intellectual disabilities indicate that this is challenging due to different clinical presentations and the lack of diagnostic instruments (21). The different clinical presentation and lack of a validated diagnostic instrument also played a role in the care of people with dementia, in this case the presentation with pain as main presenting symptom was seen (5, 22). Additionally, in a population with severe mental illness, it is shown that cognitive impairment has been a barrier experienced by clinicians who treat PTSD/trauma-related problems (23). Yet, when treated with EMDR, positive effects on PTSD symptomatology have been seen in people with a severe mental illness (24).

Regarding treatment challenges, it is likely that interfering somatic disorders or fatigue might cause the postponement and shortening of sessions. This challenge influenced the practical planning of the EMDR sessions. This required flexibility per session length and time. Also, good communication between the formal caregivers of the woman with dementia with the EMDR therapist was required to plan sessions.

We saw difficulties in concentrating and a low frustration tolerance influenced the EMDR sessions. However, declining cognition is expected affect the utalisation of EMDR for people with dementia; working memory is more limited in people with dementia. This has influences the speed of working memory tasks as reflected in eye movements (25).

When starting the EMDR sessions, patience, repetition, and simple explanations were necessary to help this woman, something that can also be expected when treating other people with dementia. The child-youth protocol provides a simplified instruction for use in future EMDR sessions for people with difficulty understanding, but the protocol possibly requires further adjustments, such as

planning shorter sessions and repeating instructions, for people with dementia (15). Studies with children aged 8-18 have shown that shorter sessions do not influence the effectiveness of EMDR for children (26).

Another challenge pertained to forming the image used during the EMDR, yet she always managed to form the image and it helped her draw it on paper. Forming an image that accesses the trauma memory is a helpful step in EMDR, to create an emotional charge, which may be used to keep someone alert while processing the unprocessed memory, during the desensitization phase. We expect this to be challenging when performing EMDR for others with dementia, as well, especially for patients more advanced stages of dementia.

In the assessment and desensitization phase, the use of the SUD scale seemed relatively more difficult, as not all questions were understood by the woman with dementia. It seemed this required too high a level of abstract thinking. Instead, we might have used supporting pictograms, like smiley faces. In people with dementia, it is important to relate the indicated SUD score to what is seen in a person's body language. With our case, when she reported an SUD of 3, her body language showed her to be clearly more at ease, and the target image did not invoke tension. Additionally, the psychologist needed to provide more guidance to determine the negative and positive cognitions compared to adults without dementia. In this case, she felt overwhelmed and helpless, seeing herself lying on the ground without help, which led to choosing the negative cognition, "I'm helpless". Clinical experience had shown us that people may link the EMDR therapist to the experience, thoughts, and in this case, the pain of the addressed trauma. Therefore, we recommend involving the environment, such as nursing professionals and family members, in the observation of treatment effect. The environment can also be leveraged to help the positive and valuable effects in the closing phase last longer, in this case, by coaching her to repeat phrases like "I matter".

A sole focus on above challenges during EMDR might obscure the otherwise positive effects for the patient. However, the effects of the EMDR were visible for the therapist during the EMDR session, as the woman seemed more relaxed. The woman receiving the treatment experienced more control over her pain, the pain was disconnected from the target memory, and she mentioned that she felt grateful that she finally received help. The TRADE-interview showed less guilt, all suggesting that further research should consider overcoming the challenges described in this case report to provide an EMDR treatment option for this population.

Strengths and limitations

This study has provided a detailed description of EMDR for a woman with dementia. Due to the extensive clinical reports and a structured retrospective analysis, we were able to gather information from different points in time, including from a 2-month follow-up.

However, with case reports, one cannot directly relate symptoms and changes to effects of a treatment, like EMDR. Also, the progression of dementia was not measured and could influence the found results, with memories of trauma possibly decreasing or changing as dementia progresses. Finally, she had a urinary tract infection and the flu during the EMDR sessions, which possibly influenced her concentration, yet as the population of people with dementia living in long-term care are vulnerable, this is something that will probably occur relatively often. This case shows us that it is possible to perform EMDR, regardless of these interfering somatic conditions.

Conclusions

This case report has illustrated the feasibility of EMDR for people with PTSD and dementia living in care facilities. All the steps in the EMDR process needed to be tailored to the individual. Challenges to consider for future EMDR sessions with patients like these should perhaps address: (a) the planning of shorter sessions to compensate for lower concentration and faster tiring; (b) the need for shorter instructions/explanations and more repetitions due to difficulties with abstraction level, language comprehension, memory, and attention deficits; and (c) more flexibility, tuning, and perseverance from the therapist. We hope that by sharing our experience, other health care professionals will consider EMDR for this population. Future research with large samples, however, is required to assess for replicable results.

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Supplement 1. TRADE-interview scores during the course of the Eye Movement Desensitization and Reprocessing (EMDR) sessions.

Questions TRADE-interview	**Answers TRADE-interview**		
	T-1 *1 month before EMDR*		
	Participant	*Informant*	*Caregiver*
A. Did the participant ever experience a traumatic event?	**Yes**	**Yes**	**/**
A. Did the participant ever witness someone else experiencing a traumatic event?	**No**	**No**	**/**
A. Has the participant repeatedly been exposed to violent images through work, television or otherwise?	**No**	**No**	**/**
B. Has the participant (in the past month) suffered from recurring memories of this traumatic event?	**Yes**	**Yes**	**/**
B. Has the participant (in the past month) experienced the traumatic event once again (flashbacks)?	**Yes**	**No**	**No**
B. Has the participant (in the past month) dreamed about the traumatic event?	**No**	**Yes**	**Yes-1**
C. Has the participant (in the past month) avoided people, places or activities that remind you of the traumatic event?	**No**	**No**	**No**
D. Has the participant (in the past month) had a lot of negative thoughts about themselves or the world?	**Yes**	**Yes**	**/**
D. Has the participant (in the past month) experienced feelings of guilt around the traumatic event?	**Yes**	**No**	**/**
D. Has the participant (in the past month) experienced negative feelings like anxiety, anger, guilt or shame?	**Yes**	**Yes**	**Yes-3**
E. Has the participant (in the past month) been annoyed easily?	**Yes**	**Yes**	**Yes-2**
E. Has the participant (in the past month) slept badly?	**Yes**	**Yes**	**Yes-1**
E. Has the participant exhibited recklessness or self-destructive behavior?	**/**	**No**	**No**
E. Has the participant been excessively alert and wary?	**/**	**No**	**No**
E. Does the participant easily scare (when touching or waking them)?	**/**	**No**	**No**

Legend: Yes = present, No = not present, ? = unknown, 1 = mild, 2 = moderate, 3 = severe, / = question not asked in this part of the question

T1 Between EMDR s1&2			*T2 After EMDR s3*			*T3 2 months after EMDR s4*		
Participant	*Informant*	*caregiver*	*Participant*	*informant*	*caregiver*	*Participant*	*informant*	*caregiver*
Yes	**Yes**	**/**	**Yes**	**Yes**	**/**	**Yes**	**Yes**	**/**
Yes	**No**	**/**	**Yes**	**Yes**	**/**	**Yes**	**Yes**	**/**
No	**No**	**/**	**No**	**No**	**/**	**No**	**No**	**/**
Yes	**Yes**	**/**	**Yes**	**No**	**/**	**No**	**No**	**/**
Yes	**No**	**No**	**Yes**	**No**	**Yes-1**	**No**	**No**	**No**
Yes	**No**	**No**	**No**	**No**	**No**	**No**	**No**	**No**
No	**No**	**No**	**?**	**No**	**No**	**No**	**No**	**No**
?	**No**	**/**	**No**	**Yes**	**/**	**No**	**No**	**/**
No	**No**	**/**	**No**	**No**	**/**	**No**	**Yes**	**/**
No	**No**	**Yes-1**	**Yes**	**Yes**	**Yes-2**	**No**	**No**	**Yes-2.5**
No	**Yes**	**Yes-1**	**No**	**Yes**	**Yes-2**	**No**	**Yes**	**No**
No	**Yes**	**No**	**No**	**?**	**No**	**Yes**	**No**	**Yes-1**
/	**No**	**Yes-1**	**/**	**No**	**No**	**/**	**No**	**No**
/	**No**	**No**	**/**	**No**	**No**	**/**	**No**	**No**
/	**No**	**No**	**/**	**No**	**No**	**/**	**No**	**No**


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Chapter 5

Posttraumatic stress disorder in people with dementia: study protocol

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Abstract

Aim and objectives: Posttraumatic stress disorder (PTSD) is considered an independent risk factor for dementia. Despite the (clinical) evidence that PTSD is associated with neuropsychiatric symptoms in people with dementia, studies on its prevalence and clinical manifestation are limited, and their quality is affected by the lack of a structured method to diagnose PTSD in this population. The primary aim of the current study is to validate the 'TRAuma and DEmentia' interview as a diagnostic tool for PTSD in people with dementia and to test feasibility of EMDR treatment for people with PTSD and dementia.

Methods: This prospective multi-centre study is divided into two parts. In study A, 90 participants with dementia will be included to test the criterion validity, inter-rater reliability and feasibility of the 'TRAuma and DEmentia' interview. In study B, 29 participants with dementia and PTSD will receive eye movement desensitisation and reprocessing therapy by a trained psychologist, and 29 participants with dementia and PTSD will be placed on the waiting list control group.

Conclusion: This study aims to improve the diagnostic process of PTSD and to assess the effects of eye movement desensitisation and reprocessing treatment in people with dementia living in Dutch care facilities.

Introduction

Traumatic life events can result in severe psychiatric symptoms, of which posttraumatic stress disorder (PTSD) is the most prevalent. The lifetime prevalence of PTSD in the general population is 7%-8% (1). However, in older adults, the diagnosis of PTSD is less frequent (1%-3%), compared with younger adults (2, 3).

The main feature of PTSD in the general population is intrusive symptoms after a traumatic event. Additionally symptoms such as hyperarousal, changes in mood or cognition and avoidance of trauma-associated triggers are seen in people with PTSD (4). Older adults with PTSD experience a high disease burden, higher risk of suicide attempts, and higher risk of anxiety, compared with older adults without PTSD (5). In addition, PTSD has a negative effect on quality of life (6). There is also a high caregiver burden related to the increased symptom severity in PTSD (7). PTSD is associated with chronic stress and cognitive dysfunctions, and it has been described as an independent risk factor for cognitive decline and dementia (8). Eye movement desensitisation and reprocessing (EMDR) is a validated treatment modality for PTSD in the general population (9). It is a protocolised psychological treatment method to reduce the distress related to an experienced traumatic life event. Recent studies have shown that it is also effective in the older population without dementia (10). Moreover, treatment of PTSD reduces the level of frailty in older people without dementia (10). Existing case reports show that EMDR may be a feasible treatment modality for people with dementia and PTSD, with the differing case reports describing the dementia severity as anywhere from mild – severe (11-14). To the best of our knowledge, there are no prospective studies on EMDR for people with PTSD and dementia.

To indicate the appropriate treatment of PTSD, it is important to recognise PTSD in people with dementia. Older adults more frequently present with a sub-threshold diagnosis of PTSD (a 6-month prevalence of 13.1%), compared with a predominantly younger population (a 6-month prevalence of 6.6%) (15, 16). In a sub-threshold diagnosis of PTSD, a person meets two or three of the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition, DSM-5) criteria (16). Van Dongen et al. 2022, suggest that people with dementia and PTSD might also exhibit different symptoms, compared with healthy adults. For example, avoidance is absent in most cases. Hence, the diagnosis is often 'sub-threshold' (17).

Following the previously highlighted studies describing feasibility and effectivity of EMDR in older people, the need to analyse feasibility of EMDR in people

with dementia arises (10). An international delphi study finds importance in developing a diagnostic tool for PTSD in people with dementia, due to the different clinical presentation (18). The TRAuma and DEmentia (TRADE) interview aiming to diagnose PTSD in people with dementia, is developed together with experts in the field but it is not yet validated (19). The TRADE-interview combines anamnestic information, informant information (of someone that knows the person well) and clinical observations from formal caregivers to determine whether PTSD is present and its severity (https://maastrichtuniversity.eu.qualtrics.com/jfe/form/SV_0AOLXSjGHsmEVVA). The TRADE-interview in its current form does not specifically diagnose sub-threshold PTSD because this term is based on the DSM-5 criteria. As described above we hypothesize these criteria are not suitable for people with dementia. The aim of part A of the current study is to test the validity of the TRADE-interview in people with dementia in clinical practice. The criterion validity will be tested using clinical examination as a comparison standard.

In this article we describe the protocol for a study that aims to (A) test the criterion validity, inter-rater reliability and feasibility of the TRADE-interview; and (B) measure the feasibility of EMDR treatment in people with PTSD and dementia in nursing homes and a mental health care facility, referred to as Dutch care facilities.

Methods

This study follows a multi-centre cross-sectional approach and is divided into two parts. The first part (study A) will assess the diagnostic process (TRADE-interview). The second part will evaluate treatment of PTSD using EMDR (figure 1).

Setting

The study will include participants from five nursing home organisations providing long-term care for people with dementia as well as one regional mental health care facility. Together, these places are referred to as Dutch care facilities. We have chosen these organisations based on their location. These are 6 important stakeholders in the care for residents with dementia in the Netherlands. By including two kinds of facilities, we hope to increase generalizability of the results. These organisations all have multiple locations in the southern part of the Netherlands. People with dementia receive day-to-day care from a team of caregivers and nurses and are supported, where necessary, by (para)medical professionals, such as physiotherapists, psychologists and physicians.

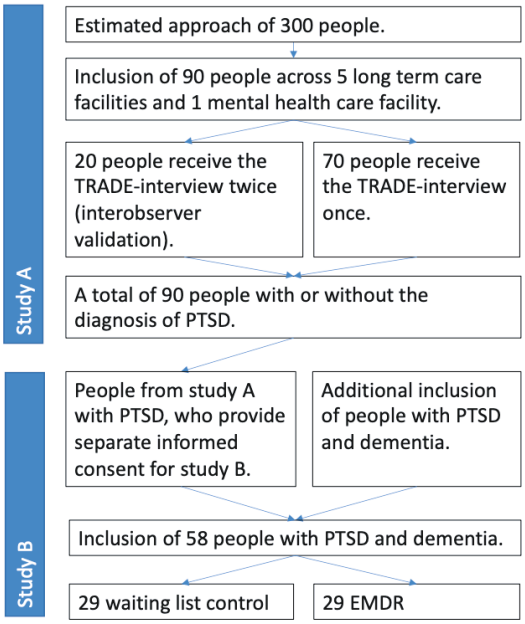

Figure 1. Overview of the design for study A and B.
Caption: EMDR: Eye movement desensitisation and reprocessing, TRADE: Trauma and Dementia, PTSD: Posttraumatic stress disorder

Study population and sample

The inclusion criteria for studies A and B are: (1) people with a DSM-5 diagnosis of dementia and (2) people with an informant, or someone who has known the participant since before their diagnosis of dementia and can assist in insights of the past, available for data collection. The exclusion criteria for studies A and B are: (1) people with an advanced form of dementia, referred to as stadium 3 or 4 according to the scale of Verdult and Van der Kooij (20), meaning a person can be disoriented at times, but also has moments in time where they are oriented in person and place; (2) people or informants who do not speak the Dutch language; (3) people with resistance behaviour possibly indicating they do not wish to participate regardless if they say otherwise; and (4) major medical or psychiatric comorbidities. For study B, an additional inclusion criterion is a diagnosis of PTSD and an additional exclusion criterion is substance abuse disorders.

Sample size calculation

To test the inter-rater reliability of the TRADE-interview in study A, 20 measurements (based on a rule of thumb) are used and independently co-rated

by two raters. This rule of thumb is based on a calculation with an intraclass correlation coefficient (ICC) of 0.60 and a power of 80% (21). Based on this, at least 15 measurements are sufficient (22). Figure 1 gives an overview of the design for studies A and B.

For criterion validity and feasibility of the TRADE-interview in clinical practice, an additional 70 participants will be included. MedCalc® was used for the power calculation (23). This software uses the method described by Hanley et al., 1982 for the power calculation based on receiver operating characteristic (ROC) curve analysis (24). Given an α value of 0.05, power of 0.8 and an area under the curve (AUC) of ≥ 0.60 (an AUC of 0.60 can be regarded as sufficient diagnostic accuracy) (25), the necessary sample size for the current study is 90.

For study B, a total of 58 participants will be included. 29 people will receive EMDR, and 29 people will be part of the waiting list control group (WLC). The amount of people included is based on a meta-analysis of the efficacy of EMDR for people with PTSD (with PTSD symptom rating as the outcome variable), in which the average Hedges' g effect size is 1.01 (26). Large effect sizes have also been reported by (27) (Cohen's d = 1.52-2.09) and by (28) (Cohen's d = 1.87). (10) proved that these large effect sizes are also seen in older adults. G*power was used to calculate the required sample size, using PTSD symptoms (based on the TRADE-interview) as the major outcome. Considering the parameters, a t-test was used to determine the difference between two independent means with an effect size of 1.01 (26), an α value of 0.05 and a power of 0.95. Each treatment arm (the EMDR and WLC groups) would have to have at least 29 participants (a total of 58 participants). In addition, two-tailed t-tests to determine the difference between two dependent means will have an effect size of 0.30, an α value of 0.05 and power of 0.80 (29).

Participant selection

The care organisations will provide different locations. The research team will advise the research representatives of the different care organisations to choose a location with multiple residential wards. At the location, the participants will be included via convenience sampling. The participants and their legal representatives will be asked to provide informed consent. If the legal representative and participants feel another person would be best suited as informant in the study, the informant shall also be asked to sign informed consent.

Study protocol

Study A

Study A aims to test the criterion validity, inter-rater reliability and feasibility of the TRADE-interview and to describe the target population for this study. Data will be collected from the participants enrolled in study A over the course of maximum 4 days, within a period of 3 weeks. The clinical diagnoses (PTSD present or absent) of the practitioner will be compared with the results of the TRADE-interviews (measure procedure is further clarified below). The investigators will be blinded, regarding the clinical diagnosis of the participants at the time of the TRADE-interview.

Measurements in Study A

The different measurements that will be done in study A are described below. Tables 1 and 2 present an overview of the instruments that will be applied during the course of the study.

PTSD symptoms

Using the TRADE-interview, the presence of PTSD symptoms and its severity will be assessed (https://maastrichtuniversity.eu.qualtrics.com/jfe/form/SV_0AOLXSjGHsmEVVA). (19). The semi-structured interview consists of an interview with the participant, informant information and a clinical observation on the presence of PTSD symptoms and their severity in the past month. In the clinical observation the formal caregiver is asked if and to what extent the following symptoms are present: intrusive symptoms (nightmares, flashbacks) avoidance, negative feelings, and changes in arousal (irritability, aggression, reckless or self-destructive behaviour, overly vigilant, heightened startle response and insomnia). The outcomes are combined to form a total score indicating the presence or absence of PTSD in the person with dementia. A patient is considered positive for PTSD when at least one sub-criterion of the main criteria A, B and E is met in one of the elements (anamnestic, informant or observational information). In addition, the duration of the disorder must be longer than 1 month and cannot be explained in any other way (criteria F, G and H; (4)). In 20 participants, the TRADE-interview will be repeated by a second researcher to test inter-rater reliability. This will happen within the 3-week period of data collection and not on the same day as the initial TRADE-interview.

Clinical psychiatric investigation

For the convergent criterion validation of the TRADE-interview, a clinical psychiatric investigation will be used as the comparison standard. This is to increase transferability to current clinical practice in nursing homes. The presence of a clinical diagnosis of PTSD will be assessed by a psychiatrist or

psychologist, who will use the standardised clinical investigation that they use in daily practice. The professional will indicate the presence or absence of each DSM-5 criteria, the final diagnosis and an EMDR indication. Tools such as the CAPS-5 or SCID are not applied in this study, as these tools are not validated in people with dementia and the staff in nursing homes is not trained in the application of these tools (18).

Demographic variables
Demographic variables will be collected to describe the population. Data concerning ethnicity, age, gender, (neuro)psychiatric history (including comorbid disorders), somatic disorders, marital status, children, education and employment history, social network, weight (loss), height, use of alcohol and smoking will be collected. Besides, the indication for residency in a long-term care facility, according to the Dutch indication system for long-term institutional care (Residency due to forestanding somatic, cognitive or psychiatric diagnosis), and the use of involuntary care, according to the Compulsory Mental Healthcare Act, will be registered (30). Involuntary care includes care in which the person's freedom is restricted (such as locked doors, limited use of communicatory devices, or psychofarmological medication outside of protocol).

Statistical analysis
First, a quantitative analysis will be performed. The results of the TRADE-interview will be compared with the results of the clinical diagnosis to assess the criterion validity of the TRADE-interview. The cut-off score, sensitivity and specificity of the TRADE-interview will be calculated based on receiver operating characteristic (ROC) curve analyses. The ROC curve that best fits the data will determine the sensitivity and specificity. Significance will be set at 0.05 (two tailed). Analyses will be performed with SPSS Statistics (IBM Corp., Armonk, NY, USA). Attrition is expected to be low in section A as the inclusion takes place over a short period of time. Demographic statistics of continuous outcomes will be presented by disorder category (PTSD vs non-PTSD in study A) and include sample size, mean, median, standard deviation, minimum and maximum.

Study B

Study B will investigate the feasibility of EMDR treatment in people with dementia and PTSD. Data will be collected over a period of 4 months. The methods and design are based on a previous study on the feasibility of EMDR in older adults carried out by our research group (10). Measurements taken during and after EMDR treatment in people with dementia will be compared with measurements from the WLC group (Table 2). To test treatment fidelity, a total of three EMDR treatments will be recorded and evaluated by other EMDR practitioners. There is a guideline available for EMDR therapists. Once every

3 weeks, the EMDR therapists will have an intervision session to guarantee treatment quality and progress. The participants and their caregivers will be asked to provide their permission.

Treatment with EMDR

EMDR will be conducted by health care practitioners who are trained in administering this therapy. EMDR is a validated psychological treatment for PTSD and is part of a standardised treatment algorithm (31, 32). EMDR is a psychotherapeutic approach that aims to resolve symptoms resulting from disturbing life events (33). This study will use the Dutch translation of the EMDR (standard) protocol developed for children and adolescents, with cognitive age-appropriate modifications. Clinical experience indicates it may represent a better fit for people with dementia as the explanations are shorter and less complex (34, 35). Bilateral visual or sensory stimulation will be used. As not all older adults can complete a 90-minute session, the sessions will be reduced to 30-60 minutes, with the aim of one session per week. The first two sessions will also consist of psychoeducation for patients, caregivers and the formal caregivers about the relation between trauma and the symptoms seen in the person included; trauma effects; a rationale for the EMDR treatment; gathering information; and treatment preparation. The psychoeducation to the formal caregivers is done as deemed fit for the EMDR therapist and no guideline is provided. There is no pre-determined minimum number of sessions (36). The number of sessions is adapted to each individual, according to the number of traumatic events being processed, the individual's capacity and clinical feasibility. A maximum of 10 sessions is set. This is based on clinical feasibility in this population, counting an average of one session per week for the three-month study period. The number of EMDR sessions will be registered. All assessments will be conducted by independent researchers who will not be responsible for the EMDR treatment.

Measurements in Study B

PTSD symptoms

Using the TRADE-interview, the presence of PTSD and its symptoms will be assessed (19). In the interview the presence and absence of PTSD symptoms will be questioned in the person, their informant and a formal caregiver, including the observed severity of these symptoms. The TRADE-interview will be administered before the start of the EMDR sessions, and during the course of the EMDR sessions the interview will be repeated every month to monitor the effects of the EMDR treatment.

Statistical analysis
For study B, the general linear model (GLM) repeated measures procedure will be used. The between-subject factors will be grouped based on whether the participants received EMDR. The within-subject factor is time. The relationship between the scores for the TRADE-interview and the scores for the main outcome variables will be investigated by using Pearson's product moment and regression analyses. Significance will be set at 0.05 (two-tailed). Analyses will be performed with SPSS Statistics (IBM Corp.).

As study B takes place over the course of 4 months, attrition is expected to be higher compared to section A. As the main outcome is feasibility, we will keep track of drop out rates including the cause of drop out. 'Missing completely at random' data will be handled using random forest plot method.

Demographic statistics of continuous outcomes will be presented by treatment category in study B (EMDR vs WLC) and will include sample size, mean, median, standard deviation, minimum and maximum.

Data management for studies A and B

A data safety management board will be appointed from the Clinical Trial Centre Maastricht (CTCM). A data management plan will be created and the data will become available according to the FAIR principles (37). The data collected during the study period will be entered into Castor. All adverse events reported spontaneously by the person, observed by the investigator or observed by his staff will be recorded in Castor. The investigator site files will be kept at the study locations in a locked cabinet only accessible by the research team.

Ethical considerations for studies A and B

The study protocol complies with the Declaration of Helsinki and has been granted approval from the Medical Ethics Committee of Maastricht University/ Academic Hospital Maastricht (NL70479.068.20 / METC 20-063). The study is registered in the Open Science Framework (OSF) trial register.

Discussion

This study will provide insight into the diagnosis and treatment of PTSD in people with dementia in Dutch care facilities. Study A will analyse validity of the

TRADE-interview as a diagnostic tool for PTSD in people with dementia living in Dutch care facilities. This validation would help health care professionals working with people with dementia to talk about traumas and the effect on the patient, and it would open the door to trauma-focused treatment. We expect study B to provide insight into the feasibility of EMDR in people with mild-to-moderate dementia in Dutch care facilities.

Prospective research on the diagnosis and treatment of PTSD has not been performed in people with dementia, possibly due to the challenges of research in this population, such as achieving (informant) information about the past, the role of cognitive decline in this population and the challenges associated with obtaining informed consent. The limitations of the current study are the high dependence on informant data (via treatment effect measurement using TRADE-interview) to determine the treatment effects and the recruitment of participants in different care settings with different levels of care burden. Selection bias may occur by only recruiting people with mild-to-moderate dementia in whom no resistance behaviour is expected. We aim to validate the TRADE-interview using clinical examination as a comparison standard supported by the DSM-5. We believe that the sensitivity of the DSM-5 criteria in people with PTSD and dementia is not high enough due to different symptom presentation [17] and the clinical examination is not protocolized. Thus, the results should be interpreted with caution, considering this context. The study of van Dongen et al. (2022) showed that avoidance seems to be a rarely present symptom (only 3/30 cases), possibly because it is not recognized, not needed in the structured and protected environment or people do not have the cognitive ability to avoid a trauma related thought. Because of this, most people with dementia will not be diagnosed with PTSD when assessed with the DSM-5 criteria of PTSD, as they do not meet all the main DSM-5 criteria.

Regarding the treatment with EMDR, there is a high level of independence for the psychologists performing the EMDR. We have not set lower limits of treatment sessions to stay as close to 'practice as usual' as possible, and this must be considered when interpreting the results. Nevertheless, the results of this study will hopefully provide tools for diagnostics and treatment.

This study differs from other studies due to the chosen population: other studies have not included people with dementia living in nursing homes and mental health care facilities. This population is provided with full-time care, giving us unique insight into the effects of the treatment from the formal caregiver's perspective. Additionally, this project forms a bridge between mental health care and long-term care facilities for older adults by building a transmural academic workplace.

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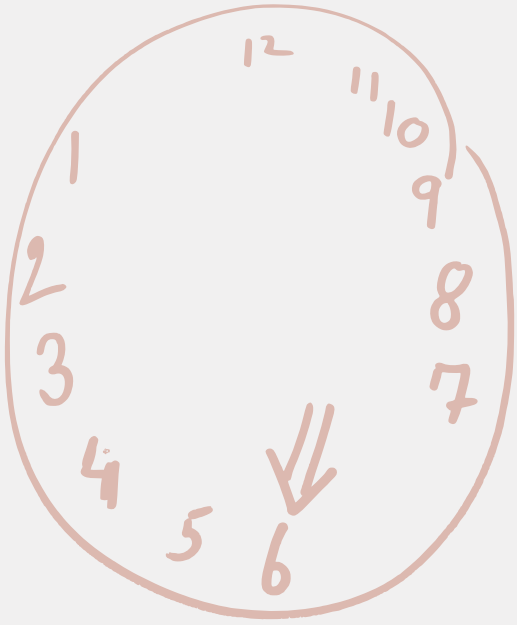
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Chapter 6

Frailty as a mediator between PTSD symptoms and quality of life in older adults with dementia: A cross-sectional study

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Abstract

Aim and objectives: Traumatic events and cognitive decline can negatively interfere with quality of life (QoL). With limited disease-modifying treatments for dementia, quality of life (QoL) is a key care outcome. This study examines whether the association between post-traumatic stress disorder (PTSD) symptoms and dementia is mediated by frailty.

Methods: A cross-sectional study including 78 people with mild to moderate dementia (mean age 83.6 years (SD 6.6); 69.2% female) and their caregivers in residential care. PTSD symptoms were assessed using the TRAuma and DEmentia (TRADE) interview, and PTSD diagnosis was established by a psychologist. QoL was assessed using the EQ-5D-5L, and frailty was assessed with the Fried criteria and the Groningen Frailty Indicator (GFI). Causal mediation analyses were performed, adjusting for gender, level of education, Mini Mental State Examination (MMSE) score, and Charlson Comorbidity Index (CCI).

Results: GFI-measured frailty significantly mediated the association between PTSD symptoms and QoL, accounting for 36.2% of the total effect. Sensitivity analyses using PTSD diagnosis instead of PTSD symptoms confirmed this mediation. Frailty assessed with the Fried criteria was not a significant mediator.

Conclusion: We find substantial impact of PTSD symptoms and frailty on QoL in dementia. This, together with the potential effectiveness of interventions targeting trauma, while accounting for both PTDS and frailty, strongly supports the need for future treatment studies in this population.

Introduction

The prevalence of dementia is rapidly increasing. In 2019, approximately 55 million people were living with dementia worldwide, and this number is projected to rise to 139 million by 2050 (1). Given the limited availability of disease-modifying treatments, quality of life (QoL) represents a highly important outcome in dementia care. Dementia is known to adversely influence QoL, not only in affected individuals, but also in their caregivers (2, 3). QoL in dementia is influenced by multiple determinants beyond the neurodegenerative process itself (4). Post-traumatic stress disorder (PTSD) symptoms are consistently associated with poorer QoL in older adults (5-7), their consequences in people with dementia remain underexplored.

In the Netherlands, 81.5% of individuals aged 16 and older reported experiencing at least one potentially traumatic event during their lifetime (8). PTSD is a potential consequence of trauma-exposure (9, 10), with a lifetime prevalence of 7-8% in the general population (8, 11) and estimated comorbidity rates between 4.7-7.8% among people with dementia (12). However, people with dementia may express PTSD symptoms differently risking under recognition of PTSD in this population (13). Accumulating evidence indicates that early life stress, including trauma, is associated with an earlier onset and faster progression of physical frailty in later life (14, 15) as well as with multidimensional frailty (15). Furthermore, multidimensional frailty has been associated with past-year traumatic events (16), although causal inferences were limited by the study's cross-sectional design.

Frailty and dementia both increase in prevalence with increasing age and are independently associated with an elevated risk of falls, disability, hospitalization and mortality (1, 17). In addition, a robust association between frailty and dementia has been consistently demonstrated (18, 19). Given the strong impact of frailty on QoL (20), frailty may constitute a key mediating pathway linking PTSD symptoms or PTSD to QoL in people with dementia. This could provide a potentially modifying target in PTSD treatment. However, to our knowledge, this mediating role has not been empirically examined.

This study aimed to examine the association between PTSD symptoms and PTSD and QoL in people with dementia, and to evaluate frailty as a potential mediator of this association. We hypothesized that frailty would partially mediate this relationship, given its high prevalence in people with dementia and its strong impact on QoL, thereby underscoring the clinical relevance of identifying PTSD symptoms and PTSD to inform targeted interventions.

Methods

Design and population

This study is embedded in the cross-sectional, multicenter TRAuma and DEmentia (TRADE) study (21). The TRADE study includes a convenience sample of residents with dementia in long-term care facilities, i.e. five nursing homes and one psychiatric care facility for older people. Inclusion criteria were (1) mild-moderate dementia, a major neurocognitive disorder, according to the DSM-5 (22); and (2) availability of a relative able to provide hetero-anamnestic information. Exclusion criteria were (1) a severe form of dementia or impaired verbal communication, defined as phase 3 and 4 according to the model of Verdult & van der Kooij (23); (2) not fluent in Dutch; (3) resistant behaviour indicating a possible reluctance to participate, even if they claimed otherwise; and (4) severe medical or psychiatric conditions which, based on the judgement of a physician or psychologist, might interfere with the study procedures such as deafness and severe psychotic disorders.

Ethical considerations

The study protocol complies with the Declaration of Helsinki and was approved by the Medical Ethics Committee of Maastricht University Medical Center + (METC20-063). Prior to participating, participants and their legal representative were informed, and written consent was collected. The researchers handled all data in accordance with the Dutch Data Protection Act.

Descriptive and co-variables

Sociodemographic characteristic (age, sex) and somatic disease burden (weight, length, medical history) were extracted from the medical records, required to calculate the Charlson Comorbidity Index (CCI) (24). Educational level was classified according to the Dutch standard 'Standaard Onderwijsindeling (SOI) 2016', based on the International Standard Classification of Education (ISCED 2011), and categorized as low, middle or high.

The CCI was independently assessed by two physicians (an elderly care physician and a resident in geriatrics); discrepancies were discussed until consensus was reached in all cases. Participants were categorised into low (<=4); intermediate (5), or high (>=6) comorbidity groups based on expected survival. A CCI score of 4 corresponds to a 10-year survival of 53%, a CCI score of 5 to 21%, and a score of 6 to 2%; any score above 0 indicates a 10-year survival below 100% (25).

Cognitive performance was assessed using the Mini Mental State Exam (MMSE, range 0 – 30) administered by the main researcher or trained research assistant (26).

Determinants

The primary determinant was the severity of PTSD symptoms, assessed using the TRADE interview. This instrument was developed to improve the assessment of PTSD in people with dementia by evaluating the presence and severity of PTSD symptoms following potentially traumatic events, integrating participant interviews, informant information, and clinical observations, with a focus on symptoms experienced during the past month. The TRADE interview comprises 36 items covering potentially traumatic events and PTSD symptoms, yielding a total score ranging from 0 to 36 (https://maastrichtuniversity.eu.qualtrics.com/jfe/form/SV_0AOLXSjGHsmEVVA). Although the instrument has not yet been formally validated (27), its clinical applicability has been described in a case report (28). For the current study, the cumulative TRADE score (0-36) was used.

The presence of a PTSD was considered a secondary determinant, given its lower prevalence and dichotomous nature, which limited statistical power. PTSD was diagnosed by a clinical psychologist working on the participant's ward.

Outcome

The primary outcome QoL, was assessed using the proxy-rated EQ-5D-5L questionnaire (29). The EQ-5D-5L is a validated instrument for measuring QoL in people with dementia and evaluates five domains: mobility, self-care, daily activities, pain/discomfort and fear/gloominess. Responses were converted into a utility score ranging from -0.446 to 1.00 using the Dutch value set (30).

Mediator

Frailty was assessed using the Groningen Frailty Indicator (GFI) and Fried criteria, as these instruments capture complementary dimensions of frailty (17, 31).

The Groningen Frailty Indicator

The GFI is a validated 15-item instrument designed to assess multidimensional frailty in older adults, covering four domains: physical, cognitive, social, and psychological functioning. Each item is scored dichotomously (0-1), with higher scores indicating greater impairment. The questionnaire was completed by a caregiver, and a total score of ≥4 indicates moderate to severe frailty (31). For the present analyses, the GFI score was treated as a continuous scale, given the high prevalence of frailty in a nursing home population (32).

Fried Frailty Phenotype

Physical frailty was assessed using the Fried frailty phenotype, based on the original five components: unintentional weight loss, low grip strength, self-reported exhaustion, slow gait speed, and low physical activity (17). All components were operationalized using the original, sex- and body size-

specific cut-off points as defined by Fried et al.; no study specific cut-off were derived. Unintentional weight loss was considered present if >4.5 kg in the past year. Grip strength was measured using a JAMAR hand dynamometer, with the mean of two measurements of the dominant hand being recorded and classified according to the original sex- and BMI-specific thresholds (Fried et al., 2001). Self-reported exhaustion was assessed using item 11 ('lack of energy') of the Cornell Scale for Depression in Dementia (Goodarzi et al., 2017) and scored as present when rated as mild, intermittent, or severe. Gait speed was measured over 15 feet (4.17 meters) and classified using the original sex- and height specific points (17); inability to walk was classified as slow gait speed. Low physical activity was defined based on the EQ-5D-5L item on usual activities and was scored as present when moderate or greater problems were reported. The five components were summed to yield a total Fried frailty score ranging from 0 to 5.

Data analysis
Descriptive statistics were used to summarize patient characteristics. Imputation for missing data was performed applying predictive mean matching on the complete dataset using the mice R package (33). After imputation, cases where the input and outcome variable were missing, were deleted ('multiple imputation, then deletion'-approach) (34).

We used logistic regression with PTSD symptoms as exposure and QoL as outcome. Mediation models were adjusted for sex (if GFI was used), level of education, MMSE score and CCI. Following this the mediators were added; Fried frailty score and GFI were added separately. Causal mediation analysis was used (mediation R package; (35)). Bootstrap resampling was used to approximate the sampling distribution and assess statistical significance. 95% CI and β coefficients for the direct, causal mediation and total effects were calculated. Statistical significance was set at an alpha of 0.05. A sensitivity analysis was performed using PTSD diagnosis instead of TRADE score if the main mediation model was statistically significant. Analyses were conducted in R version 4.4.2.

Results

Sample characteristics

Sample characteristics are shown in table 1. For the item scores on primary determinant (TRADE interview), outcome (EQ-5D-5L), and potential mediators (Fried frailty score, GFI) we refer to supplementary tables 1-4 (appendix).

Table 1: Sample characteristics (without imputed missing data), including stratification by PTSD presence

		Total sample (n=78)	PTSD + (n=8)	PTSD – (n=66)
Age		83.6 (6.6)	84.6 (4.3)	83.5 (6.4)
Gender	Male	N=24 (30.8%)	N=3 (37.5%)	N=18 (27.3%)
	Female	N=54 (69.2%)	N=5 (62.5%)	N=48 (72.7%)
Education	0	N=63 (80.8%)	N=7 (87.5%)	N=53 (80.3%)
	1	N=4 (5.1%)	N=0	N=4 (6.1%)
	2	N=6 (7.7%)	N=1 (12.5%)	N=5 (7.6%)
MMSE		19.000 (5.806) N=76	17.875 (6.424) N=8	19.391 (5.667) N=64
CCI score	0	N=8 (10.3%)	N=0	N=7 (10.6%)
	1	N=27 (24.6%)	N=3 (37.5%)	N=24 (36.4%)
	2	N=43 (55.1%)	N=5 (62.5%)	N=35 (53%)
Fried (0-5)		2.015 (1.139) N=68	1.875 (1.246) N=8	2.052 (1.146) N=58
GFI score (0-15)		7.427 (2.406) N=75	9.375 (1.874) N=8	7.125 (2.367) N=64
EQ-5D-5L		0.651 (0.233) N=75	0.517 (0.365) N=8	0.667 (0.214) N=63

Caption: CCI; Charlson comorbidity index, GFI; Geriatric frailty index, MMSE; mini mental state exam, PTSD; post-traumatic stress disorder, TRADE; TRAuma and DEmentia

Linear regression analysis adjusted for covariates (but without any mediator) revealed that a higher TRADE score was associated with a lower of QoL (β= -0.018 (95% CI: -0.028 - -0.008); p <0.001). The covariates showed no statistically significant impact on the model (p>0.05).

There was no important change after exclusion of sex from the model (β= -0.0175 (95% CI: -0.028 - -0.008), p=0.0008), which is relevant given that sex was excluded from the mediation analyses involving the Fried frailty score, as these are already sex-adjusted.

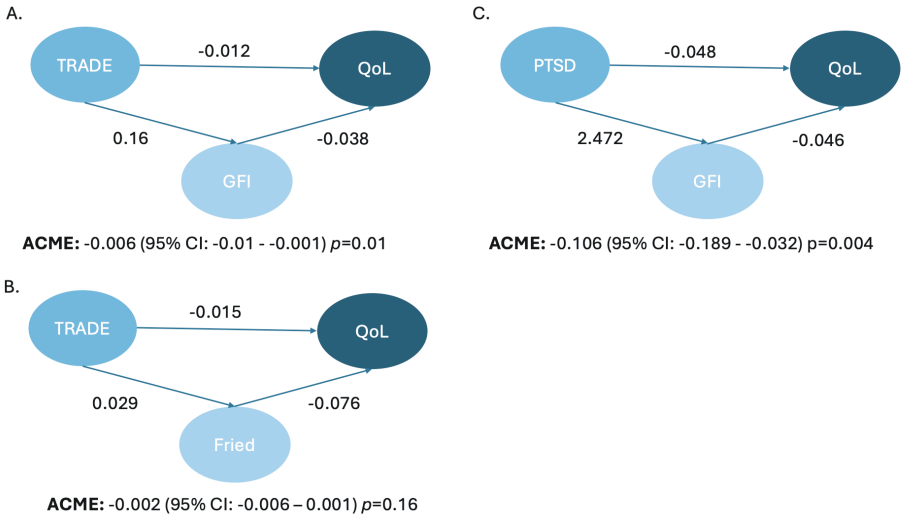
Mediation by multidimensional frailty (GFI)

The next regression model showed a significant effect of the TRADE score on GFI (β= 0.16 (95% CI: 0.056 – 0.266), p= 0.003).

When the regression model included the direct and first indirect effect through frailty (GFI), the effect of the TRADE score on QoL changed significantly from β= -0.018 (95% CI: -0.028 - -0.008) to β = -0.012 (95% CI: -0.022 - -0.002) (*p*=0.018). In this model the effect of GFI on QoL is also significant (β= -0.038 (95% CI: -0.06 - -0.017), *p*=0.0006).

Bootstrapping was applied as an inferential test to determine if the mediator (GFI) was a statistically significant mediator (figure 1A). This showed the estimated average causal mediation effect (how much of the total effect is explained by the mediator) was β -0.006 (95% CI: -0.01 - -0.001, *p*=0.01, n=75). This leads to a mediated proportion of 36.2%.

Figure 1: Results of different mediation models used for the analysis (A/B) and for the sensitivity analysis (C). Numbers provided are β coefficients unless otherwise specified.



Caption: ACME; average causal mediation effect, GFI; Geriatric frailty index, PTSD; post-traumatic stress disorder, TRADE; TRAuma and Dementia, QoL; quality of life

Mediation by physical frailty (Fried frailty score)

The association of the TRADE score with the Fried frailty score was not significant (β= 0.029 (95% CI: - 0.02 – 0.08), p=0.249) (see figure 1B).

Next, we included the direct and first indirect effect. The effect of TRADE score on QoL changed from β -0.0175 (95% CI: -0.028 - -0.008, *p*=0.0008), to β -0.015 (CI 95%: -0.025 - -0.006, *p*=0.0018). In this model the effect of Fried frailty score on QoL was β -0.076 (95% CI: -0.121 - -0.030, *p*=0.002).

Bootstrapping was applied as an inferential test to determine if the mediator (Fried frailty score) was a statistically significant mediator or not (figure 1B). This showed a non-significant estimated average causal mediation effect (how much of the total effect is explained by the mediator) (β= -0.002 (95% CI: -0.006 – 0.001), *p*=0.16) corresponding to a mediated proportion of 14.1%.

Sensitivity analysis

For the sensitivity analysis of the model with GFI we performed the linear regression using PTSD diagnosis instead of TRADE score as exposure.

Based on the first regression model in which the mediator was not included but all other covariates are included (figure 1C) people with a diagnosis of PTSD had a decreased of QoL of β -0.162 (CI 95%: -0.341 - 0.018) compared to people without PTSD, which was not statistically significant (*p*=0.077; n=72). The covariates showed no statistically significant impact on the model.

In the next regression model effect of PTSD diagnosis on GFI (figure 1C) was β 2.472 (95% CI: 0.699 – 4.25, *p*=0.007).

In the next regression model, we included the direct and first indirect effect. The effect of PTSD diagnosis on QoL changes from of β -0.162 (CI 95%: -0.341 - 0.018) to β -0.048 (95% CI: -0.218 - 0.122, *p*=0.58). In this model the effect of GFI on QoL is β -0.046 (95% CI: -0.069 - -0.0023, *p*=0.00013).

Bootstrapping was used as an inferential test to determine whether the mediator (GFI) was statistically significant. The estimated average causal mediation effect (how much of the total effect is explained by the mediator) was β -0.106 (95% CI: -0.189 - -0.032, *p*=0.004). This leads to a mediated proportion of 70.9%.

Discussion

In this cohort of 78 long-term care residents with dementia, a higher level of PTSD symptoms was significantly associated with lower QoL, with 36.2% of this association mediated by multidimensional frailty as assessed by the GFI. In sensitivity analyses, PTSD diagnosis was significantly associated with GFI, and GFI was significantly associated with QoL, whereas no significant direct association was observed between PTSD diagnosis and QoL. In contrast to our hypothesis, however, physical frailty defined by the Fried frailty score did not function as a significant mediator.

We found in this population of people with dementia, that a higher severity of PTSD symptoms was associated with lower QoL scores. This is consistent with prior studies in older populations showing that PTSD symptoms are associated with greater disability, reduced well-being, increased days in bed, and higher healthcare utilization (5) as well as lower QoL in later life (6). A meta-analysis by Pacella et al (2013) similarly demonstrated an association between PTSD symptoms and poorer physical health-related QoL across adult populations (36). Our results extend this to people with dementia in long-term care facilities.

As hypothesized, multidimensional frailty as assessed with the GFI significantly mediated the association between PTSD symptoms and QoL. This finding is consistent with evidence linking trauma exposure to increased frailty (16) and with studies demonstrating that social and multidimensional frailty are associated with poorer QoL (37). Together, these findings suggest that frailty represents an important pathway through which PTSD symptoms may contribute to diminished QoL. Importantly, prior work has shown that treatment of PTSD with eye movement desensitization and reprocessing therapy (EMDR) in older adults can reduce frailty and improve QoL (38), supporting the notion that frailty may be a modifiable mediator linking PTSD symptoms to adverse outcomes.

In contrast, frailty defined by the Fried frailty score did not mediate the association between PTSD symptoms and QoL. This discrepancy likely reflects conceptual and measurement differences between both frailty concepts. The GFI captures multidimensional frailty across physical, cognitive, social, and psychological frailty (31), whereas the Fried phenotype focusses primarily on physical frailty (17). The broader scope of the GFI may be particularly relevant in people with dementia, in whom cognitive, psychological and social vulnerability are prominent. Nonetheless, consistent with previous studies, we found an association between the Fried frailty score and impaired QoL (39). Limited variability (mean 2.015 (SD 1.139)) in physical frailty within this long-term care facility cohort may have reduced the ability to detect mediation using the Fried criteria. Indeed, only 22 participants met criteria for frailty according to the Fried phenotype, and unintentional weight loss was observed in only 3 participants (3.8%), likely reflecting the controlled care environment with structured nutrition and monitoring.

The sensitivity analysis using PTSD diagnosis yielded a significant association between PTSD and GFI and between GFI and QoL, but not between PTSD diagnosis and QoL. This finding contrasts with previous studies demonstrating poorer QoL in individuals with PTSD (Johansen et al., 2007; Olatunji et al., 2007; Rapaport et al., 2005) and is most likely explained by limited statistical power, given the small number of participants with a PTSD diagnosis (n = 8).

Several limitations should be considered. First, PTSD symptoms were assessed using the cumulative TRADE score, an instrument that has not yet been formally validated, which may affect measurement precision and generalizability. However, the sensitivity analysis using clinician-diagnosed PTSD yielded convergent findings. Second, the absence of mediation using the Fried frailty score may reflect limited power and restricted variability of the Fried frailty score, due to the controlled long-term care setting as reflected in the small variance of Fried criteria, rather than true lack of effect. On the other hand, a spurious association between the GFI and PTSD symptoms cannot be fully excluded due to some overlapping items in the psychological domain. Third, QoL was assessed using proxy ratings on the EQ-5D-5L; although proxy measures are widely used in dementia, future studies should incorporate self-reported QoL when feasible (40).

Despite these limitations, this study provides novel evidence that multidimensional frailty partially mediates the association between PTSD symptoms and QoL in people with dementia. The inclusion of a very old and a clinically representative population from a long-term care facility strengthens the clinical relevance of the findings. Although the clinical implications are preliminary due to the study design, these findings suggest that incorporating frailty-targeted interventions into trauma-related treatment may enhance improvements in QoL. Future prospective studies are needed to further study the relation of PTSD symptoms and frailty in this population.

Conclusion

The association of PTSD symptoms and frailty with QoL in dementia directly holds clinical relevance. Future studies should evaluate the effectiveness of treating PTSD symptoms and PTSD on frailty and QoL in people with dementia. Additionally, future research should include community-dwelling older people to possibly include a more diverse population of physical frailty outcome measures to confirm these findings.

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Supplements

Supplementary table 1: Overview of how the GFI was scored per question (n=75).

	YES	NO
Mobility. Can the patient perform the following tasks without assistance from another person (walking aids such as a can or a wheelchair are allowed)		
1. Grocery shopping	13	62
2. Walk outside house (around house or to neighbour)	21	54
3. Getting (un)dressed	32	43
4. Visiting restroom	51	24
Vision		
5. Does the patient encounter problems in daily life because of impaired vision?	9	66
Hearing		
6. Does the patient encounter problems in daily life because of impaired hearing?	5	70
Nutrition		
7. Has the patient unintentionally lost a lot of weight in the past 6 months (6kg in 6 months or 3kg in 3 months)?	8	67
Co-morbidity		
8. Does the patient use 4 or more different types of medication?	65	10
	Yes	**No**
Cognition		
9. Does the patient have any complaints on his/her memory (or diagnosed with dementia)?	75	0
	Yes	**no**
Psychosocial		
10. Does the patient ever experience emptiness around him? e.g. You feel so sad that you have no interest in your surroundings. Or if someone you love no longer love you, how do you feel?	37	38
11. Does the patient ever miss the presence of other people around him? Or do you miss anyone you love?	44	31
12. Does the patient ever feel left alone? e.g. You wish there is someone to go with you for something important.	27	48
13. Has the patient been feeling down or depressed lately?	37	38

Supplementary table 1: Overview of how the GFI was scored per question (n=75). *(continued)*

		YES	NO
14.	Has the patient felt nervous or anxious lately?	28	47
Physical Fitness		0-6	7-10
15.	How would the patient rate his/her own physical fitness? (0-10 ; 0 is very bad, 10 is very good)	39	36

Supplementary table 2: Overview of how the Fried was scored (n=68). N=22 scoring positive in ≥3 criteria.

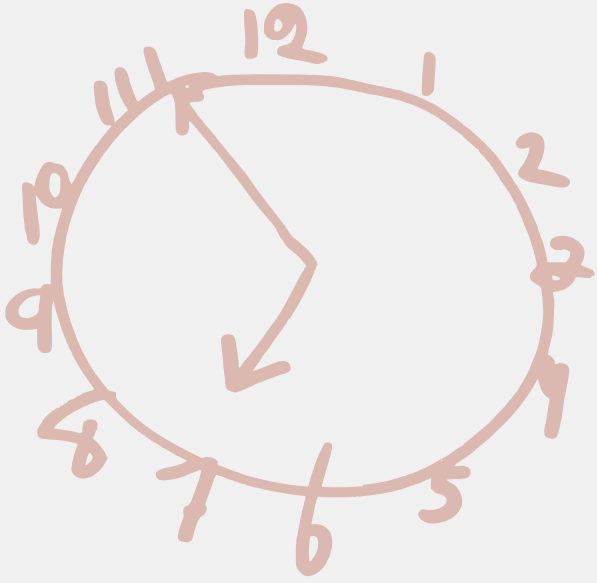
	Yes	No
Unintentional weight loss (>4.5kg in 12 months)	3	65
Weakness (grip strength)	45	23
Self-reported exhaustion	27	41
Reduced walking speed	48	20
Low physical activity	14	54

Supplementary table 3: Overview of how the EQ-5D-5L was scored per question (n=75).

	Problems with mobility	Problems with self-care	Problems with daily activities	Pain or discomfort	Anxious or depressed feelings
No problems	28	17	34	30	26
Slight problems	24	21	27	22	22
Moderate problems	10	19	9	18	24
Severe Problems	7	10	5	4	2
Extreme problems (or not able to)	6	8	0	1	1

Supplementary table 4: Overview of how the TRADE-interview was scored per question (n=75).

	Anamnesis			Hetero anamnesis			Observation		
	Yes	**No**	**?**	**Yes**	**No**	**?**	**Yes**	**No**	**?**
Criteria A									
· Experienced a trauma	52	23	0	61	13	1			
· Witnessed a trauma	17	58	0	21	51	3			
· Repeated exposure to images	2	73	0	1	72	2			
Criteria B									
· Reoccurring memories	31	43	1	24	50	1			
· Flashbacks	11	60	4	8	59	8	2	71	2
· Nightmares	15	60	0	6	67	2	5	69	1
Criteria C									
· avoidance	7	66	2	11	64	0	1	71	3
Criteria D									
· Negative thought about yourself/the world	15	60	0	10	65	0			
· Guilt	5	68	2	1	73	1			
· Fear, anger, guilt, shame	23	52	0	23	51	1	21	54	0
Criteria E									
· Agitated	19	53	3	22	53	0	22	53	0
· Self-destructive				2	73	0	3	72	0
· Over alert				9	65	1	13	62	0
· Startle response				8	67	0	2	73	0
· Trouble sleeping	18	57	0	19	50	6	11	63	1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Chapter 7

Exploring moral distress experienced by nursing professionals in daily care for people with dementia and trauma-related symptoms: a qualitative study

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A version of this chapter is submitted for publication

Abstract

Aim and objectives: Past traumatic events are associated with neuropsychiatric symptoms in people with dementia, a factor possibly causing moral distress among nursing professionals. This study explored whether and how moral distress is experienced by nursing professionals in daily care for people with dementia and trauma-related symptoms.

Methods: The study had a qualitative design using semi-structured interviews. Ethics committee of the Faculty of Health, Medicine and Life sciences of Maastricht University approved the study (FHML-REC/2023/111/Amendment/2024_03)

Participants were nursing professionals in the Netherlands, with experience in providing care for people with trauma-related symptoms and dementia in psychiatric or psychogeriatric care facilities.

Outcome measures: The interviews were transcribed, and thematic analysis was performed using ATLAS.ti.

Results: 12 semi-structured interviews were conducted from April 2024 - July 2024. The themes found were (1) trauma's recognized by nursing professionals, (2) the way they reacted to trauma-related symptoms of people with dementia, (3) moral distress this caused the nursing professionals and (4) needs of the nursing professionals. Main causes of moral distress were verbal and physical signs of self-defence of people with dementia seen in the daily personal care process. Causing discomfort or resistance in the person with dementia during the care process led to helplessness in the nursing professional. Nursing professionals reported more education on trauma in people with dementia could be beneficial.

Conclusion: This study shows moral distress was experienced by nursing professionals in relation to trauma-related symptoms in people with dementia. It was most often seen during personal care and related to a past sexual trauma. More research and education regarding the presence of trauma-related symptoms in people with dementia is necessary.

Study limitations: The definition "moral distress" is frequently debated, a vignette was provided to explain the concept. The vignette was not validated by an independent panel but designed by the authors based on clinical experience.

Introduction

The concept of moral distress was first introduced by Jameton (1984), who described it as the tension experienced when one knows the morally right action but is constrained from acting on it. In 1993 Jameton expanded this view, in which the institution or co-workers are described as the factor that limits the nurse from acting on their own judgement, thus causing distress (1). However, when studying moral distress in daily care practice, a more operational definition is needed, one that allows for empirical exploration of how moral tension manifests in the concrete experiences of healthcare professionals. Morley et al. suggest "(i) the experience of a moral event, (ii) the experience of 'psychological distress' and (iii) a direct causal relation between (i) and (ii) together are necessary and sufficient conditions for moral distress" (2). Other definitions are that moral distress arises in situations in which a difficult choice needs to be made between different courses of action, which all entail transgressing a moral principle (3). In the different definitions, moral distress often follows the requirement to enact things that are perceived by the nursing professional as harming the good of someone or something (4). This can increase work pressure and lead to higher dropout rates and lower quality of care (5). In this paper, when referring to moral distress, we try to stay close to the definition of Morley et al.

Moral distress can lead to an increase of care burden in nursing professionals(6, 7). Reflecting on and discussing moral dilemmas has been shown to strengthen resilience and reduce this burden (8). In psychogeriatric care, nurses experience high emotional demands, leading to turnover and reduced care quality (9, 10) highlighting the importance of recognising and understanding factors that influence the care burden for nursing professionals.

Besides moral distress, neuropsychiatric symptoms in people with dementia are known to also increase care burden (11). Providing care for people with dementia, who show f.e. aggression, can also cause moral distress in nursing professionals (7). Between 80-90% of the people with dementia develop such symptoms, which can lead to challenging or problematic behaviour such as aggression and agitation(12). These neuropsychiatric symptoms have been associated with higher levels of emotional exhaustion and work-related mental distress among nursing professionals (11, 13). Recent research further links neuropsychiatric symptoms to earlier traumatic experiences (14). In the Netherlands, about 81.5% of the population has experienced at least one potentially traumatic event (15). Such events, defined as exposure to threatened death, serious injury, or sexual violence (16), may lead to post-traumatic stress disorder (PTSD) or related symptoms such as anger, irritability, and sleep disturbances in people

with dementia (17, 18). These trauma-related symptoms likely intensify the care burden and moral strain among nursing staff.

To increase knowledge on moral distress in daily care for people with dementia and trauma-related symptoms and find opportunities for support of nursing professionals the current study aimed to gain insight into moral distress in nursing professionals who work with people with dementia who have trauma-related symptoms as both factors are known to increase the care burden on nursing professionals. To achieve this, we explore whether and how moral distress is experienced by nursing professionals in daily care for people with dementia and trauma-related symptoms.

Methods

The study design, data collection and reporting followed the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines (19). A completed COREQ-checklist is provided in Supplement 1. Additionally, the Big Q Qualitative Reporting Guidelines (BQQRG) were used to improve the reporting of this study (20). In this qualitative study, semi-structured interviews were used to explore whether and how moral distress is experienced by nursing professionals in daily care for people with dementia and trauma-related symptoms. The interviews were conducted using a semi-structured interview guide [Supplement 2], which was collaboratively developed by all authors with additional input from a subject-matter expert. The use of semi-structured interviews allowed us to acquire in-depth information from participants while considering the focus of the study (21). The pre-understanding of the research team consisted of elaborate backgrounds of working in dementia care as nurses, elderly care physicians or psychiatrists. Additionally, multiple researchers had experience in research in the field of trauma, PTSD and/or dementia care. The pre-understanding is mainly utilized during the preparation phase when forming the interview guide and vignette described below but also aids in forming a deeper understanding and discussion on the provided data.

During a pilot in advance of the current study, it was evident that the term moral distress was not always familiar with nursing professionals. A vignette was created by the research team to be used in the interviews to explore the nursing professionals' interpretations of a uniform situation in which a nursing professional could experience a moral dilemma. Two authors (JR and AJ) created the vignette based on realistic clinical experience which the researchers had often been consulted on in their clinical work. Consensus was reached and a third author (SS) was involved for a final check. The vignette was only used when

the nursing professional did not understand the term moral distress (22, 23) [supplement 1]. It was an example of a woman with a history of sexual abuse who refused personal hygiene care. When the vignette was used, the interviewees were stimulated to reflect on personal experiences in the interview and not on the hypothetical case described in the vignette [Supplement 1].

Setting and participants

Nursing professionals were recruited from multiple psychiatric and psychogeriatric care facilities in the south of the Netherlands through purposive sampling to facilitate gaining deeper insights into the specific research topic. The number of participants was initially aimed at n=18 based on expected feasibility taking project time and interviewer availability into account. We considered 'information power' and if interviews provided sufficient information relevant for the current study a lower amount of participants would be accepted (24). Due to the use of purposive sampling and the specific study aim information power could be increased. Participants were recruited via email via personal connections of the researchers in the relevant work field or by responding to an online post. The participants who were interested received additional information about the study via email, after which they decided if they would be willing to be interviewed. Participants were required to (1) be at least 18 years of age (2) have at least 2 years of working experience as a nurse or a nursing aid with people with dementia and (3) have cared for a person with trauma-related symptoms and dementia.

Data collection

The preferred methodology for data collection was by conducting face-to-face interviews. If a meeting between participant and interviewer was not feasible an online interview was held with individual participants. For the face-to-face interviews, participants were visited at their place of work. Interviews were conducted in a private area. Interviews were audio recorded and transcribed verbatim within one week of the interview taking place. Interviews were semi-structured, and the interview guide was developed based on expert opinion and the current literature [Supplement 1]. Interviews were performed and monitored continuously, when information power was reached according to the research group, no new interviews were planned.

Data analysis

After data collection, the a-verbatim transcribed interviews were uploaded into ATLAS.ti (Version 24.1.1 (30840)). The interviews were analysed using reflexive thematic analysis, underpinned by an experiential realist approach, to generate a detailed account of participants' lived experiences (20, 25). The analyses was informed by a hermeneutics epistemology, with the aim to understand

the participants experience as situated within their social and contextual circumstances. This, while acknowledging the interpretative and reflexive role of the researcher. An essential/realist approach was chosen assuming a unidirectional relationship to improve understanding of the complexity of moral distress in these specific situations (20, 25). Initially two authors (JR, AJ) familiarized themselves with the data by studying the interview transcripts. The initial analysis was executed by one author (JR); and discussed with the other authors (AJ, SS). First, a specific code was given for each conversation topic that had come up as answers during the semi-structured interviews. For this a semantic approach was initially chosen to collect the explicit data provided in the interviews and to aid in providing a clear overview. This was later summarised to an interpretive level to explore the deeper contextual meanings related to the experienced moral distress (20, 25). Examples of the initial themes created include World War II trauma, involvement of the care team, the use of force in personal hygiene care and family involvement. Following this, the codes were grouped by overarching theme. The main goal of the thematic analysis was to form an accurate and comprehensive representation of stakeholder experiences(26). The final themes were discussed with the whole research team to ascertain whether all information was covered within the themes and whether they allowed for a clear representation of the answers provided by interviewees. Table 1 provides an overview of final themes, codes and interview transcript sections.

Ethical considerations

Informed consent was obtained from all participants prior to the interviews and participants were asked to sign an informed consent form. Recordings were transcribed and analysed anonymously of person and place. The Ethics committee of the Faculty of Health, Medicine and Life sciences of Maastricht University approved the study (FHML-REC/2023/111/Amendment/2024_03). The study adhered to the Helsinki Declaration ethical principles for medical research.

Table 1. Examples of final themes, categories and codes created

Interview transcript (translated)	Code	Category	Theme
Partially powerlessness. A bit of knowledge shortness, could we have done differently [….] It's also a bit of failure, 'did we forget things?' or 'should we have done things differently?' P8	If we would have known more, we could have changed our way of working	A complete history of a person with dementia / knowing their past as a tool for better care	Needs of nursing professionals when caring for people with dementia and past traumatic experience
'It's horrible that those things [referring to a trauma] have happened, let alone that they experienced it. You form a bond with someone (…) that touches you' P4	It touches me to know someone had been through trauma	Emotionally involved when knowing what trauma a person has been through	Emotions experienced by nursing professionals
I can let it go (…) It is hard that someone went through something like that. But all I think is 'we are going to make the best of it together' P9	It is hard that people must go through traumas, but we can work together to avoid re-traumatisation	Being able to turn the knowledge of experience trauma into motivation to provide better care	Emotions experienced by nursing professionals

Results

Over the course of 16 weeks twelve interviews were conducted. Six were held with nurses and six were held with nursing aides who all had experience caring for people with dementia and trauma-related symptoms. No potential participants withdrew after receiving the additional information via e-mail. All interviews were conducted by the second author, a female nursing professional (AJ) with supervision from the first author, a medical doctor (JR). The participants ranged

in age from 26 to 54 years. The participants came from 9 different psychiatric and psychogeriatric care facilities in the Netherlands. Most participants were female (n=10), and all interviewees were Caucasian.

Interviews took between 15 and 45 minutes; 10 interviews were held in person at the work location of the caregiver; 2 interviews were held online. Two of the interviews were held in a private office with one other colleague present because there was no other room available. The interviews held in an open office did not significantly differ in discussed themes from the interviews in private rooms. Participants were informed of the background of the study and the interviewer; the participants had no prior relation with the interviewer. The interviews were then transcribed and coded.

Different themes arose in the analysis of the interviews. Theme one consists of examples of what nursing professionals recognised as trauma-related symptoms. The second theme was how nursing professionals reacted when they provided care for a person with dementia and trauma-related symptoms. The third theme was the moral distress experienced by nursing professionals and the final theme consisted of the needs of nursing professionals when this moral distress was present. Additionally, supplement 3 presents an overview of the type of trauma, the observed behaviour and, if present, the moral distress it resulted in with quotes of the participants.

Theme 1: Examples of what nursing professionals recognised as trauma-related symptoms

The participants were asked for examples of care for people with trauma-related symptoms. Three participants (2 nurses, 1 nursing aide) initially did not recognise situations. In these interviews, the interviewer provided the vignette [supplement 2], which resulted in recognition of personal experiences of trauma-related symptoms in people with dementia in all three participants.

> *"His partner didn't talk about it for a long time but finally she came forward. She told us her husband had been sexually assaulted in his youth" – P3*

Eight participants (4 nurses, 3 nursing aides) brought up examples of people with dementia who had, or possibly had, experienced sexual abuse in the past, prior to the interviewee presenting the vignette on this subject. In four examples, sexual abuse had explicitly been reported. In one interview, it was described as a hypothesis based on the observations. One participants said that the person with dementia told them about the trauma. In two other interviews, the participants said the family informed them of the trauma. In these examples,

the trauma-related symptoms were noticed mostly while assisting with personal care and hygiene. Participants described seeing physical signs such as people with dementia covering themselves or pushing care away in all eight cases. Five participants (3 nurses, 2 nursing aides) referred to examples of people with war-related trauma. Other potentially traumatic events briefly touched upon by one interviewee were loss of parents, loss of children, divorce, illness, or an accident.

> *"We have also had residents who have been in a Japanese camp. They also experienced traumas there. In hindsight you also think, should we have done things differently for them" – P8*

Theme 2: How nursing professionals reacted when they provided care for a person with dementia and trauma-related symptoms

All participants described a variety of different measures they have taken in the past in reaction to trauma-related symptoms in people with dementia. Four participants (2 nurses, 2 nursing aides) described executing smaller interventions executed during direct care, such as distracting the person with dementia at the moment of confrontation and adjusting the care to avoid trauma-related triggers; not having a male nursing professional provide care to a person who gets upset when a male nursing professional is present; or being calmer, more patient and explaining things carefully when proving care for people who process information slower.

> *"[…] or distracting someone a little bit so the experience (referring to care process) isn't an unpleasant one. So, you turn it into a positive experience despite them feeling unpleasant" – P11*

In cases where the person with dementia refused care, the family was often involved in discussing the care plan. Ten participants (5 nurses, 5 nursing aides) described involving the family; five of these participants described a situation in which the family was actively involved to gather information. In these situations, it was challenging to get the required information from the family for several reasons: the legal representative not knowing about the trauma and needing to involve other relatives, people feeling it was not relevant or people being embarrassed about the trauma. Three participants described examples related to personal hygiene in which the family wanted more personal care, while the nursing professionals wanted to provide less personal care due to trauma-related symptoms experienced during the care moments. Families often struggled because their parents used to be very self-aware about personal hygiene in the past.

> *"By having multiple conversations with the family and getting to know someone's background we could make choices together with the family" – P8*

Theme 3: Moral distress experienced by nursing professionals

> *"It touches you, it is terrible that something like this [referring to trauma] happens to anyone, let alone that they experienced this. You build up a bond with people […] that gets to you" – P4*

Nursing professionals described examples of situations with trauma-related symptoms in which they experienced moral distress and how this made them feel. Eight participants described emotions that can be seen as negative (5 nurses, 3 nursing aides). Of these negative emotions three participants described a feeling of powerlessness (2 nurses, 1 nursing aide). One example that led to the participants to feel powerlessness was when a woman with dementia, who was scared and lonely, did not let anyone come near her due to past trauma. Thus, the comfort the participants wanted to offer only led to more fear. Three participants described it as frustrating (all 3 nurses). An example in which the nursing professional felt frustrated was when colleagues did not see the same solution as they did; the participant thought providing more time in the care process would help, while her colleagues thought this was unrealistic because of the other people who also needed care on the ward.

> *"I think it's mainly a challenge, not really an emotion. It doesn't make me happy or sad, mainly enthusiastic to discover how we can help her." – P4*

Three nursing professionals described it as being difficult (1 nurse, 2 nursing aides). One of these participants, a nursing aide, specifically stated that the difficulty was an interesting part of their work. Four participants indicated that they did not feel a burden at all when providing care for people with trauma-related symptoms (1 nurse, 3 nursing aides). Additionally, one nursing aide described it as a good challenge to provide this care in the best way possible.

> *"Say, for example, you want to do the right thing, but on the other hand you realize, yeah, that someone is panicking because of you." – P1*

> *"You take certain situations home more often than others […]. Then I'm sitting on the sofa at home and I think 'I'll just check the patient file, to see how it is going with her' " – P2*

Six participants described having personally experienced moral distress related to the personal care of people with dementia and symptoms related to trauma from sexual abuse (3 nurses, 3 nursing aides). None of the interviewees expressed that their moral distress kept them up at night, although two participants said they were preoccupied with work-related situations at home. Three participants did not directly experience moral distress themselves but saw that others within the care team did (2 nurses, 1 nursing aide). Six participants noticed that everyone had their own, often different, way they felt and acted when providing care for people with dementia and trauma-related symptoms. Three participants explicitly noted it was hard for his/her colleagues, of which two participants noted that the trauma personally experienced by colleagues could play a role in this. One interviewee described that the past experience of sexual abuse of the person with dementia triggered the colleague's own memory of their personal traumatic history.

> *"Many colleagues who have experienced similar things (referring to traumas) have walked away in crying. When the woman said 'dad, don't do it. They struggled with this." – P9*

Participants also described that the care they provided was a trigger for trauma-related symptoms for the person with dementia, which made it difficult for them to provide care, because it felt like they would need to proceed to the use of force in hygiene care, something one participant refused to do. Nine participants mentioned accepting (what is considered as) less or poorer hygiene, but three specifically mentioned providing care when there is a health risk, such as when someone was covered in faeces or when someone had intertrigo rashes. One participant described their goal to make the person for whom they were providing care feel safe. This participant experienced the care they provided to people with trauma-related symptoms as an action that made the person feel less safe.

Theme 4: Needs for nursing professionals

> *"You can ask everyone for help if you can't figure it out within the team. It is often the psychologist we reach out to or the doctor [...]" – P5*

All participants described that discussing moral distress and difficult situations with their co-workers helped them. Nine participants mentioned involving the psychologist of the ward, while five participants described involving the behavioural counsellor and seven participants described involving the physician. Ten participants described involving the care team and talking about it together. Five (3 nurses, 2 nursing aides) of these participants specifically referred to a

moral deliberation, and two referred to interventions. A moral deliberation was held in two cases that were considered extreme, and this was mentioned as something that was held regularly and could be used in challenging situations. It was also mentioned as something that could have been helpful in hindsight.

Five participants brought up the possible benefits of more education on trauma-related care. One participant said that they felt they were not equipped for the challenges of caring for people with trauma-related symptoms. Another participant mentioned not having the specific expertise required to care for this population. One participant mentioned the urge to educate all the staff, including the supporting staff, as they are part of the daily life on the ward.

> *"What can I do to get her out of the movie (referring to a potential flashback of trauma)? I don't think we are educated enough to deal with this directly." – P4*

Discussion

Using semi-structed interviews, this descriptive qualitative study aimed to explore moral distress is experienced by nursing professionals in daily care for people with dementia and trauma-related symptoms. Four themes arose during the interviews. The first theme was the types of traumas recognised by the nursing professionals. Sexual abuse and war-related trauma were recognised frequently, but emotional and physical abuse were also described. The second theme was how the nursing professionals adjusted the care when someone was thought to suffer from a past traumatic experience. Multiple examples referred to minimising the personal care moments in people who were thought to have experienced past sexual trauma. The third theme showed that nursing professionals experienced moral distress in different situations; the most often-mentioned example was when providing personal care for people with past sexual trauma. The fourth theme consisted of the needs of nursing professionals; these appeared to be diverse but not structured. They included involving the entire care team in all participants, involving the psychologist or physician or changing the way care was provided. Five participants additionally highlighted the need for more education on trauma-related symptoms and its effects in people with dementia.

In this study, nursing professionals recognized multiple trauma-related symptoms. Often recognized were symptoms as a consequence of sexual abuse in people with dementia. Sexual abuse is known to have longstanding negative consequences on psychological wellbeing such increasing the risk

of anxiety as an adult and a risk for the development of PTSD, which varies between 9.2% and 19.0% based on the type of sexual trauma (27, 28). The nursing professionals recognised some of these longstanding consequences such as verbal and physical signs of self-defence during contact moments. However physical touch is a large and important part of nursing care that has positive effect on the receiver of care (29), and aids the nursing professional in providing care (30). This emphasises the importance of aiding nursing professionals in the recognition of long-term symptoms of sexual abuse in people with dementia to aid in adjusting the daily care process accordingly. To aid in recognising different types of trauma, gathering a trauma history is of importance (31). A trauma history is valuable, but some nursing professionals in this study indicated retrieving a complete trauma history from an informant can be challenging and might not always be possible. Establishing a care culture that stimulates and facilitates relational care may help to overcome these challenges; collaboration within the care triad (involving the person living with dementia, their family caregiver, and the nursing professional) from the very beginning of care in the nursing home can foster a trusting relationship (32, 33). Possibly making it easier to retrieve a life story.

We found that nursing professionals recognised trauma-related symptoms and actively adjusted their approach in reaction to the symptoms that the person with dementia expressed. Forms of active coping mechanisms found in the current study were minimising personal care in people who might have experienced sexual abuse and avoiding loud sounds that could be a trigger for people with war-related trauma. A previous case-series has also shown that hospital nursing professionals amend their care to acknowledge the role trauma plays (34). Previous studies have emphasised the importance of recognising trauma-related symptoms because of its high prevalence in end-of-life care; they have also illustrated the role the care team could have in providing trauma-informed care (TIC) when interacting with the patient to relieve environmentally related discomfort (35). MacRae et al. emphasised that knowledge about trauma is essential for providing a trauma-sensitive approach and highlighted the importance of further education on trauma and trauma-related care for nursing professionals in the Netherlands (31).

The ways in which nursing professionals experience moral distress vary depending on individual, organizational and contextual factors. Trauma-related symptoms in people with dementia led to situations in which nursing professionals felt powerless, felt frustrated or experienced difficulty. Geriatric care is known to also involve emotional and sensitive situations for nursing professionals due to the complex care needs of older people (36). To cope with feelings of powerlessness, frustration or experiencing difficulties the

development of soft skills in nursing professionals is also of great importance, as a disparity exists between the relational needs of people with dementia and trauma related symptoms and the training that care professionals typically receive (37). In geriatric care relational and communicative skills are often expected to come natural, while in training technical and procedural skills remain the focus. This may undervalue the complexity and therapeutic importance of relational care and place unrealistic expectations on staff (38). Previous studies have found that moral distress is often caused by the need to provide care experienced as futile, staff shortages and uncooperative behaviour by patient and family; it may also lead to higher burn-out rates and more emotional exhaustion (39-41). This study is the first to highlight the moral distress experienced by nursing professionals when their actions led to their client remembering past trauma, these situations could be seen as a dilemma as daily care needed to be provided to avoid adverse health risks (42). Our findings elaborate on previous results that are not trauma specific and highlight the importance of more support for nursing professionals when caring for people with dementia and trauma-related symptoms.

The needs of nursing professionals when recognising trauma-related symptoms were often involving other members of the care team. Such as, the behavioural consultant, the psychologist or the ward physician. Involving a spiritual caregiver (an expert on ethics, relational work and moral deliberation) could meet the needs of nursing professionals (43). Discussing moral distress is also described as helpful in previous studies in long term care settings in Canada (44). None of the nursing professionals in the current study described an available protocol or guideline. The only common approach described was a moral deliberation, although the use of this varied and was often too late. Indicating a better integration of moral deliberation could be beneficial (45). Other studies highlighted that individual coping mechanisms are not sufficient when dealing with moral distress, although organisational support structures for ethical dilemmas were required in Swedish hospital departments (46). The current study reflects these results, as most of the nursing professionals interviewed mentioned experiencing moral distress and negative emotions while often using their personal, informal coping mechanisms. A recent scoping review identified several strategies for coping with moral distress, including discussing ethical challenges with peers, obtaining support from colleagues and managers, and seeking assistance outside the immediate team or organization (47).

Future studies on moral distress in the care of older adults with dementia and trauma should explore the systemic and relational conditions that help prevent moral distress and foster moral resilience. Research could, for example, examine the impact of structurally embedded moral reflection practices, such as moral

case deliberation or intervision, on team culture, moral awareness and perceived moral distress (45, 48). Moreover, studies could investigate how enhancing residents' autonomy and relational care within the care triad (resident–informal caregiver–professional) function as protective factors against moral distress (49). This includes exploring how space for ethical dialogue, reflective practice, and relational atonement can help professionals transform moral suffering into moral resilience (50) and strengthen both care quality and professional well-being in geriatric settings.

Some methodological limitations should be considered. First, the definition of "moral distress" is frequently debated. The interviewees were given an explanation and if needed a vignette to aid in understanding the concept, but the vignette was not validated by an independent panel. Thus, the situations they described under moral distress were based on individual interpretations. The use of this vignette could lead to hypothetical reflections, even though nursing professionals were stimulated to reflect on their own experiences. Second, the conceptual layering of ethics and morality is not included, which was a deliberate choice in the design of the present study. However, the discussion aims to address this by providing a more in-depth reflection on these dimensions. Thirdly, this study included 12 nursing professionals who all work in inpatient care. Presumably moral distress can also arise in the home care setting, where it is possibly harder to discuss these situations in a care team or with (para)medics. Finally, this study focussed on the perspective of the nursing professionals, but the perspective of the person with dementia in this situation or of their family could be of added value. Regardless of the limitations, this study highlights the many forms of trauma that nursing professionals recognise in people with dementia due to the presence of trauma-related symptoms, the stress and burden this poses on the care process, the lack of structured coping mechanisms and the need for more education.

Conclusion

We found that most nursing professionals experienced moral distress centred, but not solely, around personal care, and this distress was often related to the care process, ultimately leading to powerlessness and frustration. Future research should focus on preventing moral distress and fostering moral resilience among nursing professionals in the care for people with dementia.

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Supplements

Supplement 1. COREQ checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Section 3.1
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Section 3.1
Occupation	3	What was their occupation at the time of the study?	Section 3.1
Gender	4	Was the researcher male or female?	Section 3.1
Experience and training	5	What experience or training did the researcher have?	Section 3.1
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	Section 3.1
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Section 3.1
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Section 3.1
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Section 2.3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Section 2.1
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	Section 2.1
Sample size	12	How many participants were in the study?	Section 3.1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	Section 3.1
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Section 3.1
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	Section 3.1
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Section 3.1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Supplement 1
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	n/a
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Section 2.2
Field notes	20	Were field notes made during and/or after the inter view or focus group?	n/a
Duration	21	What was the duration of the inter views or focus group?	Section 3.1
Data saturation	22	Was data saturation discussed?	Section 2.2
Transcripts returned	23	Were transcripts returned to participants for comment and/or	n/a

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	Section 2.3
Description of the coding tree	25	Did authors provide a description of the coding tree?	n/a
Derivation of themes	26	Were themes identified in advance or derived from the data?	Section 3
Software	27	What software, if applicable, was used to manage the data?	section 2.3 (ATLAS.ti)
Participant checking	28	Did participants provide feedback on the findings?	n/a
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Section 3
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Section 3
Clarity of major themes	31	Were major themes clearly presented in the findings?	Section 3
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Section 3/ table 1

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Supplement 2: GLISTEN Interview Guide:

Starting questions:
- Gender
- What's your age?
- Which education have you done?
- Can you tell me about your career and experiences in health care?
- Have you followed any additional courses or trainings?
- How many years of experience do you have in elderly care?

We'll start the interview with a few questions on moral distress. We'll define a moral distress as a situation in which there's a conflict between different moral values. For example, the value 'honesty' in the face of the wellbeing of a patient. Is it important to always be honest to a patient? Or can you lie in certain situations to protect them from negative emotions?
We'll be discussing these types of situations in the care for patients with dementia who've experience traumatic events in the past.

Exploring situations in which moral distress is present:
- Can you give examples of situations in your day-to-day job in which possible trauma of patients with dementia plays a role? What types of trauma have been experienced?
- Does this ever lead to moral distress?
- Is the situation difficult to deal with? If so, why? What values are at stake? Do you feel responsible in these situations? In what way?
- How does the situation make you feel? Do any specific emotions arise?
- What's the influence of the situation on the care team? How do you deal with the situation?
- Is there a situation that has made a big impact on you? Have there been situations that lead you to lie awake at night?
- In situations like we just discussed, do you know someone's been through trauma because they have a diagnosis of PTSD? Do you know because the patient or their family told you? Or are they just presumptions you have because of the patient behaviour?
- Do you notice a difference in the severity of dementia and how the situation makes you feel? (for example: feeling more conflicted about a situation because a patient can't be calmed down as easily because they're in a further stadium of dementia).
- Do you notice any differences in patient with a migrant background? (where there's a possible language barrier or cultural differences).
- How do you deal with the moral distress you experience at your place of work? How does the rest of your care team?

- Do you ever talk to your colleagues about the moral distress related to trauma you experience? How often does this happen? Do you experience support from your colleagues? If so, in what ways?
- Can you express the amount of support and trust you experience from your colleagues on a scale from 1 to 10? 1 being no support/trust and 10 being a lot of support/trust.

If the information gathered from the questions above is unsubstantial, the use of the following vignette can be considered.
The case of Ms Baker:
Ms Baker is an 82-year-old lady who was admitted to a psychogeriatric ward in a nursing home 4 months ago. 2 years prior she was diagnosed with dementia after which she had trouble to continue living on her own. In general Ms Baker is a friendly lady but the personal hygiene care moment is difficult for her. Since she's been admitted to the ward, she's been refusing to let nursing professionals help her with her personal hygiene. If nursing professionals try to motivate her to take a shower, she gets verbally aggressive. Ms Baker tries to keep clean by herself, but her abilities to do so are getting worse. Both the care team as Ms Bakers family notice that her personal hygiene is deteriorating.
In a conversation with Ms Bakers family, it becomes clear that Ms Bakers experienced years of sexual abuse in her youth. When nursing professionals try to help her with her personal hygiene, this evokes all kinds of negative memories and feelings. This is the reason Ms Baker becomes verbally aggressive and refuses care.
The nursing professionals on the ward are faced with moral distress: are they going to keep providing daily care while this causes a lot of anxiety and negative emotions? Or do they let Ms Bakers hygiene deteriorate?

Questions:
- Is this a situation that could occur at your place of work? Have you ever dealt with a situation like this before? Would you find it difficult to deal with? If so, what makes it difficult?
- Does it make you feel any specific emotions?
- Would this behaviour cause you to suspect any underlying trauma? If so, does that influence your feelings or emotions in this situation?
- Would you find it difficult to make the best choice in this situation? What would the influence of this situation be on your care team?
- Do you experience enough support in the situations what we've discussed, or do you require additional support?
- If you require additional support, in what way do you envision that?
- Are there any things you need in the care for patients with dementia and traumas?
- What helps you to deal with the moral distress you experience?

Supplement 3. Overview type of trauma, observed behaviour and, if present, the moral distress it resulted in. The participant number is written behind the examples (P1-P12).

Trauma	Observed behaviour	Moral distress
Sexual abuse	The refusing of personal hygiene - P3, P8, P10, P12 People saying, 'I don't want this, I did nothing wrong', 'no dad, don't do that' during personal hygiene - P2, P9 The covering of body parts during personal hygiene - P2	''You want to do good but you must also realize someone is panicking because of you.' - P1 'You want to care for someone, provide them with hygiene. But because she refuses it became a dilemma for the whole team, what do you prioritize [….]. you want to avoid complaints from bad hygiene, but you don't want to bring someone in a flashback.' - P8
	Someone cowering when males pass her on the ward – P10	'You can try to take it into account as much as possible, but you can't fully avoid it if staff, people's male family members visit. It is really sad because you can't avoid it.' - P10
	Aggression seen when someone is scared - P12	Not described
War	Reactions to loud footsteps on a ward with multiple people who were at a Japanese prisoner-of-war camp, it described the footsteps as a trigger to the memory of the persons time at the camps - P1	Not described
	Someone barricading the bedroom door - P8	'We were scared because what if she falls and we can't reach her? Do you accept this, so they feel safe, or do you take away the barricade, so she is safe?' - P8
	One person was very aggressive and suspicious during the care moments - P3	'When he needed personal care, it was always a challenge […] how far do you go? And when someone starts hitting, how far do you let it come? In the end its not only a disadvantage for the person themselves but also for the nursing professionals.' - P3

Supplement 3. Overview type of trauma, observed behaviour and, if present, the moral distress it resulted in. The participant number is written behind the examples (P1-P12). *(continued)*

Trauma	Observed behaviour	Moral distress
War	One person hid behind furniture and shouted frequently, presumably triggered by a loud sound, and one person got scared in closed or dark rooms resulting in panic attacks, the dark rooms were said to trigger her memory of hiding in the basement when airplanes flew over during the war - P4	'You want to help but you don't know how. She was so emotional that it really got to me. You also need to support the family. You want to help but you can't.' - P4
	Someone being scared in the dark, scared in closed rooms. Never allowing the door or curtains to be closed - P5	'This did not pose a dilemma; you just move along with her needs. It's about her wellbeing.' - P5
Emotional neglect	A woman lying in fetal position all day calling for her mother - P4	'I did not know what to do, I did not know how to help her. There was no quality of life. I really took that home with me.' - P4
	The need for a feeling of safety but not being able to accept this; 'you could be close to her for a short while and then she pushed you away' - P12	'In this case we couldn't do anything, nothing helped sufficiently, no one could come close to her.' - P12
Physical abuse	Walking around skittishly and scared. Combined with the mentioning a feeling of being followed - P3	'Constantly needing to invest in to gain het trust and having to see her emotional suffering every day.' - P3
Traumatic accident	A person that kept needing to talk about an accident and this person kept reliving it, as if it happened recently - P11	'Sometimes you need to lie to her for her own good, but it is a lie and that is not pleasant for her.' - P11

Chapter 8

General discussion

General discussion

What are the implications of PTSD in older adults, particularly those with dementia, for geriatric care?

This thesis focusses PTSD in older people and people with dementia. The studies in this dissertation address the broad impact of PTSD in this population and highlight how it effects not only the people themselves but also the health care professionals across many disciplines involved in geriatric care. *Chapter two* highlights the relation of PTSD symptoms with cognitive performance in older adults, where the presence of more PTSD symptoms is related to poorer performance on executive functioning tests. *Chapter three* shows that recognizing PTSD in people with dementia has potential clinical consequences in the form of psychological treatment. *Chapter four* provides an elaborate case report of EMDR in a person with PTSD and dementia, aiming to provide EMDR-therapists with treatment recommendations and highlighting the role of nursing professionals and informal caregivers. *Chapter five* provides a study protocol for a cross-sectional study in people with dementia on the diagnostics and treatment of PTSD, the TRADE-study. *Chapter six* provides us with a first analysis from the TRADE database showing the mediation of frailty in the relation between PTSD symptoms and QoL. Lastly, *chapter seven* presents a qualitative study delving into the moral distress nursing professionals, caring for people with dementia and PTSD symptoms, can experience.

In the current chapter, the findings of the above-mentioned studies are combined, and the insights they provide are reflected upon in more detail. The main research question will be addressed by answering the sub-questions outlined below. In addition, the strengths and limitations of this thesis will be addressed and implications for practice and future research will be highlighted.

1. Do ACEs and / or PTSD symptoms impact cognitive performance in older adults?
2. What are feasible treatment options for PTSD in people with a diagnosis of dementia?
3. What is the impact of PTSD on quality of life in people with dementia in geriatric care?
4. What is the impact of caring for people with trauma and dementia on nursing professionals in geriatric care?

Impact of PTSD symptoms and ACEs on cognitive performance in older adults

The available research on the impact of PTSD is broad and extensive; research looks at many different factors such as biological ageing, psychological

comorbidities and QoL (1, 2). One important topic of research is the relation of PTSD, PTSD symptoms and / or ACEs with cognitive performance. So, *chapter two f*ocusses on how PTSD symptoms and ACEs impact cognitive performance of older adults, using data from the PANDORA study including a group of healthy controls and people with PDs. In the paragraphs below, PTSD symptoms, ACEs, and PDs will be reflected on in greater detail. In addition, resilience, a potentially important factor that may influence the relation between PTSD symptoms/ACE and cognition, will be considered.

PTSD symptoms

When looking at current PTSD symptoms with the PSS-SR a significant relation is found with cognitive functioning in *chapter two*, where people with more PTSD symptoms perform worse on executive functioning. This could indicate that PTSD symptoms, that follow from a PTE, can still have an impact later in life. A PTE is any adverse event, regardless of the timing in life, that could potentially be or become a trauma for a person.

Other studies looking at PTSD symptoms highlight the relation of PTSD symptoms with poorer executive test performance in middle-aged woman (3). Additionally, current PTSD symptoms are found to mediate the relation between ACE and executive functioning in young adults with a mean age of 29 years (4). Specifically in older adults, cognitive deficits are described in people with a PTSD diagnosis in the domains of memory and executive functioning (5, 6). On the other hand, van Rossum et al. find inconclusive results in the relation between PTSD diagnosis and executive functioning. A possible explanation for the difference between the results in *chapter two* and the results by van Rossum et al. is that *chapter two* does not look at PTSD diagnosis but at PTSD symptoms. Both the study by van Rossum et al. as well as *chapter two* exclude people with a diagnosis of dementia. Because the effects of trauma in people with dementia remain underexplored, the studies in *chapter three* through seven are performed to shed light on this population. Results of these studies indicate that people with dementia also experience PTSD symptoms, can have a PTSD diagnosis and can receive treatment for PTSD. But these studies do not aim to analyse the relation of these symptoms with cognitive performance. It could be hypothesized that it is not the PTE itself (as we will see in the next paragraph) but the PTSD symptoms someone experiences that influence cognitive performance. Future studies could examine the mediating effect op PTSD symptoms in the relation between trauma and cognition.

Adverse childhood events

Additionally, *chapter two* examines cognition in older adults in relation to ACE. An ACE is an event during childhood that can be considered adverse (7). An

ACE is not necessarily a trauma but can be or become one. The study in *chapter two* confirms that a higher CTBS, reflecting more ACEs, is not directly related to significant impairment in memory or executive functioning compared to people with a lower CTBS. Unlike other studies a relation with specific types of ACE is not found, although, this could possibly be explained by insufficient power. *Chapter two* supports the previously described hypothesis that it is not the PTE itself but the PTSD symptoms someone experiences that influence cognitive performance.

Other studies find that ACEs influence cognitive performance in adults (8-10) but also specifically in older adults (11-13). However, Grainger et al. show that global cognition is not related to overall early life stress in older adults, but global cognition is poorer in people who had experienced physical abuse (14). Additionally, Ritchie et al. find that specific types of ACE, and not total ACE, are related to different outcomes in cognitive performance. For example, people who have been sent to a foster home have poorer visuospatial memory than people who haven't been sent to a foster home and severe abuse is related to a lower risk of decreased cognitive performance compared to people who have not experienced severe abuse (11). Presence of deprivation-related ACEs is also related to cognitive decline in older adults (mean age 57.2 years), whereas people with threat-related ACE do not show poorer cognitive performance when compared to people without threat-related ACE (13). A possible explanation for these diverse results is the finding that older adults with more ACEs are associated with a larger cognitive variability than older adults who experienced less ACEs; this cognitive variability is not necessarily a poorer cognitive performance (15). An account for this greater variance could possibly be found in resilience. People who are more resilient potentially may experience less PTSD symptoms and a better cognitive performance. In the TRADE-study described in detail in *chapter five* we ask about PTEs over the entire course of life, but not specifically about ACE. Including PTEs over the course of life could provide a better lifetime perspective as trauma can also be a cause of PTEs in adults and cognitive performance can continue to change after childhood, especially in older adults.

Personality disorders

The study in *chapter two* contains a group of healthy controls and a group of people with PDs. In *chapter two* the presence of PDs is a significant confounder in memory functioning in relation to ACE, where people with PDs perform significantly lower than people without PDs. This is also the case with executive functioning in one of the used measurements (Tower of London test). People with PTEs are known to have a higher comorbidity rate of PDs, a review by Baltjes et al. finds a comorbidity rate of 22-26% in older adults over the age of

60 years (16, 17). Moreover, research on treatment outcomes of PTSD shows less symptoms improvement in people with PDs (17).

Interestingly the incidence of PDs is higher in care facilities (8.1-14.5% outside of care facilities compared to 22.5-57.8% in care facilities) (18). So, in the TRADE-study in *chapter five* additional questionnaires are included to include the relation of personality functioning in people with dementia and PTEs. Besides the relation of trauma and PDs, PDs are also related to decreased physical health and reduced QoL, two important criteria we included in *chapter six* (19-22). Highlighting the importance to, even though studies are limited, realize the complex interaction of PDs with factors such as cognition and PTEs in clinical practice.

Resilience in older adults

Resilience influences the reaction of a person to a PTE or ACE. Resilience is based on the concept that outcomes differ between people even when experiencing the same level of adversity (23). The term resilience is defined in many ways across research, it is said to contain aspects of psychosocial factors such as personality variables, level of education and emotion regulation strategies (24, 25). But also to be rooted in epigenetics and neurobiology e.g. by differences in the stress response system (26).

When specifically considering ACE in older adults', resilience measured with the Brief Resilience Scale (BRS) is not significantly related to ACE, yet resilience is hypothesized to be a mediator in relation to long term outcomes after ACE (15). Resilience is also included in studies looking at cognitive performance, without trauma. A study by Franks et al. find a lower resilience is related to a poorer performance across cognitive domains of attention and working memory (27), thus resilience could be a mediator in *chapter two*. Additionally, better resilience is related to a lower mortality risk in older adults with a mean age of 86 years old (28). Resilience is also related to functional outcomes, for example improved recovery of walking speeds after hip fracture in older adults ≥ 60 years (29). Resilience, measured as a combination of low distress and high psychological well-being, is also related to different somatic outcomes such as a lower risk of cardiometabolic outcomes in adults with a mean age of 64 years (30). As resilience is related to both psychological and functional outcomes, resilience may be reflected in the frailty measures used in *chapter six*. These measures include walking speed (Fried) and psychological well-being (GFI).

A limitation of the studies in this thesis is the absence of a measure for resilience when looking at the consequences of PTE, ACE or PTSD (symptoms).This highlights the importance of considering and including resilience as a mediator

in future studies on ACE or PTSD in older adults to further understand the large range of outcomes of studies of PTSD symptoms in relation to cognitive performance.

To conclude, the relation between PTSD symptoms and executive functioning and the absence of a relation between ACE and cognitive functioning can indicate that it is not ACEs itself but the symptoms someone has afterwards that effect cognitive functioning. These results from *chapter two* highlight that physicians and psychologists should consider the role of PTSD symptoms when analysing cognition. Additionally, future studies should aim to include a measure of resilience to further explore this relation in older adults.

Feasible treatment options for PTSD in people diagnosed with dementia

Research on PTSD and ACE is limited in older adults, but even more limited in people with dementia. However, clinical experience and the studies available of PTSD in people with dementia, such as in *chapter three* to seven, show us that PTSD and PTSD symptoms can be present in people with dementia. Thus, it is also important to elaborate on the existing knowledge of treatment options in people with PTSD and dementia. Raising the question "What are feasible treatment options for PTSD in people with a diagnosis of dementia?"

To answer this question *chapter three* provides a review on the treatment options for PTSD in people with dementia. Strikingly, at the time of the review the only available studies were case reports. These case reports describe interventions previously validated in adults such as prolonged exposure (n=1), cognitive behavioural therapy (n=1), different types of medication (n=4) and EMDR (n=3). Multiple case reports suggest feasibility of EMDR in people with dementia, a treatment also included in the PTSD treatment guideline for adults (31). But the available case reports lack a detailed description of the performed therapy. This limits reproducibility and clinical applicability of these results.

In older adults, without dementia, evidence of different PTSD treatment options is also limited (1, 32). Trials describe the effectiveness of interventions such as narrative exposure therapy (n=4), cognitive behavioural therapy (n=2) and physical activity (n=1) (32). Prolonged exposure shows significant clinical improvement of the clinical administered PTSD-scale (33, 34). EMDR is studied in older adults with PTSD showing that it is feasible, even in the presence of psychiatric and somatic comorbidities (35). EMDR can improve frailty, QoL and personality functioning in older people (36, 37).

Chapter four provides a case report that focusses on the treatment of PTSD with EMDR in a woman with dementia, while providing a clear overview of the challenges faced by the EMDR-therapist. It reflects feasibility of EMDR in a person with dementia and highlights the need for adjustments such as shorter therapy sessions and support of nursing professionals in for example planning the sessions. The study aims to provide a practical guideline for treating PTSD in people with dementia and hopefully minimizing possible barriers experienced by EMDR-therapists to provide this treatment. When looking at other populations in which one can expect more challenges in the performance of EMDR; such as adults with (mild) intellectual disability, a significant benefit from EMDR for PTSD is seen in slightly larger populations (n=29 and n=11) (38, 39). Larger studies exist in children, also showing evidence for the effectiveness of EMDR for PTSD (40, 41). As does the retrospective case series by Janssen et al., 2023 in people with acquired brain injury (42).

The studies above, in combination with clinical experience, suggest to seriously consider the treatment of PTSD (e.g. with EMDR) in people with dementia. This is also concluded in a recent Delphi study, where the consensus between experts was that treatment of PTSD in people with dementia can be beneficial to reduce PTSD symptoms and increase QoL (43). These recommendations have been included in the Dutch PTSD treatment guideline emphasizing that, although scientific evidence remains limited, it is important to integrate practice-based experiences and treat conform the psychotherapy (31). The Dutch PTSD treatment guideline refers to different forms of psychotherapy but highlights the need for trauma focussed treatments such as; EMDR, exposure therapy and cognitive processing therapy. As seen in *chapter three* evidence of all these treatment forms remains limited in this population, highlighting the importance of including people with dementia in PTSD treatment studies.

Treatment indication

The first and most important step before feasible treatment options can be considered, is recognizing the need for treatment by diagnosing PTSD. A large variety of PTSD diagnostic tools and symptom assessment methods exist and are used both clinically and in research (44). But diagnostic criteria and tools are not adjusted for people with dementia, even though clinical cases and reviews show signs of a different clinical presentation (45). In *chapter five* we describe the TRADE-study. A study with two main aims: (1) To validate the TRADE-interview, which is based on consensus in an international Delphi study (46). And (2) to study the effects of EMDR in people with PTSD and dementia. Both sections of this study have not yet been completed (April 2025). Future studies such as the TRADE-study and the Traumacare (TRACE) in dementia study can hopefully provide more guidance for physicians and psychologists

in diagnosing and treating PTSD in people with dementia. Additionally, the case report in *chapter three* shows the valuable role of nursing professionals in recognizing and monitoring PTSD symptoms, by educating the entire care team the recognition and diagnostic process improves, and treatment effects can be monitored.

Other challenges relevant for research and treatment

Inclusions of the TRADE-study, especially for the EMDR intervention section, have proven challenging. We observe a high number of people who match the in- and exclusion criteria but who do not want to participate. A reason often heard is the worry that discussing a PTE or ACE could exacerbate PTSD symptoms. Research shows a tendency of informal caregivers to shield the person with dementia from research (47). However, a study by Jaffe et al. finds that even though low to moderate levels of distress can indeed occur in trauma research, participants are overall positive about having participated (48). Experience during the first part of inclusions of the TRADE-interview also shows enthusiasm in people with dementia who are grateful to be involved and who welcomed researchers and research students, an effect also seen in other studies (49). Worries such as emotional distress are also strictly considered in the ethical consideration of the study in *chapter five* as well as in other studies. A survey finds 61.4% of researchers have experienced concern from an institutional review board and 13.3% have received refusal due to the concerns of talking about PTE (48). The worry that talking about and ACE or PTE would lead to more stress in a person with dementia also withheld people from treatment outside of the research setting. This while, literature highlights the importance of talking about PTE to raise awareness, improve research and avoid stigmatisation (50).

So even though future randomized controlled trials would provide the strongest scientific evidence, considering practice-based research or retrospective data collection is more realistic. Moreover, reducing uncertainty about how to respond in clinical practice is a first and more important step. Practical and informative tools developed for people involved in the care for people with dementia and PTEs could facilitate the recognition of PTSD symptoms, such as the TRADE-interview in *chapter five*. But tools could also help other members of the multidisciplinary care team in this setting, as will be highlighted later in the discussion regarding moral distress. Regardless of the challenges in this population, this research is important to improve geriatric care and outcomes of PTEs in people with dementia and should remain an important focus.

> **Follow-up clinical case (page 14):** *'In the introduction Mr T. is introduced, an 84-year-old man with a mild-moderate dementia. He was anxious going to bed and had nightmares of a past world war II PTE he has experienced. He does not meet all the criteria of PTSD as described in the DSM. After an interdisciplinary meeting with EMDR-therapists an indication to treat with EMDR was determined. He received six sessions over the course of 4 weeks and described better nights; the nursing professionals also saw this improvement. Going to bed was often, though not always, easier than before the EMDR sessions.' – case based on personal experience*

Chapter three and four highlight the feasibility of treatment of PTSD (e.g. with EMDR) in people with dementia. It also highlights the importance of larger studies on these treatment options in people with dementia to explore whether the clinical benefits observed in older adults also translate to people with dementia on a larger scale. Therefore, the inclusion of individuals with dementia and trauma in research should be encouraged. But this should not withhold professionals from treating PTSD in people with dementia at this time, this as the impact on people with dementia has been highlighted. The development of tools such as the TRADE-interview in *chapter five* can hopefully aid in the recognition of PTSD symptoms and in lowering the barrier to initiate treatment in this population.

The impact of PTSD on quality of life in people with dementia in geriatric care

Studies in older adults show that PTSD negatively affects quality of life, which is also a key outcome in dementia care (2, 51, 52). Whether a similar impact exists in people with dementia, however, has not yet been studied.

Thus, in *chapter six* the consequences of PTSD symptoms (measured with the TRADE-score) and PTSD on QoL in people with dementia are explored. Due to the broad impact of PTSD the study in *chapter six* analyses the mediation of frailty in the relation between PTSD (symptoms) and QoL. Frailty measured with the GFI is found to significantly mediate the relation between PTSD and QoL, but frailty measured with the Fried criteria does not.

The significant results of frailty, measured with GFI, as mediator are consistent with prior studies in older populations outside the long-term care facilities finding that PTSD symptoms are associated with frailty, greater disability, reduced well-being, increased days in bed, and higher healthcare utilization (2, 53) as well as lower QoL in later life (51, 54). PTSD symptoms are shown to have a negative effect on a broad range of outcomes such as frailty and QoL in older

people with dementia. But it is not known what the role is of the timing of PTE, the duration of PTSD symptoms or the course of trauma across the life span is.

Mediation of frailty

Frailty may be a modifiable mediator linking PTSD symptoms to adverse outcomes in older adults. Thus, interventions to decrease frailty could potentially decrease the negative effect of PTSD symptoms on QoL. Previous studies show frailty can be decreased by interventions such as mind-body training and aerobic training (55) and that multimodal exercise programs can also decrease PTSD symptoms in adults (56). Additionally, EMDR for PTSD in community based older people without dementia can decrease frailty (36). Extending these findings, the study population in *chapter six* consists of long-term care residents with dementia. In the Netherlands these people all have easy access to a physical therapist on the care location, illustrating the importance of involving the readily available multidisciplinary care team and the informal caregivers to recognize and potentially treat the broad clinical implications of PTSD symptoms in older people with dementia.

As the study in *chapter six* only includes people residing in long term care facilities, research including community dwelling older people (with dementia) can further help gain insight in the relationship between PTSD symptoms, QoL and frailty. Previous studies confirm the inverse relation between frailty and QoL in community dwelling older adults and between PTSD symptoms and QoL (57, 58). Additionally, *chapter two* shows that current PTSD symptoms still have impact on community-dwelling older people, although this chapter did not examine QoL or frailty but rather cognition. Cognition is a factor included in some frailty scales such as the GFI used in *chapter six*. Because of this, in geriatric care, it is beneficial to involve the entire care team in trauma related care.

> **Follow-up clinical case (page 10):** *'In the introduction Mrs L. is introduced, an 84-year-old woman with dementia who walks around the ward all day. This constant walking tires her, she has lost weight because of it, she is becoming more frail. Medication has not helped her sufficiently. Psychological tests showed depressive symptoms and a PTE; a car accident. The current living location is close to a busy road that can be seen through the windows. The constant walking could be an expression of PTSD symptoms. Further delving into this could help to consider treatment of her PTSD symptoms. In the case of Mrs L, extra attention on the role of her increasing frailty is valuable to potentially increase her QoL.' – case based on personal experience*

With *chapter six* we show the mediation of frailty in relation to PTSD symptoms with QoL in people with dementia. Additionally, we find literature indicating that this mediation is potentially modifiable by decreasing frailty or by decreasing PTSD symptoms. Emphasizing the importance of educating the geriatric care teams to aid in recognition of PTSD symptoms as seen in the case *chapter four.* Future studies should include frailty and interventions to reduce frailty as it is a potentially modifiable factor in this population leading to a possibly more improvement of QoL.

The impact of caring for people with trauma and dementia on nursing professionals in geriatric care

During the inclusions of the TRADE-study, in *chapter five*, nursing professionals shared additional stories of their experiences of PTE in people with dementia and the challenges this raised in the care process. Additionally, *chapter four* highlights the valuable role nursing professionals can have in this care process. Literature on this potential impact of PTE on nursing professionals is not available. This raises the research question: What is the impact of caring for people with trauma and dementia on nursing professionals in geriatric care?

Chapter seven provides a qualitative study demonstrating that multiple nursing professionals are faced with challenges, often due to resistance during the care process. The nursing professionals hypothesize the impact of PTE, proving to be a valuable link in recognizing and treating PTSD symptoms in long-term care residents with dementia. *Chapter seven* further highlights that nursing professionals can recognize PTE, but it also highlights the broad variety of how the PTE is recognised and how the care process is adjusted. Unknowingly the nursing professionals consider and provide certain principles that are also incorporated in a trauma informed care (TIC) approach (59, 60). For example, they recognize a person has potentially experienced sexual abuse, so they try to avoid re-traumatization by adjusting the care process, but they lack the proper guidance and support to perform this on a structured basis. The case in *chapter four* reflects the practical role of nursing professionals in planning and facilitating therapy sessions for long term care facility residents with dementia. The nursing professionals schedule the meetings with the psychologist and make sure the person is on the ward to receive this treatment, if the person is sick the nursing professionals inform the psychologist. They also have a role in reinforcing positive cognitions after EMDR by repeating the positive cognition after the therapy session in daily care. With the decreasing availability of nursing professionals as well as the level of education of the nursing professionals it becomes more important to find structured ways to recognize PTEs and evidence-based ways to help nursing professionals cope in these situations.

Trauma informed care

Other studies also recognize the ability of nursing professionals to adjust care in these situations (61). TIC is a widespread method for adjusting care to avoid trauma related triggers (59, 60). In TIC, nursing professionals can play an important role to relieve discomfort caused by trauma related triggers (62). MacRae et al. emphasizes that knowledge about trauma is essential to provide TIC (63). *Chapter seven* highlights that getting this information can be experienced as challenging for nursing professionals. Thus, having these conversations with people with dementia or their informal caregivers, could be a role for the psychologist or elderly care specialist involved in the person's care. *Chapter four and seven* highlight the importance of considering the moral distress a nursing professional can experience in the care for people with PTSD and dementia. Future research should study methods of approach for nursing professionals and possible tools they can apply.

Moral distress

Above we emphasize the role of nursing professionals and the complexity of this role. *Chapter seven* further explores the moral distress these situations could cause, nursing professionals for example mentioned feeling conflicted when the care process caused the person with dementia to relive their trauma, this while informal caregivers felt the need for the daily care was important to stay true to the identity of the person with dementia. In these, or comparable, situations involving other members of the geriatric care team helped, but all interviewees and scenarios involved different members of the care team (psychologists, physicians, behavioural consultants or spiritual care providers). Clinical practice has shown that in the current clinical field of long-term care facilities, different departments and different organisations tend to have a variety of ways to help members of the geriatric care team address moral distress. One of the always available options is a moral deliberation often guided by a psychologist or spiritual care provider. But this moral deliberation requires the physical presence of all involved people at the same point in time, making the moral deliberation complex and time consuming. In palliative care, the CURA tool (Dutch abbreviation for 'Concentreren', 'Uitstellen', 'Reflecteren' and 'Actie ondernemen; translated to: 'Concentrate', 'postpone', 'reflect' and 'take action') has been developed as a low-threshold tool, designed specifically for nursing professionals to apply in situations in which moral distress arises (64, 65). Following the study in *chapter seven*, an implementation study for CURA in psychiatric care has been set up. An initial step that can already be implemented is to recognize the potential presence of moral distress among members of the care team and to raise awareness by openly discussing these situations and their emotional impact with the entire geriatric care team.

> **Follow-up clinical case (page 12):** *'In the introduction Mrs A is introduced, a 70-year-old woman with dementia. She had pain complaints in her hip and pelvic region during the care process. A medical doctor, physical therapist, occupation therapist and a behavioural expert were all involved. The most positive effects were seen by the consultation of the behavioural expert who suggested the nursing professionals adjust their care process. But her informal caregiver, her daughter, questions the role of previous sexual abuse during her early adulthood. TIC could help her, and the involved care givers better understand and further adjust the care process, even if trauma is not the only cause of her symptoms it is a non-invasive way to consider the role trauma can play for her. Additionally, nursing professionals who experience moral distress when required to provide care that may trigger a PTE could benefit from an easy-to-use tool such as CURA.' – case based on personal experience*

We can conclude there is a significant impact of caring for people with trauma and dementia on nursing professionals in geriatric care. This highlights the need for more evidence-based support for nursing professionals when addressing the enduring effects of PTE and PTSD. More knowledge, such as which symptoms to recognize, how to act upon recognizing these symptoms and how to take a trauma history can also help the geriatric care team. This could use the principles of TIC or practical, easy-to-use tools to help them cope with the moral burden that may arise.

Strengths and limitations

This dissertation has several strengths and limitations which are important to consider when interpreting the results.

Strengths

One important strength is the inclusion of people with dementia, a growing population in which trauma and PTSD research has been very limited until now. Research in populations with dementia is challenging due to rules and regulations enforced to protect people that are possibly not capable of providing informed consent in this regard. However, this thesis shows that it is possible to overcome these barriers and gain valuable insights. In *chapter four* we provide a detailed case description in which consent was retrieved from both the person with dementia and her son. *Chapter five* describes the TRADE-study protocol, a METC approved study, in people with dementia. In this TRADE-study informed consent is obtained prospectively from the person with dementia and their legal representative. Although it was not easy, it has proven to be feasible to include and obtain data in a relatively large sample

size of people with dementia living in a long-term care facility and their legal representatives (n=84).

Another strength of the current thesis is that the studies are clinically relevant and translatable to daily clinical practice. The studies in this thesis aim to provide care professionals with clinically applicable knowledge to directly apply in the care process for people with dementia who have experienced PTE. The clinical implications are further discussed in the implementation section of this chapter. The high number of requests to share the obtained knowledge from this thesis additionally illustrate the importance of continuing research in this field, aiming to obtain empirical evidence.

Additionally, the thesis is strengthened by including multiple perspectives. Data is obtained from people with dementia, nursing professionals, family informants and psychologists using questionnaires and observations in the case report (*chapter four*) and the TRADE-study (*chapter five and six*). Furthermore, *chapter seven* uses semi-structured interviews to collect more in-depth data from nursing professionals. This thesis integrates expertise from psychiatrists specialized in care for older people, elderly care physicians, nursing professionals and psychologists with attention to somatic, psychological, functional and social consequences of trauma. Providing multiple dimensions throughout the studies increases the generalizability of this thesis. The thesis highlights the importance of combining expertise to improve geriatric care in people with dementia.

Limitations

This thesis aims to provide a broad overview of PTSD in older adults and people with dementia. It also seeks to offer practical support for professionals who frequently encounter these challenges and strives to serve as a stepping stone for future research. Despite these aims, the thesis has several limitations.

Chapter two and six, are cross sectional studies thus a causal relation cannot be established. Additionally, confounding bias, for example by not included confounders such a resilience, could be present. Although the cross-sectional aspect can lead to the risk of confounding bias, the cross-sectional design increases the feasibility of the TRADE-study. As it limits missing data in a vulnerable population, often affected by disease or mortality and the cross-sectional design decreases study burden on participants.

The cross-sectional studies in *chapter two and six* also increase the risk of recall bias. The different questionnaires used to assess PTSD symptoms or ACE all require the person, and their chosen informant, to recall events that occurred over the entire course of life. Possibly leading to people forgetting smaller

traumatic events or older traumatic events in the presence of recent or larger traumatic events. Although participants are encouraged to speak openly and freely, some information may still have been withheld. This can be due to barriers such as stigma surrounding trauma, generational differences, shame, feelings of guilt, or simply gaps in memory.

Another limitation of *chapter two, four and six* is the possible selection bias, as the studies use convenience sampling. In *chapter four* a representative case was chosen to increase clinical value of the case report. Additionally, although entire patient wards are screened in *chapter six* people who experienced PTEs and people with PTSD symptoms were presented to the researchers relatively often. Potentially leading to selection bias in this group. This is a probable consequence of the direct benefit for the person with dementia who can receive EMDR if PTSD is diagnosed. This also increases motivation of the person with dementia and their legal representative to participate in the study.

Notably, the TRADE-study described in *chapters five and six* includes only individuals with mild to moderate dementia for whom the multidisciplinary care team did not anticipate resistance. This limits the transferability of the findings to the broader population of individuals with more advanced dementia.

The different studies use multiple different methods of assessing PTE, PTSD or ACEs leading to information bias and making generalizability of the results found in this thesis challenging (44). Additionally, the TRADE-interview has not been validated yet (46). In *chapter six* a clear description of the use of the TRADE-interview is provided. It is used as a tool to assess presence of PTSD symptoms.

Conclusion

This thesis shows that impact from old and recent PTEs can endure through a lifetime in older people and people with dementia. It highlights the diverse impact by demonstrating a relationship between PTSD symptoms and executive functioning, frailty and QoL but, more importantly, on multidisciplinary teams and throughout the whole geriatric care system. Future research should aim to further expand knowledge on diagnostics, validating treatment options in larger cohorts with dementia. Regardless of the limited body of evidence available to date, this thesis highlights the importance of recognizing trauma in geriatric care, providing treatment for PTSD in this population and supporting not only the older person or person with dementia but the entire geriatric care system, including nursing professionals.

Implications for clinical practice

The current dissertation aims to take a first step towards improvement of geriatric care for older adults and people with dementia and PTSD, focussing on this broad clinical context across the multidisciplinary care team. The most important clinical implications are summed up below:

- When analysing cognition as a **medical doctor or psychologist;** be aware of the possible long-term influences of PTSD symptoms on cognitive performance in adults without dementia, especially, but not only, in relation to executive functioning as seen in *chapter two.*
- Treatment options of PTSD in people with dementia are available, as seen in the literature review in *chapter three*. Treatments such as EMDR, well established in people without dementia, can be provided by an **EMDR-therapist in this population as well**, albeit in adjusted form.
- EMDR therapy can benefit people with dementia and PTSD when adjusting it to the needs of the person with dementia; providing shorter instructions, administering multiple cues – possibly visual, and observing the subjective units of distress based on body language are possible examples described in the case report in *chapter four.* It is important that **psychologists and EMDR-**therapists are aware of the feasibility of treatment and the possibly necessary adjustments.
- *Chapter four* further illustrates that the **multidisciplinary care team** plays an important part in recognition and treatment, and *chapter three* emphasizes the role of **nursing professionals**. Closely observing the person with dementia and describing certain behaviours that are seen can provide a good foundation to discuss possible causes of this behaviour. When bringing the knowledge of the entire multidisciplinary care team together with the knowledge of the person with dementia and their informal caregivers we can be more alert to the possible role of trauma.
- Frailty is a possible mediating factor in the relation between PTSD symptoms and PTSD. Involving the **multidisciplinary care team** to actively decrease frailty could potentially increase the QoL of people with dementia and PTSD symptoms.
- *Chapter seven* further describes challenges experienced by **nursing professionals** resulting in moral distress in the daily care. Such as people with dementia resisting care and the thought of the nursing professionals that this is possible caused by (a sexual abuse related) trauma. These situations can benefit from **multidisciplinary** support and trauma sensitive approach highlighting the importance of a trauma history. Additionally, more schooling of nursing professionals on trauma related to sexual abuse can be beneficial.

- Thus, it is important to acknowledge PTSD symptoms and PTSD in the daily care for people with dementia as well as the role of **all members of the multidisciplinary care team in recognizing and treating the broad implications in geriatric care.**

Implications for future research

Besides its clinical implications, this thesis also provides a stepping stone for future research. The findings of the current thesis show that PTSD and PTSD symptoms can be associated with different clinical outcomes, also in people with dementia. It shows us treatment options should not be disregarded in people with dementia, but the treatments do potentially need case specific adjustments. It also highlights that the consequences of trauma are not only felt by the person with dementia but also by the geriatric care team around them, such as their nursing professionals.

Future research on the late life impact of PTSD in people with dementia should aim to increase recognition of PTSD in this population. This can possibly be achieved by further examining the broad range of clinical presentation and long-term consequences of PTE and PTSD. Additionally, longitudinal studies, though challenging, can help to examine potentially modifiable confounders to further emphasize the importance of recognizing ACE, trauma and PTSD in this population. In these studies, resilience, although complex, should be explicitly considered and incorporated into the research design.

Above can be aided by further development and validation of PTSD diagnostic tools and symptom assessment methods for people with dementia, such as the TRADE-interview from *chapter five.* Additionally, a study comparing different PTSD diagnostic tools and symptom assessment methods in people with dementia could highlight the strengths and limitations of different tools in this population. As this can work to further improve the recognition and signalling of PTSD symptoms by the geriatric care team.

Improving recognition and diagnostics to be more fitting for people with PTSD and dementia opens the door to consideration and scientific validation of different treatment options in this population. Due to the complexity of longitudinal studies in this populations considering retrospective studies extracting data from medical files can provide a next stepping stone with reduced publication bias compared to case studies. But case series with elaborate description of the PTSD treatment and its effects in people with dementia or single-case experimental design studies can also provide insight into which treatment options to consider. Overall, we should continue to aim

to decrease the reluctancy of managing and treating PTSD in people with dementia.

Lastly, further studies on moral distress in nursing professionals, caused by possible PTSD or PTSD symptoms, can be beneficial. The current qualitative study provides a global overview in a selected population. Including a more diverse group of (nursing) professionals by not specifically including nursing professionals who already recognize PTSD symptoms. And by building on the results of the current study within depth interviews or focus groups could provide this insight. After which it could be possible to provide a more practical approach to dealing with these situations such as the use of a simple tool.

Regardless of the many advances that are to be made in the research in this field, I hope this thesis stimulates people across the geriatric care field to talk about, recognize, treat and acknowledge PTSD in older people and people with dementia and its broad implications for geriatric care.

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Chapter 9

Summary
Samenvatting (NL)

Summary

Potentially traumatic events (PTE) and adverse childhood experiences (ACE) occur frequently (81.5% and 45.3% respectively in the Netherlands) (1, 2). 7-11% of people who experience a PTE develop a post-traumatic stress disorder (PTSD) (2, 3). PTSD can be related to many conditions, such as accelerated metabolic and physiological ageing, personality disorders, frailty and reduced quality of life (QoL) (4-7). Consequences of PTSD are mainly studied in adolescents and adults in which the veteran population is overrepresented (4). So, this thesis focusses on PTSD in older people and people with dementia. The studies in this dissertation address the broad impact of PTSD in this population and highlight how it effects not only the person themselves but also the health care professionals involved in geriatric care.

Chapter 1 is the introduction of this thesis, it provides the aim of the thesis with the main question; 'What are the implications of PTSD in older adults, particularly those with dementia, for geriatric care?'.

Chapter 2 examines the association of PTSD symptoms and ACE with memory and executive functioning in older adults, while taking the moderating effect of personality disorders into account. It is a cross-sectional study including adults aged 60 or older with a group of older adults with a personality disorder and a healthy control group. This study finds higher Posttraumatic Symptom Scale Self-Report (PSS-SR) scores to be related to lower scores of executive functioning. While the childhood trauma burden scale, representing ACEs, did not significantly influence memory or executive functioning at older age. This could indicate that it is not the PTE itself but the PTSD symptoms someone experiences that influence cognitive performance.

The aim of **chapter 3** is to provide an overview of treatment option of PTSD in people with dementia. A systematic literature review was performed and included nine articles, all case reports, with a total of 11 cases. The treatment options in the literature were eye movement desensitisation and reprocessing (EMDR) (n = 3), prolonged exposure (n = 1), cognitive behavioural therapy (n = 1) and pharmacological treatment (n = 4). All articles reported a positive effect of interventions on several monitored symptoms. This review shows us that people with PTSD and dementia can benefit from PTSD treatment. While research is ongoing therapists should consider these treatment options in this population.

To aid therapists in providing treatment for people with PTSD and dementia **chapter 4** provides clinicians guidance for EMDR treatment in people with dementia. The chapter describes an 89-year-old nursing home resident with

mild–moderate dementia and PTSD. She received four EMDR sessions using the child/ youth protocol. Debriefing questionnaires for the psychologist showed that EMDR was well tolerated and overall experienced as pleasant, but some challenges occurred. During the EMDR sessions she was easily distracted, she requested multiple breaks, and she required the use of shorter sentences, with a more directive approach. PTSD symptoms of recurring memories and negative thoughts were reduced. It appears necessary to adjust the EMDR standard child/youth protocol to a further simplified form, due to reduced concentration and endurance because of dementia. **Chapter 4** provides more details on how to make these adjustments.

Studies on the clinical manifestation of PTSD in people with dementia remain limited, and their quality is affected by the lack of a structured method to diagnose PTSD in this population. **Chapter 5** provides a study protocol of the 'TRAuma and DEmentia' (TRADE) study. This study aims to validate the TRADE interview as a diagnostic tool for PTSD in people with dementia and it aims to test feasibility of EMDR treatment for people with PTSD and dementia.

Chapter 6 provides data of a subsection of the inclusions of the above-mentioned TRADE-study. The aim of the study in **chapter 6** is to access the relation between PTSD symptoms and QoL, mediated by frailty. The study included 78 people. A significant relation of PTSD symptoms, mediated by frailty measured with the Geriatric Frailty Index (GFI), on QoL in people with dementia was found. This, together with the potential effectiveness of interventions targeting PTSD, strongly supports the need for a multidisciplinary approach in this population.

The studies in the previous chapters highlight the role and challenges for nursing professionals. Following this **chapter 7** is a qualitative study that aims to explore moral distress in nursing professionals when caring for people with dementia and PTEs. The main themes found during the interviews were (1) the types of past traumas recognised by nursing professionals in people with dementia, (2) the moral distress they lead to in nursing professionals, (3) the coping situations applied and (4) the needs of nursing professionals in these situations. Behavioural patterns that caused moral distress were verbal and physical signs of self-defence seen in the daily personal care process, often presumed to be because of past sexual trauma. Moral distress was often a consequence of not being able to provide care without causing discomfort or resistance in the person with dementia. To cope with this care was kept to a minimum, only providing care when health risks arose. Supporting and involving nursing professionals in the care for people with trauma and dementia is important to possibly limit moral distress.

In **chapter 8** the findings of this thesis, in relation to the main and sub-research questions, are discussed. Followed by the strengths and limitations, and the implications for future research and clinical practice.

Samenvatting (NL)

Potentieel traumatische gebeurtenissen en negatieve jeugdervaringen komen regelmatig voor (81.5% en 45.3% respectievelijk in de Nederlandse bevolking) (1, 2). 7-11% van de mensen die een potentieel traumatische gebeurtenis meemaakt ontwikkeld een posttraumatische stressstoornis (PTSS) (2, 3). PTSS kan gerelateerd worden aan verschillende aandoeningen zoals versnelde metabole veroudering, psychische veroudering, persoonlijkheidsstoornissen, kwetsbaarheid en verminderde kwaliteit van leven (4-7). Gevolgen van PTSS zijn voornamelijk onderzocht bij jongeren en volwassenen, waarbij de doelgroep veteranen oververtegenwoordigd is (4). Deze thesis zal zich focussen op PTSS bij ouderen mensen en mensen met dementie, een onderbelichte populatie. De onderzoeken in deze thesis kijken naar de brede impact van PTSS in deze doelgroep en benadrukken hoe het niet alleen de persoon zelf beïnvloed maar ook de zorgprofessionals in de geriatrische zorg.

Hoofdstuk 1 is de inleiding van de thesis, hier wordt het doel omschreven met de hoofdvraag: 'Wat zijn de implicaties van PTSS bij oudere volwassenen, voornamelijk die met dementie, voor geriatrische zorg?'.

In **hoofdstuk 2** wordt de associatie tussen PTSS-symptomen en negatieve jeugdervaringen met geheugen en executief functioneren in oudere volwassenen onderzocht. Daarin wordt de rol van persoonlijkheidsstoornissen meegenomen. Het is een cross-sectioneel onderzoek waarin een groep mensen met persoonlijkheidsstoornissen is onderzocht en een gezonde controlegroep. Beide met mensen van 60 jaar of ouder. Het onderzoek toont dat meer PTSS-symptomen geassocieerd is met verminderd executief functioneren. Terwijl de CTBS, een som score van negatieve jeugdervaringen, geen relatie toont met geheugen of executief functioneren. De analyse van de negatieve jeugdervaringen nam géén potentieel traumatische gebeurtenissen mee die na de jeugd plaats gevonden hadden. Dit terwijl dit mogelijk wel invloed heeft op het cognitief functioneren. Dit is een mogelijke verklaring waarom huidige PTSS-symptomen wel een relatie hebben met executief functioneren maar enkel de negatieve jeugdervaringen niet.

Het doel van **hoofdstuk 3** was om een overzicht te vormen van de wetenschappelijk onderzochte behandelopties voor PTSS bij mensen met dementie. Een systematisch literatuuronderzoek leverde negen artikelen op, allemaal case-reports, met in totaal 11 casuïstiek beschrijvingen. De behandelopties beschreven in de literatuur waren eye movement desensitisation and reprocessing (EMDR) (n = 3), prolonged exposure (n = 1), cognitieve gedragstherapie (n = 1) en farmacologische behandeling (n = 4). Alle artikelen

omschreven positieve effecten van de interventie op verschillende symptomen. Deze review laat zien dat mensen met PTSS en dementie profijt kunnen hebben van behandeling. Terwijl grotere onderzoeken hiernaar lopen kunnen behandelaren deze behandelopties al wel overwegen voor deze doelgroep.

Om therapeuten te ondersteunen in het behandelen van PTSS bij mensen met dementie wordt in **hoofdstuk 4** een gedetailleerde omschrijving van EMDR bij iemand met PTSS en dementie gegeven. Het hoofdstuk omschrijft een 89-jarige vrouw met een mild-matige dementie, woonachtig in het verpleeghuis. Zij kreeg vier EMDR-sessies. Evaluatie vragenlijsten van de psycholoog toonden dat de EMDR goed getolereerd werd en over het algemeen als prettig werd ervaren. Maar er deden zich ook uitdagingen voor: Tijdens de EMDR-sessies was ze makkelijk afgeleid, ze verzocht meerdere pauzes en ze kon het beste aangesproken worden met kortere instructies met een directieve benadering. PTSS-symptomen bestaande uit herbelevingen en negatieve gedachte namen af. Het leek nodig om het toegepaste EMDR kind/jeugd protocol verder te simplificeren in verband met de verminderde aandacht en uithoudingsvermogen ten gevolge van haar dementie. **Hoofdstuk 4** biedt meer details over hoe deze aanpassingen gemaakt kunnen worden.

Onderzoeken naar de klinische manifestatie en gevolgen van PTSS bij mensen met dementie zijn beperkt, daarnaast wordt de kwaliteit hiervan beïnvloed door de afwezigheid van een passende diagnostische tool in deze doelgroep. **Hoofdstuk 5** presenteert een onderzoeksprotocol van het 'TRAuma en DEmentie' (TRADE) onderzoek. Dit onderzoek heeft het doel om het TRADE-interview te valideren als diagnostisch instrument voor PTSS bij mensen met dementie en heeft ook het doel om de haalbaarheid van EMDR-behandeling bij mensen met PTSS en dementie verder in kaart te brengen.

Hoofdstuk 6 biedt een eerste inkijk in de dataset van dit TRADE-onderzoek. Het doel van het onderzoek in **hoofdstuk 6** is om de relatie tussen PTSS-symptomen en kwaliteit van leven te onderzoeken met kwetsbaarheid als mediator. Het onderzoek had 78 deelnemers. Een significante relatie tussen PTSS-symptomen en kwaliteit van leven, gemedieerd door kwetsbaarheid gemeten met de 'Geriatric Frailty Index' (GFI), werd gevonden. Dit, samen met de mogelijke positieve effecten van PTSS-behandeling, steunt de noodzaak voor een multidisciplinaire aanpak bij deze doelgroep.

De onderzoeken beschreven in de hierboven genoemde hoofdstukken benadrukken de belangrijke rol en de uitdagingen voor verpleegkundig en verzorgend personeel. Hieruit volgt **hoofdstuk 7**, een kwalitatief onderzoek met als doel om morele stress bij verpleegkundig en verzorgend personeel in

de zorg voor mensen met dementie en potentieel traumatische gebeurtenissen uit te diepen. De voornaamste thema's gevonden tijdens de interviews waren (1) de soorten potentieel traumatische gebeurtenissen die verpleegkundig en verzorgend personeel herkende (2) de morele stress dat deze situaties kan geven aan verpleegkundig en verzorgend personeel (3) de manieren waarop zij hiermee omgingen en (4) de behoeftes die verpleegkundig en verzorgend personeel hebben in deze situaties. Geobserveerd gedrag dat morele stress opleverde waren verbaal en fysieke tekenen van afwering bij mensen met dementie tijdens de dagelijkse zorg. Vaak vermoede het verpleegkundig en verzorgend personeel dat dit een gevolg was van seksueel trauma. Morele stress kwam dan voort uit het niet kunnen leveren van zorg zonder discomfort of weerstand op te roepen bij de persoon met dementie. Om hiermee om te gaan werd zorg soms tot een minimum beperkt, en bijvoorbeeld enkel geboden bij het ontstaan van gezondheidsrisico's. Het is van belang steun te bieden aan verpleegkundig en verzorgend personeel betrokken bij de zorg voor mensen met trauma en dementie. Dit kan mogelijk morele stress beperken.

In **hoofdstuk 8** zijn de bevindingen van deze thesis, in relatie tot de hoofd onderzoeksvraag en de sub-vragen bediscussieerd. Gevolgd door de sterktes en zwaktes en de implicaties voor toekomstig onderzoek en klinische praktijk.

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Appendix

Valorisation
Dankwoord
Curriculum vitae
List of publications
Conference contributions and other forms of knowledge dissemination

Valorisation

How will the findings of this thesis impact future research?
The findings of this thesis, on the implications of PTSD in older adults and people with dementia, highlight the importance of a multidisciplinary approach in geriatric care and emphasize the importance of a multidisciplinary approach in the care for people with a trauma history and dementia.

The thesis provides a foundation for further research on PTSD in people with dementia by reflecting the clinical relevance and feasibility of research in this population. It additionally points to possible future research direction, as described in chapter eight, of which some studies have already been initiated. An example is the recently started study regarding the application of the CURA method in psychiatric care, following this a further implementation in specifically care for people with a trauma history can be considered. The TRADE-study as described in chapter five is ongoing and will hopefully provide more insight in clinical presentation, diagnosis and treatment of PTSD in people with dementia.

What potential influence might these findings have on future practice?
The findings of the current thesis have had a direct impact on clinical practice. The Dutch PTSD treatment guideline included a subsection on treatment of PTSD in people with cognitive deficits referring to the literature review presented in chapter three (FMS, 2025). Additionally, chapter four provides directly applicable clinical suggestions to consider for EMDR therapists when treating PTSD in people with dementia.

For people with dementia and their carers and/or family members, highlighting the importance of recognizing trauma, talking about the studies available and bringing attention to the topic can hopefully lower the barrier of sharing sensitive trauma histories with health care professionals. Additionally, in the future, further evidence of treatment options in people with dementia can provide more incentive to share this information.

In what way is the target audience involved and informed of the results of this research?
Due to the aim and set-up of the current thesis the target audience involved is diverse. We directly involved people with dementia, informal caregivers of people with dementia, nursing professionals, psychologists and medical doctors in the data collection of included studies to lead to a minimal burden for the person with dementia. More specifically, the TRADE-study described in chapters five and six began with a small pilot, in which a person with dementia and their family provided detailed feedback. Following this, a crowdfunding

campaign was launched to raise funds for the TRADE-study, involving various foundations, care organisations, and individual supporters. These contributors received updates in the form of reports, updates on the traumaendementie.nl website and in the form of presentations.

Findings of this thesis can be beneficial for researchers in the fields of trauma, older adults and/or dementia research by showing feasibility and bridging the knowledge gap highlighted in chapter one. But findings are more directly beneficial for health care workers in geriatric care such as medical doctors, paramedical professionals and nursing professionals. This is achieved by reflecting the importance of recognizing trauma, highlighting the challenges and suggesting possible treatment options. Most importantly the clinical implications aim to directly benefit people with dementia and their informal carers as an important outcome of treatment is to ultimately improve quality of life for people with dementia.

The relevance is also reflected in the requests the research team receives for sharing knowledge gained by the research group (See; 'Conference contributions and other forms of knowledge dissemination' on page 197**)**. The knowledge has been shared both nationally and internationally on both small and large scale; Nationally the TRADE-study research group has been involved in symposia, conferences, smaller presentations for health care professionals, articles and information videos. Internationally, I have contributed to the published "Posttraumatic stress disorder in older adults: A global collaboration on setting the future research agenda" (Sobczak et al. 2025) and a review and meta-analysis on the 'Biomarkers of Accelerated Ageing in PTSD' is being written with a subsection of this group. Data obtained by the TRADE-study in chapter five has been presented at international meetings by colleagues of the research team and will be further disseminated upon completion of data collection. Additionally, the outcomes are currently being translated into knowledge products through a 'ZorgOnderzoek Nederland en Mediche Wetenschappen' (ZonMw) grant, in collaboration with 'Centrum voor Consultatie en Expertise' (CCE), 'Dementie en zeer ernstig probleemgedrag' (D-ZEP), 'Regionaal Instituut voor Nascholing en Opleiding' (RINO) Zuid, and Traumanet, and are being implemented in practice.

Dankwoord

Dit proefschrift is de uitkomst van het harde werk van vele betrokkenen. Graag wil ik iedereen die daaraan heeft bijgedragen hieronder in het zonnetje zetten.

Allereerst bedankt aan alle deelnemers van de verschillende onderzoeken: de deelnemers van de PANDORA-studie, de mensen met dementie die hun verhaal hebben willen delen voor casereports, de deelnemers van het TRADE-onderzoek en de verpleegkundigen en verzorgenden die hun persoonlijke kijk en ervaringen hebben gedeeld in de kwalitatieve interviews. Allemaal mensen die, ondanks de beperkte energie die aan het einde van de dag vaak over is, de moeite hebben genomen om bij te dragen aan wetenschappelijk onderzoek.

Onmisbaar bij een promotie is natuurlijk een goed promotieteam. Mijn dank gaat uit naar mijn promotieteam, bestaande uit prof. dr. Koen Schreurs, dr. Mariëlle van der Velden en dr. Sjacko Sobczak. Een groep die wordt versterkt door verschillende achtergronden, aandachtsgebieden en kwaliteiten. Prof. dr. Koen Schreurs bedankt voor je heldere en realistische blik, duidelijk feedback en opbouwende aanpak. Dr. Mariëlle van der Velden bedankt voor je frisse kijk, het inbrengen van je inzichten uit het verpleeghuis en ook je rol in het vormgeven van mijn traject met zowel de opleiding tot SO als het promotieonderzoek. Mijn dank gaat in het bijzonder uit naar dr. Sjacko Sobczak, die mij omarmde in het TRADE-onderzoek, altijd mogelijkheden en kansen zag voor mij om verder te ontwikkelen en eindeloze versies van papers, hoofdstukken en presentaties heeft voorzien van snelle feedback.

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De samenwerking met alle coauteurs was een groot plezier en een verrijking. Bedankt voor jullie bijdragen aan de papers die we samen geschreven hebben.

Ook de EMDR-therapeuten, locatiecoördinatoren en de betrokken zorg-organisaties (Envida, Sevagram, Mondriaan, Cicero, Meander, Zuyderland) binnen het TRADE-onderzoek waren essentieel. Bedankt voor jullie inzet! Ik wil Envida en de collega's daar expliciet erkennen als organisatie die het belang van onderzoek in combinatie met klinisch werk niet alleen inziet, maar ook faciliteert.

Mijn waardering gaat ook uit naar de thesis studenten betrokken bij het TRADE-onderzoek: Koen, Armand, Caro, Kevin, Jana, Django, Mila, Kyra, Diede, Lieke, Aimee, Larissa, Janne, Timika, Michiel, Dana, Josje, Frouke, Froukje, Benthe, Tijl, Berdine, Zoë en Fabienne. Hartelijk bedankt voor jullie hulp bij de inclusies, jullie kritische vragen en jullie creatieve blik. Jullie brachten frisse energie en stimuleerden de werving van deelnemers voor het onderzoek.

Mijn traject begon als AIOS in de opleiding tot SO, waarbij ik mijn groep mede-AIOS wil bedanken voor alle onderwijs vrijdagen met borrels en cappuccinopauzes, referaten en de vele gedeelde ervaringen. Hierbij in het bijzonder ook mijn dank aan Babette. Zij zag overal kansen en uitdagingen om het onderzoek onder de aandacht te brengen en mijn competenties verder te ontwikkelen.

Dat gezegd hebbende ben ik überhaupt ontzettend blij met de cappuccino; het bestaan ervan is een essentieel onderdeel gebleken van het schrijven van dit proefschrift.

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Ten slotte verdienen twee mensen in het bijzonder een speciale vermelding.

Mijn persoonlijke barista, grafisch vormgever, medeauteur, klankbord, mede-promovendus, maar bovenal mijn lieve, wijze en rustige man; Daniel. Bedankt voor al je steun, hulp en onvoorwaardelijke liefde.

Onze lieve, vrolijke en ultra-schattige dochter Mathilda, de meest welkome stok achter de deur om dit proefschrift tijdig af te ronden en de gelukkige ontvanger van mijn extra vrije tijd nu dit boekje – tijdelijk – gesloten is.

Curriculum Vitae

Jessica Everdina Ruisch was born on February 19th, 1995 in Roosendaal. She spent most of her primary school years at the "Hong Lok Yuen International school" in Hong Kong. After which she graduated from her high school at the "Stedelijk College", in Eindhoven in 2013. She went on to study medicine at Maastricht University. During her studies she developed her interest in research under supervision of Prof. Dr. H.I. Grabsch studying lymph node reactions in people with cancer at the pathology department of MUMC+. In her clinical rotations she found an interest in the field of geriatric medicine at the department of geriatrics of Zuyderland hospital. She graduated with a double masters degree in 2020 (Medicine and Healthcare, Policy and Innovation Management). After working for a year as a resident at the geriatrics department of Zuyderland hospital and at Envida, care for older people, she started her training as an elderly care specialist in 2021. This was combined with a position as junior researcher affiliated to the TRAuma and DEmentia (TRADE)-study. In 2024 she graduated as an elderly care specialist and started work as an elderly care specialist in 2025 at Envida, whilst continuing her PhD.

List of publications

2026

Ruisch JE, De Groot LGR, Oude Voshaar R, Havermans D, Kreiter D, Daamen MAMJ, Schruers KRJ, Sobczak S. Frailty as a mediator between post-traumatic stress disorder symptoms and quality of life in older adults with dementia: A cross-sectional study. 2026. Submitted

Ruisch JE, Janssen AJJ, Daamen MAMJ, van Dun L, Schruers KRJ, Sobczak S. Exploring moral distress experienced by nursing professionals in daily care for people with dementia and trauma-related symptoms: a qualitative study. 2026. Submitted

Ruisch JE, Quaedflieg CWEM, van Alphen SPJ, Schulkens JEM, Daamen MAMJ, Schruers KRJ, Sobczak S. The Association of Childhood Adversity and Post-Traumatic Stress Symptoms with Cognition in Older Adults: A Cross-Sectional Study. Clin Gerontol. 2026 Feb 25:1-13. Doi: 10.1080/07317115.2026.2631041. Epub ahead of print. PMID: 41741113.

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2025

Sobczak S, Orgeta V, Beenakker M, Boks M, Boltri M, Cations M, Coeur E, Cook JM, Corveleyn X, Dorame AN, van Dijk GC, Forresi B, Fréel S, Gómez-Bautista D, Günak MM, Havermans DCD, Hopwood M, O J, Lawrence KA, Lee LO, Maercker A, Marsman A, Olivé I, Quaedflieg CWEM, **Ruisch JE**, Thorp SR, Woudsma JS, Zabihi S, Olff M; Global Collaboration on Traumatic Stress. Post-traumatic stress disorder in older adults: a global collaboration on setting the future research agenda. Lancet Healthy Longev. 2025 Jun;6(6):100720. Doi: 10.1016/j.lanhl.2025.100720. Epub 2025 Jun 20. PMID: 40550237; PMCID: PMC12673637.

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2023

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2021

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2020

Ruisch JE, Sipers W, Plum PF, Spaetgens B. Individualized approach to reconsider perioperative do-not-resuscitate orders in frail older patients. Geriatr Gerontol Int. 2020 Oct;20(10):989-990. Doi: 10.1111/ggi.14030. PMID: 33003252; PMCID: PMC7590086.

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Conference contributions and other forms of knowledge dissemination

2025		
Presentation	Trauma en dementie	Dubbel zorgvragers symposium
Presentation	TRADE-studie en achtergronden	Ouderengeneeskunde 2.0
Symposium	Traumabehandeling bij ouderen: Geschiktheid van EDMR bij een 89-jarige vrouw met dementie en PTSS – een casusbeschrijving	Voorjaarscongres NVvP
Presentation	GLISTEN onderzoek	Verenso voorjaarscongres
Posterpresentation	GLISTEN onderzoek	Voorjaarscongres NVvP
2024		
Video recording	Trauma bij mensen met dementie - Het belang van traumagerichte zorg	CCE
Presentation	TRADE-studie update	Verenso regiobijeenkomst Zuid-Limburg
Posterpresentation	Casereport EMDR bij dementie	Verenso voorjaarscongres
2023		
Prize	GLISTEN	Verenso beurs
Presentation	Samen voor een geestelijk gezond limburg-Zuid – het traumatische levensverhaal centraal: Trauma en dementie	Netwerkbijeenkomst
Presentation	PTSS bij dementie	SCEM-congres Psychiatrie en Dementie
Presentation	Trauma en dementie	Meet & Greet Envida
2022		
Presentation	PTSS bij dementie en de TRADE-studie	Verenso regiodag Noord-Holland-Noord
Presentation and workshop	Herkennen PTSS bij dementie	Het Alzheimercongres
Presentation	TRADE-studie	Verenso regiobijeenkomst Zuid-Limburg