

A first insight into the clinical manifestation of posttraumatic stress disorder in dementia

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REVIEW ARTICLE

A first insight into the clinical manifestation of posttraumatic stress disorder in dementia: a systematic literature review

Dorien H.E. van DONGEN ^[D],¹ Demi HAVERMANS,² Kay DECKERS,² Miranda OLFF,^{3,4} Frans VERHEY² and Sjacko SOBCZAK^{5,6}

¹Department of clinical geriatrics, Zuyderland Medical Hospital, Sittard-Heerlen, ²Department of Psychiatry and Neuropsychology and Alzheimer Centrum Limburg, School for Mental Health and Neuroscience (MHeNs), Maastricht University Medical Centre+ and ⁶Department of Neuropsychology and Psychopharmacology, Faculty of Psychology and Neuroscience, Maastricht University, Maastricht, ³Department of Psychiatry, Amsterdam Neuroscience & Public Health, Amsterdam UMC, Amsterdam, ⁴Department of psychotrauma, ARQ National Psychotrauma Centre, Diemen and ⁵Department of Old Age Psychiatry, Mondriaan Mental Health Center, Heerlen-Maastricht, The Netherlands

Correspondence: Drs Dorien H.E. van Dongen, MSc, Dr. H. van der Hoffplein 1, 6162 BG Sittard-Geleen, The Netherlands. Email: d. vandongen@zuyderland.nl

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Abstract

Posttraumatic stress disorder (PTSD) is a prevalent disorder worldwide and often co-occurs in dementia. Both have a major impact on disease burden and quality of life. PTSD may be difficult to recognize in dementia and a structured diagnostic method is lacking. In order to get insight into the clinical diagnostics of PTSD in dementia, this systematic literature review evaluates the clinical presentation of PTSD and other relevant symptoms in people with dementia. PubMed, PsycINFO, Embase, and CINAHL were searched for all publications through 30 December 2021. Articles were included which met the following criteria: (i) description of at least one case with a current diagnosis of dementia and co-morbid PTSD; (ii) clinical presentation of symptoms being adequately described; (iii) no difference being made between chronic PTSD, PTSD with re-activation, and delayed onset PTSD. Of the 947 identified abstracts, 13 papers met the inclusion criteria and were included (describing 30 cases). Based on our rating, only one case completely fulfilled the DSM-5 criteria of PTSD. Avoidance was only described in three cases. Most commonly described symptoms were irritability and anger (E1, 9%), persistent negative emotional state (D4, 9%), and sleep disturbances (E6, 8%). In 93% of the case reports, other symptoms were also described, i.e. memory problems (58%), screaming (33.3%), and wandering (22.2%). People with dementia who have experienced a traumatic event seem to present, based on our rating method, with insufficient symptoms to meet all criteria for a PTSD DSM-5 diagnosis. The DSM-5 core symptom of avoidance was absent in most of the cases. Clinical presentation consists mainly of symptoms of irritability, anger, persistent negative emotional state, and sleep disturbances, often accompanied by other symptoms. These findings suggest that older people with dementia may have other symptom presentations than people without dementia.

INTRODUCTION

Posttraumatic stress disorder (PTSD) is a prevalent disorder worldwide and has been reported as an independent risk factor for cognitive decline and dementia.^{1–6} Veterans with PTSD are twice as likely to develop dementia than veterans without PTSD,^{4,7,8} with a 7-year cumulative dementia incidence of 10.6%.⁹

The estimated comorbidity rate of PTSD in dementia, based on only three studies in veterans,^{10–12} varies

between 4.7% and 7.8%. However, PTSD may be difficult to recognize in people with dementia due to cohort properties such as underreporting of psychological symptoms, memory dysfunctions, and difficulties in self-report of symptoms.¹³ Besides PTSD, depression and fear¹⁴ are also difficult to recognize and consequently go undertreated in people with dementia.

Presentation of PTSD in dementia may be masked by other psychological and possible behavioural disorders, described as behavioural and psychological symptoms of dementia (BPSD).¹¹ Reported BPSD are anxiety, irritability,¹⁵ sleep disturbances, and nightmares.¹⁶ As PTSD is potentially a treatable condition, also in dementia, recognition is essential for personalized treatment interventions.¹⁷

PTSD symptoms can appear with delayed onset or in chronic form with fluctuating course. The prevalence of PTSD declines with age.^{1,18-20} In addition. three distinct clinical courses of PTSD have been described, namely: (i) chronic PTSD in which patients continuously suffer from PTSD;^{21,22} (ii) PTSD with reactivation whereby PTSD is provoked, e.g. by loss of loved ones, after retirement, and other re-activation of feelings experienced during early life trauma;²³ and (iii) delayed onset PTSD in which people functioned normally after the traumatic event but develop symptoms of PTSD after decades.^{12,24} Delayed onset PTSD may be easily missed especially in dementia because of lack of a valid life history. Associated behavioural problems may then be easily interpreted as BPSD.

In the general population, PTSD may go along with a lower quality of life which is even more compromised in people with dementia.^{25–27} Accordingly, several studies have shown that PTSD is associated with physical and psychological comorbidities which may lower the quality of life even more.^{12,28}

There is no clear overview of the clinical presentation of PTSD in people with dementia. In order to improve recognition of PTSD symptoms in these individuals, the current systematic literature review was designed to summarize the available literature with regard to the clinical presentation of PTSD symptoms (according to the *Diagnostic and Statistical Manual of Mental Disorders* fifth edition (DSM-5)) in people with dementia.²⁹

METHODS

Data sources and searches

The literature search was conducted in PubMed, PsycINFO, Embase, and CINAHL on 30 December 2021. The search strategy consisted of terms related to PTSD and terms related to dementia, as well as specific limitations (see Appendix S1 in the Supporting Information). In particular, the search was made for the umbrella term dementia and not each subtype of dementia separately. Subsequently, a reference list of publications and secondary literature was hand-searched for possible missing publications. See Sobczak *et al.*⁶ for more details.

Study selection

As the goal of this study is to investigate the clinical presentation of PTSD in people with a current diagnosis of dementia, we included all papers in which current post-traumatic stress symptoms in dementia cases were described. We used the following inclusion criteria: (i) description of at least one case of a patient with a current diagnosis of dementia with comorbid PTSD symptoms;^{21,22} (ii) clinical presentation of symptoms being adequately described;²³ (iii) no difference being made between chronic PTSD, PTSD with re-activation, and delayed onset PTSD.^{12,24} The search was limited to English language publications. Publications were excluded when the described PTSD symptoms predated the onset of dementia.

Data extraction and description of data

The selection process of this exploratory study followed the PRISMA (Preferred reporting items for systematic reviews and meta-analyses) guidelines.³⁰ Titles and abstract were screened for broad suitability and the above-mentioned eligibility criteria. Next, selection took place after reviewing the full-text papers by two independent authors (S.S. and D.v.D.). In order to describe the clinical presentation of PTSD in dementia, included papers were checked for PTSD symptoms according to the DSM-5²⁹ using the following steps: (i) For the first DSM-5 criteria, traumatic life events were checked using the Life Event Checklist-5 (LEC-5) and were rated using DSM-5 criteria A (1-4), trauma exposure;³¹ and (ii) psychiatric symptoms described in the case were rated using PTSD DSM-5 criteria (the number of items required for a PTSD diagnosis indicated in brackets for each symptom group): B(1–5) intrusion symptoms (\geq 1), C (1, 2) avoidance symptoms (\geq 1), D (1–7) negative cognition and mood symptoms (≥2), E (1-6) marked alterations in traumarelated arousal and reactivity (≥ 2).

DSM-5 criteria F (duration >1 month), G (distress/ impairment), and H (not attributable to another disorder) were not used in the symptom rating as these are regarded as difficult to check in the literature and less relevant for our specific research question. A standardized data collection form was used to extract information (see Appendix S1). We rated all described symptoms in the cases. If symptoms could not be classified as PTSD symptoms according to DSM-5, these were rated as 'other symptoms'. These other symptoms are relevant as they may give hints for a possible alternative symptom presentation of PTSD in dementia.

We give here as an example case 2 from van Achterberg et al. (2001, p. 206; see also Appendix S2):

Mr. B became progressively more anxious and began to startle more easily. Car horns caused him to jump dramatically, making it difficult for him to drive. He awaked from sleep physically fighting, and his wife described 'rage attacks', during which Mr B yelled, threw objects, and slammed doors.

The rated symptoms were anxiety (D4), easily startled (E4), disturbed sleep (E6), physical aggression (E1), rage attacks (E1), and screaming (other symptoms).

Next, operationalization of the search and selection criteria, data extraction, and subsequent rating of PTSD symptoms (using DSM-5) were done by two authors (D.v.D. and S.S.) independently. Possible discrepancies were discussed by the study team.

Assessment of risks of bias

Since this is an exploratory study of a qualitative character, the empirical quality of the included studies is not expected to affect results. To check the impact of quality on our findings, quality assessment of the included papers was done using the method of Murad *et al.*³⁰ This method is based on the Newcastle Ottawa Scale (NOS) reports.³² We applied this method (performed by D.v.D.) to the reviewed papers (see Appendix S2).

Results

The literature search resulted in 947 abstracts of which 33 (3.5%) were included for full-text screening. Two additional studies were found by checking reference lists^{17,33} and were included after full-text screening. Finally, of the 33 full-texts, 13 studies (1.1%) met the eligibility criteria and were included (Fig. 1).

Of the 13 papers included in the review, 12 consisted of case reports^{16,17,22,33–41} and one paper was a review which included three case reports.²³ In total, this review includes 30 cases. The most common trauma was combat or exposure to a war zone (21/30 = 70%). The PTSD diagnosis in the described cases was mainly established by a clinical psychiatric investigation (25/30 = 83%).^{16,17,23,33–38,40} Only in one

case (1/30 = 3.3%) were diagnostic tools applied (an adapted version of the Clinician-administrated PTSD scale for DSM-IV (CAPS), Mini international neuropsychiatric interview (MINI) and PTSD Checklistcivilian version (PCL-C)).²² Two studies did not give information about how PTSD was diagnosed.^{35,40}

A first insight into the clinical manifestation

DSM-5 symptom rating

Table 1 shows the characteristics of the 13 papers and 30 cases that were included in this review. According to the LEC-5, all cases met the first DSM-5 criterion for PTSD (A1). Only one case of the 30 included (3.3%) fulfilled, using our rating method, all necessary DSM-5 criteria of PTSD.³⁹ The total number of rated PTSD symptoms varied per case between two and five. Avoidance, as a main symptom of PTSD, was not rated in 27 of 30 cases (90%). A more extensive version of Table 1 is shown in Appendix S2. Appendix S2 shows that the mean age was 74.9 years (range 57–95 years), most cases were men (22 male/8 female, 73%) and most people were veterans and have the trauma type of combat or exposure to a war zone (n = 21, 70%).

The total rated DSM-5 PTSD symptoms of the included cases are presented in Table 2.

Frequencies of rated PTSD symptoms

Table 2 shows that irritability and anger (E1) is the most frequently described PTSD symptom in people with dementia (9%).^{16,17,22,23,34–36,38} Symptoms of irritability and anger (E1) were physical and verbal aggression, agitation, and irritability. Next, persistent negative emotional state (D4) is as often (9%) described. Symptoms of a persistent negative emotional state (D4) were anxiety, depression/depressive symptoms, unstable mood, and suicidal ideations.^{16,22,23,34–40} Sleep disturbances (E6) (8%) were described, often in co-occurrence with vivid nightmares (10 out of 16 cases) and nightly wandering (4 out of 13 cases).^{16,17,22,23,34–37,39–41}. Avoid-ance (C) was only described in three cases.^{33,37,38}

Items in the category of 'other symptoms' were described in 29/30 cases (97%) (see Appendix S2). Most frequent were memory problems (in 16/30 cases, 53%),^{16,17,22,23,33-39} screaming (9/30 cases, 30%),^{16,17,23,34,36,37}, and wandering (6/30 cases, 20%).^{1,7,17,34-36} Less frequently described other symptoms were suicidal ideation (4/30 cases, 13.3%),^{22,35,37,39} paranoid ideas (3/30 cases, 10%),^{34,39} hallucinations (3/30 cases, 10%),^{17,35}

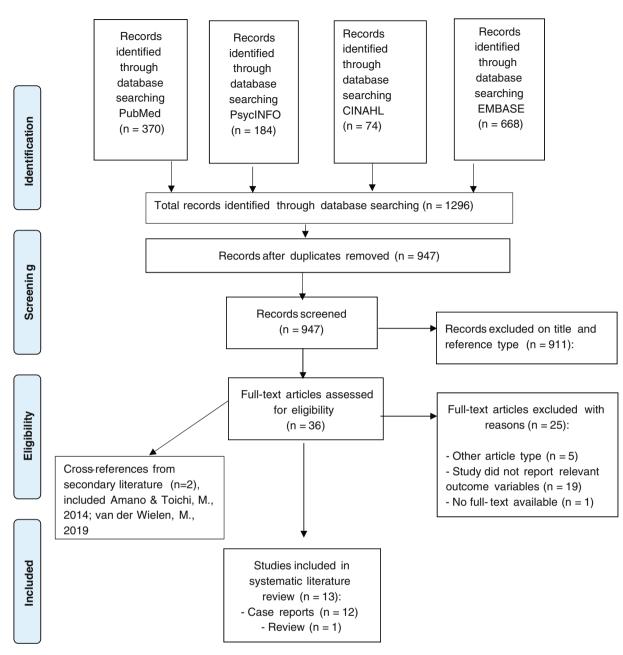


Figure 1 PRISMA flow chart documenting the search and screening process.

delirium (3/30 cases, 10%), 17,34 resistance against caregivers (3/30 cases, 10%), 16,17 and psychomotor agitation/acceleration (3/30 cases, 10%). 17,35,36

DISCUSSION

In this systematic literature review we examined the clinical presentation of PTSD in people with dementia. Symptoms of PTSD in dementia were described in 13 papers (1.4% of total found literature) from which 30 cases were included in this review.

PTSD diagnosis in dementia

Of the 30 reviewed cases 24 were clinically diagnosed with PTSD, but using our rating method only one completely fulfilled the DSM-5 criteria for PTSD. A side note in these findings should be that if

			Total rated PTSD symptoms
Authors (year)	LEC-5 trauma	Psychiatric symptoms	(DSM-5)
Martinez-Clavera <i>et al.</i> , 2017 ²³	Review Case 1: Combat or exposure to a war zone Case 2: Combat or exposure to a war zone Case 3: Severe human suffering	 Anxiety (D4), flashbacks (B3), sleeping disturbances (E6), distractibility (E5), memory problems (o) Physical aggression (E1), anxiety (D4), sleeping disturbances (E6), paranoid ideas (B3), agitation (E1), Disliking seeing other residents in distress (o), memory problems (o) Anxiety (D4), flashbacks (B3), nightmares (B2), sleeping disturbances (E6), screaming (o), dislike physical touch (o), easily startle (E4), memory problems (o) 	Three Three Three
van Achterberg <i>et al.</i> , 2001 ³⁶	Case report Case 4: Transportation accident Case 5: Combat or exposure to a war zone Case 6: Combat or exposure to a war zone	 Flashbacks (B3), agitation (E1), distress (D4) psychomotor agitation (E1), memory problems (o) Physical and verbal aggression (E1), anxiety (D4), nightmares (B2), sleeping disturbances (E6), easily alarmed/easily startle (E4), screaming (o), negative beliefs (D2), memory problems (o) Agitation (E1), anxiety (D4), flashbacks (B3), intrusive memories (B3), nightmares (B2), easily alarmed/easily startle (E4), suspiciousness (o), memory problems (o) 	Three Four Three
Ahmed, 2018 ⁴⁰	Case 7: Sexual assault, stressful event	Depressive symptoms (D7), anxiety (D4), sleep disturbances (E6), visual hallucinations (o)	Тwo
Amano <i>et al.</i> , 2014 ¹⁷	Case 8: Childhood trauma Case 9: Combat or exposure to a war zone Case 10: Combat or exposure to a war zone	 Physical and verbal aggression (E1), agitation (E1), hallucination (B1), wandering (o), screaming (o), memory problems (o) Sleeping disturbances (E6), resistance against caregivers (o), screaming (o), wandering (o), restlessness (E6), delirium (o), hallucination (o), agitation (E1), memory problems (o) Sleeping disturbances (E6), physical aggression (E1), screaming (o), wandering (o), delirium(o), resistance against caregivers (o), bizarre eating habits (o), inappropriate dressing and undressing (o), frequently calling a caregiver (o), psychomotor acceleration (o), memory 	Three Two Two
Bruneau <i>et al.</i> , 2020 ³⁴	Case 11: Combat or exposure to a war zone Case 12: Combat or exposure to a war zone Case 13: Imprison Case 14: Drugged and robbery Case 15: Imprisoned during Pinochet regime	problems (o) Visual hallucination (o), physical aggression (E1) suicidal ideation (o), nightmares (B2), depressive symptoms (D7), screaming (o), memory problems (o) Physical aggression (E1), emotional lability (D4), visual and auditory hallucination (o), sleeping disorder (E6), memory problems (o), vivid intrusive memories of war (B1), wandering (o), inside talking (o), dissociative trauma flashback (B3)	Two Three Two Two Three

Table 1 Characteristics of included studies, LEC-5 trauma, psychiatric symptoms, and total rated PTSD. The psychiatric symptoms are those described in the 30 cases. The PTSD symptoms are rated based on DSM-5 criteria

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Table 1 Continued

Authors (vear)	LEC-5 trauma	Psychiatric symptoms	Total rated PTSD symptoms (DSM-5)
		Physical aggression (E1), screaming (o),	()
		depressive (D7), physical and	
		psychological distress (B4 and B5),	
		memory problems (o)	
		Aggression (E1), agitation (E1), anxious (D4),	
		memory problems (o),	
		Agitation (E1), resistance against caregivers	
		(o), sleeping disorders (E6), avoidance (C1),	
		aggression (E1), psychomotor restlessness (o), memory problems (o)	
Chopra <i>et al</i> .,2011 ⁴¹	Case 16: Combat or exposure to a war	Nightmares (B2), sleeping disturbances (E6),	Three
	zone	flashbacks (B3), easily startle (E4),	
		depressive symptoms (D7)	
Duax <i>et al</i> ., 2013 ²²	Case 17: Combat or exposure to a war	Physical aggression (E1), nightmares (B2),	Four
2000 00 00, 2010	zone	memory problems(o), sleeping	
	20110	disturbances (E6), irritability (E1), apathy	
		(D5), suspiciousness (o), anxiety (D4), depression (D7)	
Hamilton <i>et al</i> ., 1998 ³⁷	Case 18: Combat or exposure to a war	Nightmares (B2), sleeping disturbances (E6),	Three
	zone	psychomotor retardation (o), agitation (E1),	11100
	20110	disorientation (D6), screaming (o), delusion	
		of beliefs (o), memory problems (o),	
		delirium (o), re-experiences (B1), easily	
		startle (E4)	
acono <i>et al</i> ., 2020 ³⁵	Case 19: Combat or exposure to a war	Memory problems (o), irritability (E1),	Two
	zone	depression (D7), agitation (E1), physical	Two
	Case 20: Combat or exposure to a war	aggression (E1),	Three
	zone	Nightmares (B2), suicide (o), memory	One
	Case 21:	problems (o), beliefs (D3), sleeping	One
	Combat or exposure to a war zone	disturbances (E6)	
	Case 22:	Memory problems (o), attention (E5),	
	Combat or exposure to a war zone	dissociative episodes (B3), guilt and shame	
	Comparer expectate to a war zone	(D3), distressing memories (B1, B4),	
		irritability (E1), physical aggression (E1),	
		wandering (o), paranoia (o)	
		Suicidal ideations (o), memory problems (o),	
Johnston, 2000 ¹⁶	Case 23: Combat or exposure to a war	Flashback (B3), nightmares (B2), memory	Four
Johnston, 2000	zone	problems (o), sleeping disturbances (E6),	Three
	Case 24: Combat or exposure to a war	dissociation (B3), irritability (E1), agitation	Four
	zone	(E1), easily alarmed/easily startle (E4).	i oui
	Case 25: Combat or exposure to a war	disorientation (D6), wandering (o),	
	zone	screaming (o), aggression (E1), paranoid	
	20110	ideas (o), social withdrawn (D5)	
		Physical aggression (E1), depression/	
		depressive symptoms (D7), nightmares	
		(B2), memory problems(o), concentration	
		problems (E5), sleeping disturbances (E6),	
		physiological distress on trauma	
		(B4 and B5)	
		Physical aggression (E1), anxiety(D4),	
		nightmares (B2), memory problems(o),	
		sleeping disturbances (E6), paranoid ideas	
		(o), delusion (D3), agitation (E1)	
McCartney <i>et al</i> ., 1997 ³⁸	Case 26: Sexual assault	Anxiety (D4), concentration problems (E5),	Four
McCartney <i>et al.</i> , 1997		agitation (E1), easily alarmed/easily startle	
		(F4) psychomotor restlessness (a) memory	
		(E4), psychomotor restlessness (o), memory problems (o), physiological distress (B4),	

ngen *et al.*

Authors (year)	LEC-5 trauma	Psychiatric symptoms	Total rated PTSD symptoms (DSM-5)
Mittal <i>et al.</i> , 2000 ³⁹	Case 27: Combat or exposure to a war zone Case 28: Combat or exposure to a war zone Case 29: Combat or exposure to a war zone	Suicidal ideations (not attempted) (o), depression/depressive symptoms, anxiety (D7), flashbacks (B3), memory problems (o), impaired abstract reasoning (E5), anxiety (D4), concentration problems (E5) Suicidal ideations (no attempt) (o), restricted affect (D4), depression/depressive symptoms (D7), flashback (B3), nightmares (B2), memory problems (o), concentration problems (E5), sleeping disturbances (E6), psychomotor retardation (o), hopelessness (D3), negative beliefs (D4), avoidance (C2) Depression/depressive symptoms (D7), anxiety (D4), nightmares (B2), memory problems (o), sleeping disturbances (E6), psychomotor acceleration (o), impaired attention (E5), impaired abstract reasoning (E5), recall (B1)	Four Five Four
van der Wielen, 2019 ³³	Case 30: stressful experience	Memory problems (o), flashbacks (B3)	Two

Table 1 Continued

Psychiatric symptoms: symptoms described in cases. A, Exposure via any of the following: A1, Directly exposed to trauma; A2, Eyewitness to others directly exposed to trauma; A3, Learning of direct exposure to trauma of a close family member or close friend; A4, Repeated or extreme exposure to aversive details of traumatic event, in person or via work-related electronic media. B, Intrusion, including the following: B1, Recurrent, involuntary, distressing, trauma, related dreams; B3, Dissociative reactions/flashbacks related to trauma; B4, Intense or prolonged psychological distress to trauma reminders; B5, Marked, physiological reactions to trauma reminders. C, Avoidance, including: C1, Avoidance/efforts to avoid distressing internal trauma reminders; C2, Avoidance or efforts to avoid distressing external trauma reminders. D, Negative cognition and mood, including: D1, Amnesia for important parts of trauma exposure; D2, Persistent, exaggerated negative beliefs about self, others, or the world; D3, Persistent, distorted trauma-related cognitions leading to inappropriate blame of self/others; D4, Persistent negative emotional state; D5, Loss of interest or participation in significant activities; D6, Detached/estranged feelings from others; D7, Persistent loss of positive emotions. E, hyperarousal, including: E1, Irritability and angry outburst with little/no provocation; E2, Reckless or self-destructive behaviour; E3, Hypervigilance; E4, Exaggerated startle; E5, Concentration problems; E6, Sleep disturbance. G, Distress/impairment. H, Not attributable to another disorder. O, other symptoms. DSM-5, *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition; LEC-5, Life Event Checklist-5; PTSD, post-traumatic stress disorder.

symptoms were not described, this does not mean that they were not present. Previously, altered clinical presentations of PTSD in different age-groups has been reported.⁴² For example, PTSD may be accompanied by more arousal symptoms and lower intrusive symptoms in older adults.⁴² Such different clinical presentations may hamper diagnosing PTSD in older age groups. Consequently, differences in reported comorbidity rates between age groups may possibly be attributed to unrecognized PTSD symptoms. For example, in the general population, the 3-month prevalence of PTSD is 7–8%, and it is even lower in older adults.^{18,43}

The concept of sub-threshold PTSD has been suggested by McLaughlin *et al.*,⁴⁴ defined as meeting two or three of the DSM-5 criteria for PTSD (among the symptom groups B, intrusion; C, avoidance; D, negative cognition and mood; and E, hyperarousal).⁴⁴ In older adults, the 6-month prevalence of sub-

threshold PTSD is 13.1%.45 Compared to the 6-months prevalence rate of 0.9% in adults this is relatively high, suggesting a blunted expression of PTSD in older adults. In adults, the prevalence of sub-threshold PTSD is 4.6%.44 Possibly, the prevalence of PTSD is lower in older adults because of inadequate recognition of PTSD symptoms, resulting in relatively more frequent diagnosis of sub-clinical PTSD. We suggest that in people with dementia inadequate recognition of PTSD symptoms may also be reflected in relatively more sub-threshold PTSD diagnoses. However, even sub-threshold PTSD in older adults may cause mental suffering and be clinically relevant, as trauma-focused treatment can improve PTSD, general well-being and quality of life in older adults with sub-threshold PTSD.46-49 As Eve Movement Desensitization and Reprocessing (EMDR) has been shown to relieve neuropsychiatric symptoms in three cases with severe dementia,¹⁷ we suggest that

Table 2 Percentages of reported PTSD symptoms (using DSM-5 criteria) of reviewed cases (n = 30)

DSM-5 Criteria for PTSD		
Trauma, actual of threatened violent death, serious injury		
or accident, or sexual violence		
A: Exposure via any of the following	100%	
1. Directly exposed to trauma		
2. Eyewitness (in person) to others directly exposed to trauma	0	
3. Learning of direct exposure to trauma of a close family member or close friend	0	
4. Repeated or extreme exposure to aversive details of	0	
traumatic event, in person or via work-related		
electronic media		
B: Intrusion		
1. Recurrent, involuntary, distressing trauma memories	6%	
2. Recurrent, distressing, trauma-related dreams	7%	
3. Dissociative reactions/flashbacks related to trauma	5%	
 Intense or prolonged psychological distress to trauma reminders 	2%	
5. Marked physiological reactions to trauma reminders	1%	
C: Avoidance,	10/	
 Avoidance/efforts to avoid distressing internal trauma reminders 	1%	
2. Avoidance or efforts to avoid distressing external	1%	
trauma reminders		
D: Negative cognition and mood		
1. Amnesia for important parts of trauma exposure	0	
2. Persistent, exaggerated negative beliefs about self,	1%	
others, or the world	.,.	
3. Persistent, distorted trauma-related cognitions leading	2%	
to inappropriate blame of self/others	270	
4. Persistent negative emotional state	9%	
5. Loss of interest or participation in significant activities	1%	
6. Detached/estranged feelings from others	1%	
7. Persistent loss of positive emotions	5%	
E: Hyperarousal	070	
1. Irritability and angry outbursts with little/no provocation	9%	
2. Reckless or self-destructive behaviour	0	
3. Hypervigilance	0%	
4. Exaggerated startle	3	
5. Concentration problems	3%	
6. Sleep disturbance		
Additional criteria	8%	
F: Duration >1 month		
G: Distress/impairment, clinically significant distress, social/occupational/other important functioning		
impairment		

PTSD, posttraumatic stress disorder; DSM-5, *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition.

in clinical practice diagnosing sub-threshold PTSD in people with dementia is also relevant.

People with dementia constitute a population in which the expression of several diagnostic DSM-5 symptoms may be challenging. The DSM-5 criteria are primarily designed for the younger and healthier population. Besides PTSD, symptoms of depression¹³ and fear¹⁴ are also difficult to recognize and

consequently undertreated in people with dementia. For example, Olin *et al.*¹³ proposed adapted diagnostic criteria for depressive disorder in Alzheimer's disease. We suggest that adapted diagnostic criteria for PTSD in people with dementia may also be relevant.

Furthermore, the underlying aetiology of dementia can affect the clinical manifestation of PTSD. For example, people with Lewy body dementia more often have hallucinations and flashbacks compared to people with Alzheimer disease.¹⁴ In addition, the presentation of PTSD in people with dementia may also differ depending on the type of trauma.³⁴ It is unknown whether or not some manifestations are more likely to relapse or exacerbate with the onset of dementia.

Avoidance is a key symptom in PTSD. However, in our reviewed cases we only found avoidance symptoms (C1-2) in three cases.^{34,38,39} We suggest that avoidance is difficult to signal when patients stay in nursing homes or other closed clinical settings, possibly due to the following factors: (i) older adults are physically less mobile; (ii) older adults living in nursing homes or other closed clinical settings live in an environment where the door is often closed; (iii) avoidance includes thought, memories, and feelings which are difficult to assess in people with dementia; and (iv) older adults with cognitive problems are often impaired in planning their activities, and thus in avoiding. Therefore, as avoidance may be difficult to recognize, and difficult for patients to realize themselves, caregivers and family members should be asked for avoidance symptoms. Possibly, the wandering seen in 22.2% of our reviewed cases can be taken as a sign of avoidance. Avoidance symptoms of PTSD are more often reported as absent in PTSD subpopulations, such as Mexican hurricane victims,⁵⁰ women living in South African townships,⁵¹ and Palestinian survivors of war of mass violence.⁵² Not only do PTSD patients have an inconsistent avoidance symptom presentation, in anxiety disorders, avoidance may also often be difficult to recognize, especially in older adults.⁵³ Besides, many older adults have been exhibiting coping behaviour for years and may, therefore, be not aware of their avoidance behaviour.23

Clinical presentation of PTSD in dementia

The most frequently described DSM-5 symptoms of PTSD in dementia were irritability and anger

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(E1, 9%), persistent negative emotional state (D4, 9%) and sleep disturbances (E6, 8%). There is evidence for increased BPSD in people with dementia and PTSD in some reports⁹ but not in others.^{10,12} As specific BPSD symptoms can reflect an expression of delayed onset PTSD, but may be often not recognized as such,²³ we suggest that PTSD is frequently treated as BPSD.^{23,34} Next, a persistent negative emotional state (mainly anxiety) is often seen. We suggest that anxiety is a relatively easy PTSD symptom to recognize in people with dementia, as anxiety seems to be often related to re-experiencing of trauma as a cause of problem behaviour.⁵⁴ Sleep disturbances in our cases were often accompanied with dissociative reactions and flashbacks during the night. We cannot be certain that reported sleep disturbances were all PTSD symptoms, as sleep disturbances are a widely known problem in older adults in general.⁵⁵ More specifically, 60%-70% of people with cognitive impairment or dementia have sleep disturbances.⁵³ In conclusion, it can be difficult to differentiate between PTSD symptoms and BPSD symptoms because symptoms such as anger and irritability may be related to both.^{10,30}

Other symptoms

Other symptoms were rated in 29/30 of the reviewed cases. In addition to memory problems (53%), screaming (30%) and wandering (20%) were most frequently described.

For example, screaming was accompanied with re-experiences of traumatic events^{23,36} in case 4 (see Table1). She was a woman who survived the sinking of the Titanic. Every time she was distressed, she screamed 'The water is coming up! Go to the lifeboats! Save the children! We'll all be dead!'³⁶ However, in some cases patients scream frequently during the day without a specific trigger.²³ Screaming in dementia is a BPSD seriously impacting on the quality of life of both patients and those involved (bystanders and care-givers). For example, a whole department may suffer when a patient is screaming throughout the entire day.⁵⁶ Treatment of screaming in dementia is difficult; the challenge is to find which emotional or physiological discomfort causes the screaming.⁵⁷ We suggest that screaming may provide a hint to possible previous traumatic events. Diagnosing PTSD may support the clinician in his considerations to start trauma-focused therapy.

During the disease course of dementia, about 60% of patients are considered to exhibit wandering behaviour.¹³ It has major health consequences, e.g. getting lost, leading to injury or even death.⁵⁸ It also impacts on caregivers,⁵⁹ e.g. by causing distress due to consequent worries or by being confronted with aggression.¹⁵ Aimless wandering should be differentiated from trauma-related avoidance behaviour in order to diagnose PTSD in dementia.

Though cognitive dysfunctions, e.g. impaired memory performance, are described in PTSD,⁵⁹ the reported memory problems are probably inherent to the studied dementia population.

Methodological considerations

The scientific evidence of this exploratory study is mainly restricted by: (i) using a small number of papers (n = 13); and (ii) using only case reports, which have very limited scientific evidence. Most of the articles have a sufficient quality (NOS 2-3 out of 4, 96%). The lower quality article (case 1) had symptoms conforming to the major findings in our article. Thus it is assumed that there is no interference with the main findings. Next, information bias may be present due to our applied rating method of PTSD symptoms in which we rated symptoms using the DSM-5 as a reference. In addition, there is limited translatability of the results to the general population, because the case reports include a limited group of patients, for instance we included a relatively low number of women and the most common trauma was combat or exposure to a war zone. We did not check psychiatric comorbidities, therefore our rated symptoms were either rated as PTSD symptoms or as other symptoms. Misinterpretation of symptoms may therefore not be fully excluded. In addition, cases were all described in different ways, with different aims of the reports, and differences in the extent of case descriptions. Another limitation is associated with our rating procedure. As we only rated the described symptoms it cannot be ruled out that we overlooked symptoms that were present in the cases but were not described. Thus the findings of our paper give information about clinical symptoms of PTSD that were at least present. Furthermore, this implies that reported symptoms may be skewed toward symptoms that are more observable and therefore more described in the cases. This may explain the low rate of symptoms such as irritability/ anger and persistent negative emotional state.

As, except one, all papers did not use a diagnostic tool for PTSD, descriptions of PTSD symptoms in the reviewed cases may have been incomplete and hence symptoms were missed.²² The methodological quality (range 2–3 on a scale of 4)³⁰ between the cases are mainly of low but sufficient and equal quality.

Our findings must therefore be regarded as a first exploration of the clinical presentation of PTSD in people with dementia.

Conclusion and recommendations

Overall, a first insight into PTSD in people with dementia shows that, based on our rating method, subjects present mainly with insufficient criteria to fulfil the DSM-5 diagnostic criteria for PTSD. Avoidance seems to be a rarely present symptom, possibly because it is not recognized. Next, the clinical presentation of PTSD in dementia seems to be mainly with irritability and anger symptoms (E1), persistent negative emotional state (anxiety, D4), and sleep disturbances (E6). Furthermore, it could be suggested that PTSD in dementia is accompanied by other symptoms, e.g. screaming and wandering. We suggest that all these symptoms may be indicative of possible PTSD. Based on this, in dementia, PTSD may have an alternative clinical presentation. In clinical practice, PTSD may then be easily interpreted as BPSD. Therefore, the use of diagnostic tools to diagnose PTSD (e.g. TRADE-interview, LEC of Clinician-Administered PTSD scale) is recommended in care and research. This will improve diagnosing PTSD in people with dementia, the quality of research, and comparison of studies.

We suggest conducting a life review of traumatic events and consider PTSD in people with dementia who present with symptoms of irritability and anger, anxiety, and sleep disorders, especially when there is concurrent screaming or wandering.

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AUTHOR CONTRIBUTIONS

D.v.D. did the search, selected articles, did the data collection and wrote the paper. D.H. assisted with writing the article. K.D. was responsible for the

literature search. F.V. supervised the writing. M.O. supervised the writing. S.S. checked the selection of the articles and data collection and supervised writing.

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SUPPORTING INFORMATION

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Appendix S1: Complete search strategy.

Appendix S2: Characteristics of included studies.

Supplementary 2: Subjects, number of cases, setting, age, dementia measure, neuropsychological scales, PTSD measure, PTSD scales, quality case description, Lec-5 trauma, gender, MMSE, psychiatric symptoms, total rated PTSD symptoms. The psychiatric symptoms are the symptoms described in the 27 cases. The PTSD symptoms are the rated PTSD symptoms based on the DSM-criteria of PTSD.

*Study quality was assessed with an adapted version of the Newcastle Ottawa Scale (Murad, 2018).

BNT = Boston Naming Test; Clock = Clock Drawing Test; CAPS (IV-TR) = Clinician-Administrated PTSD Scale for DSM-IV; CCSE = Cognitive Capacity Screening Exam; MINI = Mini International Neuropsychiatric Interview; MMSE = Mini Mental State Examination; MSE = Mental State Examination Table 1. Characteristics of included studies; NIT = Number Information Test; PCL-C = PTSD Checklist-Civilian Version; PTSD = Post Traumatic Stress Disorder; RBANS = Repeatable Battery for the Assessment of Neuropsychological Status; SUD = Subjective Unit of Distress scale; TMT = Trail Making Test; VLT = Verbal Learning Test; WAIS = Wechsler Adult Intelligence Scale Psychiatric symptoms: symptoms described in cases. A = Exposure via any of the following; A1 =Directly exposed to trauma: A2 = Evewitness to others directly exposed to trauma; A3 = Learning of direct exposure to trauma of a close family member or close friend; A4 = Repeated or extreme exposure to aversive details of traumatic event, in person or via work-related electronic media; B = Intrusion; B1 =Recurrent, involuntary, distressing, trauma, related B3 = Dissociative reactions/flashbacks dreams: related to trauma; B4 = Intense or prolonged psychological distress to trauma reminders; B5 = Marked, physiological reactions to trauma reminders; C = Avoidance; C1 = Avoidance/efforts to avoid distressing internal trauma reminders; C2 = Avoidance or efforts to avoid distressing external trauma reminders; D = Negative cognition and mood; D1 = Amnesia for important parts of trauma exposure: D2 = Persistent, exaggerated negative beliefs about self, others, or the world; D3 = Persistent, distorted trauma-related cognitions leading to inappropriate blame of self/others; D4 = Persistent negative emotional state; D5 = Lossof interest or participation in significant activities; D6 = Detached/estranged feelinas from others: D7 = Persistent loss of positive emotions; E = hyperarousal; E1 = irritability and angry outburst with little/ no provocation; E2 = Reckless or self-destructive behaviour; E3 = Hypervigilance; E4 = Exaggeratedstartle; E5 = Concentration problems; E6 = Sleep disturbance; G = Distress/impairment; H = Not attributable to another disorder; O = other symptoms.