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Impact and Needs in Caregiving for Individuals With Dementia and Comorbid Posttraumatic Stress Disorder Living in Nursing Homes

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Exposure to potential traumatic events (PTE) can result in long-lasting psychological disorders, such as posttraumatic stress disorder (PTSD). Most knowledge about PTSD is based on research on adults in specific survivor groups, including veterans and women who were in abusive relationships. In later life, cognitive and functional decline can make it harder to cope with PTE, resulting in delayed-onset PTSD symptoms.

There is limited information about the prevalence of PTSD in individuals with dementia, but recent research suggests it to be between 4.7% and 7.8% (Sobczak et al. 2021). It is difficult to diagnose PTSD in this population due to a lack of appropriate tools (Havermans et al. 2023). As the global dementia population triples by 2050, there is a critical need to improve the identification and treatment of PTSD in individuals with dementia.

Given that PTEs are usually characterised by a sense of powerlessness, the limited choice and control inherent to dementia care can be distressing. Individuals who have survived PTE may find that common care practices (e.g., washing and dressing), as well as environmental factors (e.g., lighting, smells and uniforms) and interpersonal factors (nursing staff speaking loud, giving commands, appearing angry or impatient) trigger memories of PTE and may experience threatening. This can result in challenging behaviour for nursing staff, who might relate the behaviour solely to cognitive decline or dementia (Cations et al. 2024). However, these symptoms are called 'PTE-related neuropsychiatric symptoms', which require a calm, controlled approach. Ethical dilemmas, such as 'Should an individual with dementia be forced to change dirty clothing if efforts to do so result in very distressed behaviour?' may arise and cause moral distress.

Summary

- What does this research add to existing knowledge in gerontology?
  - Recognition of possible PTSD is essential for a trauma-sensitive approach in individuals with dementia in nursing homes.
  - Research in this area is needed and feasible.
  - The current article mentions available treatment possibilities and care approaches in individuals with both possible PTSD and dementia in nursing homes.
- What are the implications of this new knowledge for nursing care for and with older adults?
  - By improving the understanding and needs of individuals with dementia and possible PTSD, nursing staff can adapt their care accordingly.
  - Nursing staff are better able to accept and understand the challenging behaviour when it is clear what caused the behaviour (e.g., fear).
- How could the findings be used to influence practice, education, research, and policy?
  - The current findings emphasise the need to enhance knowledge of PTSD in individuals with dementia in nursing homes as well as its impact on both the individuals themselves and nursing staff.
  - With an increasing number of individuals with dementia, educating nursing staff will be important to distinguish neuropsychiatric symptoms and possible PTSD symptoms, and improve care approaches.

Mrs. A is a 77-year-old woman with dementia, married with two children. She currently resides in a nursing home and has been exhibiting increased cognitive decline and neuropsychiatric symptoms. These include: physical and verbal aggression towards staff during care moments, screaming, crying, and pinching or hitting. In particular, being woken up in the morning by means of touch and taking a shower seems to increase Mrs. A's agitation. Besides, recently Mrs. A has exhibited increased wandering and shouting. This behaviour has led to heightened tension and caregiver burden within the care team.

The clinical manifestation of PTSD in individuals with dementia may differ from those without dementia (van Dongen et al. 2022). PTSD symptoms can be difficult to distinguish from neuropsychiatric symptoms. For example, it is possible that 'screaming' is a fear response to a flashback that the individual is experiencing and, thus, a potential PTSD symptom. Another example is 'resistance against caregivers' due to a history of violence or sexual abuse, and 'wandering' as a form of avoidance behaviour. Earlier research showed that the DSM-5 PTSD symptoms of re-experiencing, anxiety and sleep disturbances are commonly reported in individuals with dementia, while avoidance behaviour was less commonly seen (Amano and Toichi 2014; Martinez-Clavera et al. 2017). This difference in clinical manifestation could lead to misinterpretation and misdiagnosis, potentially resulting in ineffective treatment.

In collaboration with nursing homes and a mental health care institute in the Netherlands, our research group recently developed a semi-structured diagnostic tool to diagnose PTSD in individuals with dementia: the TRAuma and DEmentia (TRADE)-interview (Havermans et al. 2023). The diagnostic accuracy of this interview is currently under investigation (Ruisch et al. 2024).

Initially, Mrs. A's symptoms were thought to be due to cognitive decline, but further investigation revealed a history of sexual abuse. Mrs. A has been sexually abused in the bathroom by her uncle several times in the past. The TRADE-interview was indicative for PTSD. Analysis of potential triggers showed that suddenly touching (during daily care moments) was the most relevant trigger.

To our knowledge, there are no guidelines available for treating PTSD in individuals with dementia. While psychotropic drugs are commonly used to manage symptoms in clinical practice, they come with significant risks. Little research has been done on psychological treatments, but some studies show promising effects for eye movement desensitisation and reprocessing (EMDR). A Delphi study from Driessen et al. (2023) concluded that there are several treatment options available and appropriate (e.g., EMDR, behavioural counselling and prolonged exposure). More research is needed to determine the most suitable treatment for PTSD in individuals with dementia.

Referral is made to a psychologist, who pursues EMDR-treatment. The EMDR approach was deemed viable with modifications to the protocol, such as the selection of the child and youth protocol, utilisation of visual analogue scales (VAS) for the Subjective Units of Disturbance (SUD) scale and the Validity of Cognition (VOC) scale, and active involvement of the psychologist in formulating negative and positive cognitions. After a few sessions, the nursing staff reported improvement in daily care: physical and verbal aggression decreased, there was less wandering and screaming.

In general, nursing staff receives little education on the effects of trauma, and the psychological literacy of dementia care workers is insufficient. Specific education is crucial to know the impact of PTE on individuals with dementia. This emphasises also the relevance of trauma-informed care (TIC) principles in nursing homes. The TIC model recognises how PTE affects a person's life and their experience of care. Implementing TIC principles can promote staff and patient safety, reduce the risk of re-traumatisation and minimise adverse events (Cations et al. 2020). Personalised care methods such as the Personalised Integrated Stepped-Care (STIP) method (Verstraeten et al. 2022), Grip on Challenging Behaviour (GRIP) method (Zwijsen et al. 2014) and the Stepwise, Multidisciplinary Intervention for Pain and Challenging Behaviour in Dementia (STA OP!) method (Pieper et al. 2016), should be integrated with TIC principles to address PTE related neuropsychiatric symptoms

effectively. This integration should include routine screening for past PTE and triggers, care adaptations and team review to develop non-triggering care approaches. The ultimate goal is to integrate this knowledge into the policies, procedures and practices of all nursing homes worldwide.

> In addition to EMDR, an approach plan is personalised in consultation with the family and the multidisciplinary team to ensure the emotional and physical safety. This includes waking her by talking and gradually turning on the lights, instead of touching her immediately, and using a washcloth for care instead of daily showers.
>
> According to the TIC model, the care team introduces behavioural rules to make Mrs. A. feel safe. Where possible, a permanent nursing staff member is assigned to Mrs. A instead of a substitute nursing staff member. This way Mrs. A. hopefully grows accustomed to their presence, so a trustworthy relationship is formed. When assisting Mrs. A., the nursing staff will inform her in a calm way about every following step and demonstrate their action beforehand and ask for her permission. This ensures transparency and shared decision-making. When assisting Mrs. A., the nursing staff makes sure that Mrs. A. has several choices in clothes, jewellery, deodorant in order to promote autonomy and a sense of control. The care team evaluates their alternative care actions every two weeks to explore the effects of avoiding triggers.

Let us remember that nursing staff are facing challenges with individuals who suffer from PTE-related neuropsychiatric symptoms. It is time to improve trauma-sensitive care for these individuals. This can be achieved by: recognising possible PTSD, improving treatment and personalising an approach. The ultimate goal is to improve quality of life for people who have PTE-related symptoms in dementia. This approach will definitely promote staff and patient safety.

Author Contributions

Demi C.D. Havermans: conceptualization, methodology, writing – original draft preparation. **Monica Cations:** writing – original draft preparation, writing – reviewing and editing. **Jelte S. Woudsma:** writing – original draft preparation, writing – reviewing and editing. **Isabelle Janssen:** writing – reviewing and editing. **Janine Collet:** writing – reviewing and editing. **Debby L. Gerritsen:** writing – reviewing and editing. **Chris M. Hoeboer:** methodology, supervision, writing – reviewing and editing. **Miranda Olff:** methodology, supervision, writing – reviewing and editing. **Sjacko Sobczak:** methodology, supervision, writing – reviewing and editing.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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