Reliving trauma near death: a systematic review

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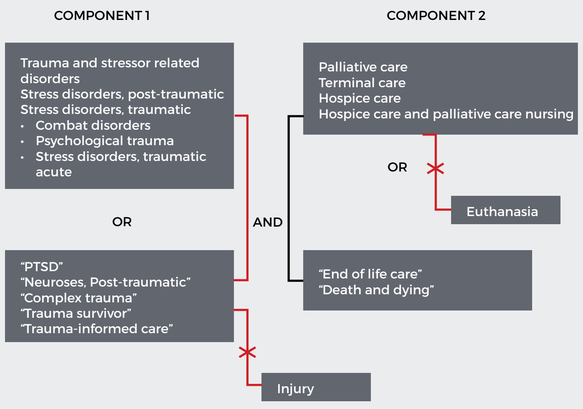
Background

Little is known as to why some people behave or respond differently at the end of life, withdrawing from care, rhythmically calling out or becoming aggressive. One hypothesis is that these symptoms are reliving previous trauma, but little is known about its impact on the experience of dying. This integrative review set out to address the following research questions: 1) how is previous trauma identified in people who are dying, 2) how is previous trauma associated with the experience of death/dying in people with or without cognitive impairment? and 3) what palliative care interventions are available to people with previous trauma at end of life?

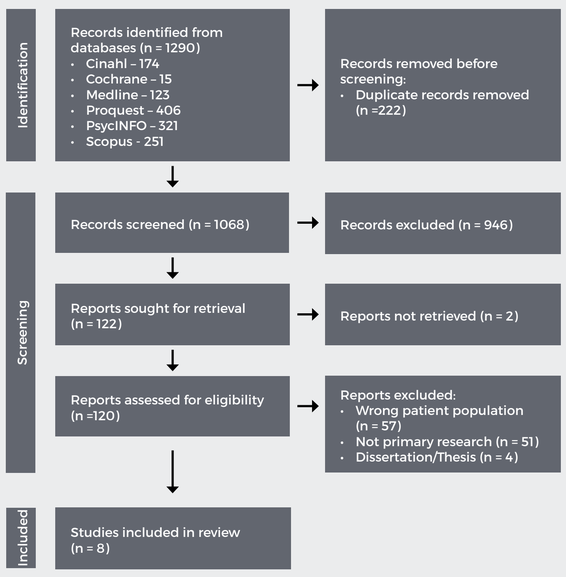
Methods

Figure 1: Eligibility criteria



Psychological trauma: An emotionally painful, shocking, stressful, and sometimes life-thyreatening experience. It can result from witnessing or experiencing distressing events such as natural disasters, physical or sexual abuse, and terrorism or other acts of violence; or from experiencing childhood abuse, or exposure to distressing events.

Figure 2: PRISMA 2020 flow diagram for Reliving trauma near death: A systematic review.



Quality appraisal conducted using the mixed method appraisal tool (MMAT) and a narrative synthesis undertaken.

Table 1 Part 1: MMAT- Qualitative Studies

Reviewer Nikki Johnston	Screening questions		Qualitative studies				
	S1.	S2.	1.1	1.2	1.3	1.4	1.5
Feldman et al. 2013	Yes	Yes	Unclear	Unclear	Unclear	No	No
O'Connor et al. 2013	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes
Prince-Paul et al. 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Screening Questions (for all types)

S1. Are there clear research questions?

S2. Do the collected data allow to address the research questions?

Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.

Yes

No

Unclear

1.1. Is the qualitative approach appropriate to answer the research question?

1.2. Are the qualitative data collection methods adequate to address the research question?

1.3. Are the findings adequately derived from the data?

1.4. Is the interpretation of results sufficiently substantiated by data?

1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

Table 2 Part 4 MMAT – Quantitative Descriptive Studies

Reviewer Nikki Johnston	Screening questions		Quantitative Descriptive Studies				
	S1.	S2.	4.1	4.2	4.3	4.4	4.5
Casarett et al. 2019	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes
Roth et al. 2013	Yes	Yes	Yes	Yes	Yes	No	Yes
Bickel et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Alici et al. 2010	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Akechi et al. 2004	Unclear	Unclear	Yes	Yes	Yes	Unclear	Unclear

S1. Are there clear research questions?

S2. Do the collected data allow to address the research questions?

Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.

4.1. Is the sampling strategy relevant to address the research question?

4.2. Is the sample representative of the target population?

4.3. Are the measurements appropriate? 4.4. Is the risk of non-response bias low? 4.5. Is the statistical analysis appropriate to answer the research question?

Findings

Of the 1068 studies identified, 8 studies met the inclusion criteria, see Figure 1. Overall the methodological quality of the retained studies was fair, see Table 1 & 2. A total of 3 qualitative, 4, quantitative methods and 1 mixed methods study were included, underscoring that this is an emerging clinical field. The studies were conducted in Australia (n=1), Canada (N=1), Japan (n=1), USA (n=4) and USA / Canada (n=1).

The populations included mainly war veterans from the USA and Australia. Noteworthy, the studies conducted from Japan and North America (including USA and Canada) represented individuals who were dying and diagnosed with cancer or receiving palliative care with Post Traumatic Stress Disorder (PTSD) diagnosis.

Bickel (2019) provided evidence to support the hypothesis that individuals with PTSD have increased symptom burden in the final months and days of life. Those with diagnosed PTSD were more likely to be hospitalised in their last 12 months of life and more likely to have received antipsychotics in the last seven days of life. Bickel (2019) concluded that there is evidence of increased symptom burden for individuals with PTSD at the end-of-life and that PTSD may be a separate risk factor for terminal delirium.

Two studies Roth (2013) Bickel (2019) identified that pain and PTSD-related symptoms can increase suffering at end of life. Alici et al. (2010) also agrees with Bickel et al. (2020); Roth (2013) and states that previous studies have concluded that PTSD is often underdiagnosed in medical settings, and these results suggest that this may also be true of PTSD-related symptoms near the end of life. Akechi et al. (2004) write that one quarter of the terminally ill cancer patients in their study experienced adjustment disorders and/or major depression. The study, however, could not report on PTSD as PTSD assessment that was started at the beginning of the study were stopped after the first 100 patients. The authors were not clear about why they stopped, and this feature of the study raises questions about the feasibility of PTSD screening and assessment tools at end of life.

Two studies identified that veterans who were older, and living with more co-morbidities that included PTSD, were identified to be more vulnerable than non-veterans (O'Connor et al, 2013; Prince Paul et al 2016). Thus, PTSD screening might need to be further explored as part of the home hospice program.

Therapies

There is a dearth of evidence which has explored interventions among people who are reliving trauma at end of life. Feldman et al. (2014) provide an alternative to existing psychosocial treatments for PTSD that may be effective for people at end of life. Elsewhere, Casarett et al. (2019) studied the effectiveness of increased tetrahydrocannabinol (THC) ratios with cannabidiol (CBD) and PTSD related flashbacks. This study concluded that the evidence to support the use of (CBD) for PTSD-related symptoms is still limited.

This is a developing area which limits the generalisability of the evidence to specific cohorts, populations, culture, or experiences. However, what the data does indicate is that this is an important clinical area worthy of further research.

Conclusion / Implications

This review has identified several important implications for practice and research which include:

1. Further exploration to understand how reliving trauma at end of life manifest & uncover mechanisms of pathogenesis,
2. To develop an understanding of the appropriateness of trauma screening tools and assessment tools for patients reliving trauma at end of life,
3. To develop and test treatments and therapies for patients reliving trauma at end of life, and
4. To understand pain and other symptoms relating to reliving trauma at end of life.

References

Akechi, T., Okuyama, T., Sugawara, Y., Nakano, T., Shima, Y., & Uchitomi, Y. (2004). Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol*, 22(10), 1957-1965. https://doi.org/10.1200/JCO.2004.08.149

Alici, Y., Smith, D., Lu, H. L., Bailey, A., Shreve, S., Rosenfeld, K., Ritchie, C., & Casarett, D. J. (2010). Families' perceptions of veterans' distress due to post-traumatic stress disorder-related symptoms at the end of life. *J Pain Symptom Manage*, 39(3), 507-514. https://doi.org/10.1016/j.jpainsymman.2009.07.011

Bickel, K. E., Kennedy, R., Levy, C., Burgio, K. L., & Bailey, F. A. (2020). The Relationship of Post-traumatic Stress Disorder to End-of-life Care Received by Dying Veterans: a Secondary Data Analysis. *J Gen Intern Med*, 35(2), 505-513. https://doi.org/10.1007/s11606-019-05538-x

Bickel, K. E. K., R. Levy, C. Burgio, K and Bailey, A. (2019). The Relationship of Post-Traumatic Stress Distorder to End-of Life Care received by Dying Veterans: a secondary Data Analysis. *Journal of General Internal Medicine*, 35(2), 505-513. https://doi.org/10.1007/s11606-019-05538-x (Research)

Casarett, D. J., Beliveau, J. N., & Arbus, M. S. (2019). Benefit of Tetrahydrocannabinol versus Cannabidiol for Common Palliative Care Symptoms. *J Palliat Med*, 22(10), 1180-1184. https://doi.org/10.1089/jpm.2018.0658

Feldman, D. B., Sorocco, K. H., & Bratkovich, K. L. (2014). Treatment of posttraumatic stress disorder at the end-of-life: application of the Stepwise Psychosocial Palliative Care model. *Palliat Support Care*, 12(3), 233-243. https://doi.org/10.1017/S1478951513000370

O'Connor, M., Brennan, B., Bloomer, M. J., & Shimoinaba, K. (2013). Vulnerability at the End of Life. *Home Health Care Management & Practice*, 26(3), 134-140. https://doi.org/10.1177/1084822313514978

Prince-Paul, M., Peereboom, K., & Daly, B. J. (2016). Confronting Mortality: Narratives of Military Veterans Enrolled in Home Hospice Care. J Hosp Palliat Nurs, 18(3), 219-226. https://doi.org/10.1097/NJH.0000000000000250

Roth, M. L. H., I. and Katz J.D. . (2013). Relationship Between Pain and Post-Traumatic Stress Symptoms in Palliative Care. *Journal of Pain and Symptoms Management*, 46(2), 182- 191.

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