Trauma-Informed End-of-Life Care

Nursing Homes and Trauma-Informed Care

NHPCO
Leading Person-Centered Care

CMS recognized the importance of providing trauma-informed care for nursing homes in their 2016 regulations and that has only grown more important during COVID-19. Trauma-informed care is a whole organization approach to care that makes sure residents and staff operate in an environment that fosters safety; trustworthiness and transparency; peer support; collaboration and mutuality; and provides empowerment, voice, and choice, and takes into consideration cultural, historical, and gender issues (SAMHSA, 2014). These approaches reduce re-traumatization of anyone connected to the organization.

Trauma informed care makes sense for hospice and palliative care because people who are dying often need to come to terms with earlier life events that may have been traumatic (Ricks-Aherne et al., 2020). As hospice and palliative care professionals, we often care for people in nursing homes. COVID 19 arrived just as many nursing homes were implementing trauma informed care (the rule went into effect in November of 2019). COVID 19 rules made trauma informed care more important for all nursing home residents including those at end of life.

Examples of potentially traumatic events for nursing home residents during COVID 19 that raise the need for trauma informed care:

- Restricted visitors, limited contact, and necessity to wear personal protective equipment may make some residents feel isolated or frightened.
- Lack of contact with family members may make residents feel less safe.
- Some nursing homes required residents to stay in their rooms.
- It is more difficult to have goals of care conversations when residents, family members, and providers are unable to be in the same room.
- Dying residents may be unable to fully benefit from hospice services due to visitation restrictions.

Providing trauma-informed care to nursing home residents at the end of life requires the ability to apply the Substance Abuse and Mental Health Services Administration (SAMHSA; 2014)'s four R's to every client interaction.

The 4 R's

	What does it mean?	What can it look like?
Realizes	Hospice and palliative care providers should **realize** the long-term impacts of trauma on people at end of life.	Older adults at end of life may react to earlier traumas previously hidden or experience new trauma as a result of end-of-life experiences. Complicated family dynamics may be a symptom of unrevealed trauma.
Recognizes	Hospice and palliative care providers should be alert for trauma-related symptoms in dying patients, their families, and the staffs that work with them.	Trauma symptoms may not look like we expect them to. They may include irritability, recklessness, hypervigilance, exaggerated startle response, concentration problems, and sleep disturbance
Responds	Hospice organizations should integrate trauma informed care at all levels of practice.	Consider use of language, policies, and practices that are used with staff, clients, and in interactions with nursing home providers. Discuss concerns in a trauma informed way and work collaboratively with non-hospice staff.

Resist re-traumatization	Be alert to the ways agency policies and procedures can be rigid and inadvertently re-create coercive environments	Any organizational change is a journey, not a destination. Policies and procedures should be reviewed on an ongoing basis for slippage, to ensure that they continue to provide a trauma-informed experience.

Nursing Home Residents and Trauma-Informed Care (Kusmaul & Anderson, 2018).

Assessing for trauma in patients at the end of life is complex due to the variability in how it presents and the many layers of trauma an older adult at the end of life may have experienced. In addition, in cases where cognitive impairment is present, a patient may display trauma-related symptoms in response to a past traumatic event about which adult children are unaware. Certain types of trauma, such as child sexual abuse have stigma attached to them and they were often not discussed in families.

Older adults in nursing homes may have experienced more recent traumas, such as trauma related to medical treatments or ICU stays, or trauma related to the losses experienced in the sequelae of events related to nursing home placement. It is not unusual for an older adult to lose a spouse, receive a significant medical diagnosis, lose their home, and lose their independence in rapid succession. Even someone who was coping quite well with an earlier trauma may find themselves in renewed distress when coping strategies are no longer available or working. A trauma survivor who coped in their own home where they could control who entered and exited, what lights to leave on or off, and so on, may now be living in a shared room where staff comes in and out through the night.

There is a growing population of adolescents and young adults in nursing homes; many because they have outlived their prognosis and their families are no longer able to provide all their care. There is the trauma of losing home, usual caregivers, living in a place geared for a completely different population. And trauma for caregivers who have not cared for this younger population and who are not familiar with many of the conditions they have.

These traumas and environmental stimuli can cause increased distress in patients at the end of life. Hospice and palliative care providers should remain alert to trauma related symptoms, and as they have always done, find ways to relieve suffering and distress and whatever level the patient is interested in (Ricks-Aherne et al., 2020).

Final Thoughts

Trauma informed care hospice and palliative care for nursing home residents follows many of the concepts that hospice is known for- collaborating with patients and families, addressing symptoms and suffering, and walking this journey alongside people at end-of-life. COVID has made this more difficult in many ways in the nursing home setting and hospices should be alert to ways they can address/relieve these symptoms and provide additional support.

Resources

Kusmaul, N. & Anderson, K. (2018). Applying a Trauma-Informed Perspective to Loss and Change in the Lives of Older Adults. *Social Work in Health Care, 57*(5), 355-375.
https://doi.org/10.1080/00981389.2018.1447531
Available full text at: https://mdsoar.org/handle/11603/19046

Ricks-Aherne, E., Wallace, C., & Kusmaul, N. (2020). Practice Considerations for Trauma- Informed Care at End of Life. *Journal of Social Work in End-of-Life and Palliative Care,* 6(4), 313-329. **https://doi.org/10.1080/15524256.2020.1819939**
Available full text at: **https://mdsoar.org/handle/11603/19947**

Substance Abuse and Mental Health Services Administration. *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach*. HHS Publication No. (SMA) 14-4884. Author. **http://store.samhsa.gov/product/SAMHSA-s-Concept-of-Trauma-and-Guidance-for-a-Trauma-Informed-Approach/SMA14-4884**

The Institute on Trauma and Trauma Informed Care Organizational Change Manual **http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/Trauma-Informed-Organizational-Change-Manual0.html**

COVID 19 Considerations for a Trauma Informed Workplace **https://traumainformedoregon.org/wp-content/uploads/2020/03/Considerations-for-COVID-19-Trauma-Informed-Response.pdf**

COVID 19 and Stress (for healthcare providers) **https://www.acesaware.org/heal/covid19/**

52 million caregivers (or one out of every five households) are involved in caregiving to persons aged 18 or over.

The young adult population accounts for 37% of the nursing home residents. [Updated February 2015]

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This resource was developed by the NHPCO Trauma Informed EOL Care Work Group, April 2021.