

Trauma-informed Hospice and End-of-Life Care

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The Issue: Over the past two decades, we have learned about the widespread prevalence of trauma experiences in our society and the long-term implications of that exposure (Felitti et al., 1998; Muskett, 2014). The Adverse Childhood Experiences (ACEs) study found high rates of exposure to physical, emotional, and sexual abuse in a general health care population sample (Felitti et al., 1998). Exposure to trauma, particularly during one's formative years, is linked to poorer physical health outcomes, mental health needs, and exposure to the legal system (Muskett, 2014). The DSM-5 defines trauma as an "exposure to actual or threatened death, serious injury or sexual violence..." (p. 271) that someone may experience, witness, learn about from a close family member or friend, or experience secondhand in a counseling capacity (American Psychiatric Association, 2013). Trauma informed care is an organizational approach to care that assumes that everyone who encounters the system might have had a past traumatic event and seeks to ensure practices avoid re-traumatization (Fallot & Harris, 2008). This approach is critical in end-of-life care because past trauma plays a role in how people react to and cope with pain, terminal illness, and loss.

The Evidence: You may be thinking: Wait, we've all suffered through hardships in life. Why this? Why now? Although pain and suffering are often a fact of life, traumatic events – and our coping responses to such events – differ widely. Trauma is simply experiencing a threatening event, and different people will likely have very diverse responses to the same traumatic event. Some people have no reaction at all. Some develop adverse responses immediately following the event. Still others have maladaptive responses to trauma experiences that lie dormant for long periods only to emerge later in life. Lein et al (2016) found that older adults who had experienced trauma were more likely to engage in self neglect at end of life, which can exacerbate care needs as someone comes into hospice. The very definition of trauma includes being threatened with the prospect of death, which is also a requirement for hospice enrollment. A history of psychological trauma can make managing the symptoms of end-of-life more challenging, as trauma history is associated with post-traumatic stress disorder (PTSD) and higher levels of chronic pain (Sigveland, Ruud, & Hauff, 2017). From a developmental perspective, normal aging includes life review (Davison et al., 2016), which may include the integration of past traumatic events. This review may become more urgent as end of life approaches, and may activate or re-activate trauma related symptoms (Davison et al., 2016).

Additional concerns for the hospice team are past trauma experiences of family members and staff. For family members, experiencing the death of a loved one can be a new traumatic experience that can activate trauma related symptoms. The other consideration is past traumatic experiences that may be activated related to the new trauma, especially traumatic experiences related to the person who is dying. Staff members may also be vulnerable to traumatic reactions due to the repeated exposure to actual death (APA, 2016).

Practice Implications/Recommendations: A trauma informed organization recognizes the prevalence and impact of trauma (SAMHSA, 2016; Ganzel, 2018). Trauma-informed Care Principles are: (1) Safety; (2) Trustworthiness; (3) Choice; (4) Collaboration; and (5) Empowerment (Fallot & Harris, 2008). A

trauma informed agency includes operational practices that ensure everyone experiences these principles. While these principles may seem like just good customer service, they can make a significant difference to trauma survivors. Important questions for agencies to ask themselves include: Do direct care staff feel safe enough to make suggestions about care or report problems? Do families trust the staff to show up when they say they will and deliver the services promised? Are patients and families offered choices about when, where, and how services are provided? Is care planning a collaborative effort that includes all levels of staff and the patient and family?

Most hospice agencies include patients and their families in care planning. A trauma-informed agency includes direct care workers as well. Trauma-informed agency staff make sure to provide consistent services, when, where, and how they say they will, and communicate when they are unable to do so.

While hospice is one of the most collaborative and interdisciplinary service models in the US healthcare system, hospice agencies still must examine their individual practices to meet these goals. There are many tools available to assist agencies with assessing their climate and becoming trauma informed.

Resources and Tools:

- [Training and Technical Assistance on Trauma](#) (Substance Abuse and Mental Health Services Administration- SAMHSA)
- [What is Trauma-Informed Care?](#) (University at Buffalo Institute on Trauma and Trauma Informed Care (ITTIC))
- [Impacts of Trauma in Later Life](#) (inSocialWork Podcast Series, Episode 208)