



Practice Considerations for Trauma-Informed Care at End of Life

Elizabeth S. Ricks-Aherne, Cara L. Wallace & Nancy Kusmaul

To cite this article: Elizabeth S. Ricks-Aherne, Cara L. Wallace & Nancy Kusmaul (2020) Practice Considerations for Trauma-Informed Care at End of Life, *Journal of Social Work in End-of-Life & Palliative Care*, 16:4, 313-329, DOI: [10.1080/15524256.2020.1819939](https://doi.org/10.1080/15524256.2020.1819939)

To link to this article: <https://doi.org/10.1080/15524256.2020.1819939>



Published online: 22 Sep 2020.



Submit your article to this journal [↗](#)



Article views: 6807



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 5 View citing articles [↗](#)



Practice Considerations for Trauma-Informed Care at End of Life

Elizabeth S. Ricks-Aherne^a , Cara L. Wallace^a , and Nancy Kusmaul^b 

^aSchool of Social Work, College for Public Health and Social Justice, Saint Louis University, St. Louis, Missouri, USA; ^bSchool of Social Work, University of Maryland Baltimore County, Baltimore, Maryland, USA

ABSTRACT

Trauma is widespread, and its symptoms can adversely impact wellbeing at end of life, a time when hospice seeks to maximize quality of life. This article reviews research on trauma at end of life, provides an overview of trauma-informed principles, and explores possibilities for applying trauma-informed care through an illustrative case study of a patient at end of life. The case discussion applies findings from the literature using Feldman's Stepwise Psychosocial Palliative Care model as a roadmap. As shown in the case study, trauma-related symptoms may complicate care, making it an important subject of clinical attention for interdisciplinary hospice team members. As part of this team, social workers are particularly well suited to provide more targeted interventions where indicated, though all members of the team should take a trauma-informed approach. Lastly, this article reflects on the need for organizations to take a systems-level approach when implementing trauma-informed care and suggests implications for practice through a universal approach to trauma and the need for trauma-specific assessments and interventions at end-of-life, along with areas for future research.

KEYWORDS

Hospice; palliative care; social work; trauma

Patients at end of life are more likely than the general population to have experienced trauma either in their past or more recently, due to medical interventions and other experiences related to their life-limiting diagnosis (Ganzel, 2018). The risk for having been exposed to at least one traumatic event increases with age, as does the probability that a person may experience multiple traumatic events (Ramsey-Klawnsnik & Miller, 2017), making trauma an important potential factor for older adults and people at end of life. Older adults (age 65 or older) constitute approximately 80% of hospice patients and estimates show that about 70–90% of people in this age range have experienced a prior traumatic event (Ganzel, 2018). Unmitigated trauma-related symptoms of intrusion, avoidance, negative alterations in

CONTACT Cara L. Wallace  cara.wallace@slu.edu  School of Social Work, College for Public Health and Social Justice, Saint Louis University, St. Louis, Missouri 3550, USA.

© 2020 Taylor & Francis Group, LLC

cognitions and mood, and hyperarousal can adversely impact what many people consider a “good death” (Feldman, 2011). These trauma symptoms might result in reduced social supports, challenges in communication with and trust of healthcare providers, complications in the process of life review, barriers to acceptance of death, increased emotional distress, exacerbation of pain symptoms, and decreased overall well-being (Feldman, 2011; Ganzel, 2018).

Given how common traumatic experiences are across the human life course and the negative impacts that trauma-related symptoms can have at end of life, social workers should be trained in trauma-informed approaches, trauma assessment, and trauma intervention (Levenson, 2017; Strand et al., 2014). This paper adds to literature by establishing trauma as a clinical consideration at end of life. Though it is not practical to expect that hospice workers will all become trauma experts, understanding a trauma-informed approach (described in greater depth below) in this setting is particularly important and will allow them to respond to trauma-related distress that may arise at end of life. Hospice and palliative care organizations are generally trained in providing team-based, person-centered care, making them well positioned to provide generalist, trauma-informed care. Following a review of literature, definition of trauma, and description of trauma-informed care, this article applies current knowledge to an illustrative case example (based on a real case with names and identifying details changed to protect privacy), followed by a discussion of practice implications. Additionally, this article provides insights from other care settings where a trauma-informed perspective is already being used.

What is trauma?

Definitions of trauma vary in scope. The U.S. Substance Abuse and Mental Health Services Administration (SAMHSA, 2019), describes trauma as “an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being.” This definition includes but is not limited to full-threshold post-traumatic stress disorder (PTSD). This is important because, among older adults, the presence of sub-syndromal trauma-related symptoms may adversely impact quality of life, with some literature raising the question of using a lower diagnostic criteria threshold for PTSD in older adults (Reynolds, Pietrzak, Mackenzie, Chou, & Sareen, 2016). Furthermore, each person’s perspective on a trauma experience is subjective, and their coping thresholds are unique (Ramsey-Klawnsnik & Miller, 2017).

The expression of trauma-related symptoms varies over the life course and can include delayed onset symptoms, symptom remission, symptom recurrence, and symptom exacerbation (American Psychiatric Association (APA), 2013). Experiences common among older adults and those at end of life, such as shifts in physical or mental health and cognitive impairment, are often associated with symptom variation (APA, 2013; Davison et al., 2016; Feldman, Sorocco, & Bratkovich, 2014; Glick, Cook, Moye, & Kaiser, 2018; Hiskey, Luckie, Davies, & Brewin, 2008; Reynolds et al., 2016). Not all people who experience traumatic events necessarily develop PTSD, with lifetime incidence in the United States estimated to be 8–9% (American Psychiatric Association, 2013). Even trauma-related symptoms that do not meet PTSD diagnostic criteria can cause clinically significant distress, adversely impacting quality of life and ability to receive healthcare in later life and at end of life (Feldman, 2017; Ganzel, 2018; Glick et al., 2018; Kusmaul & Anderson, 2018; Osei-Boamah, Pilkins, & Gambert, 2013).

Yet not all difficult events in a person's life should necessarily be viewed as trauma. In particular, the death of someone significant may lead to bereavement (APA, 2013). However, if the death event itself was traumatic, trauma and/or persistent complex bereavement may co-occur (APA, 2013). They have similar symptoms, including avoidance and intrusive thoughts, and can be difficult to differentiate (APA, 2013). Unlike PTSD, persistent complex bereavement includes “preoccupation with the loss and yearning for the deceased” (APA, 2013). Additionally, some distress at end of life may be unrelated to loss or trauma. However, end-of-life constraints such as limited time and patient energy may make differential diagnosis between trauma, complex bereavement, and other distress impractical. For this reason, the authors recommend using a universal precautions approach within the hospice and other end-of-life settings.

Principles of trauma-informed care

SAMHSA's trauma-informed care guidelines provide a roadmap for agencies that do not provide trauma-specific services. According to SAMHSA (2014), trauma-informed organizations have a basic understanding of the impacts of trauma, recognizes its signs, and responds using trauma-informed approaches across the organization, actively avoiding re-traumatization. There are six principles to providing trauma-informed care: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; and cultural, historical, and gender issues (SAMHSA, 2014). Organizations should ensure the physical and psychological safety of all clients and staff. They should operate with

transparency to build trust with those who serve and whom they serve. By utilizing peer support, they empower those who have experienced trauma and their stories to be agents of healing. Organizations promote collaboration through shared decision-making, seeking to minimize power differentials. They use a strengths-based approach to empower clients and staff to engage in meaningful decision-making activities. Finally, organizations recognize historical trauma and power differentials related to identities and work to provide responsive, culturally-appropriate services.

Trauma and end of life

Numerous articles note the paucity of research exploring trauma and older adults (Dinnen, Simiola, & Cook, 2015; Hiskey et al., 2008; Osei-Boamah et al., 2013; Ramsey-Klawnsnik & Miller, 2017) and trauma and end of life (Ganzel, 2018; Glick et al., 2018; Woods, 2003). A significant portion of the available literature focuses on veterans (Glick et al., 2018; Hiskey et al., 2008). One study found that although veterans reported PTSD symptoms less often than pain or dyspnea, when they did report them, family members described those symptoms as being more distressing to the veterans than dyspnea (Alici et al., 2010). PTSD symptoms were also associated with lower satisfaction with emotional support in end-of-life care, communication problems, and the perception of less attention being paid to the dying person's dignity and well-being (Alici et al.). People with a history of trauma and those with trauma-related symptoms report higher levels of pain at end of life (Ganzel, 2018). Glick and colleagues (2018) note that evidence points to a "bidirectional relationship" between pain and PTSD: those with PTSD report higher pain levels and people with pain report more trauma-related symptoms. Trauma-related symptoms fundamentally shift how a person experiences the world and these changes can have an especially pointed impact at end of life. Trauma symptoms have a negative impact on quality of life and increase the likelihood of emotional distress and comorbid mental health issues such as anxiety, depression, and substance use disorders (Feldman, 2011; Ganzel, 2018).

In the context of overlapping symptoms and complex comorbidities, accurately assessing for trauma can be challenging, but important. The risk of missing the cause of a symptom brings the risk of mistreating the symptom and inadequately alleviating distress (Feldman & Periyakoil, 2006). It is also essential to screen for common comorbidities, such as depression, anxiety, substance use disorder, and suicidality (Glick et al., 2018). While valid and reliable assessment tools exist for PTSD, no research validates them for use at end of life (Glick et al., 2018).

A person at end of life may have recent traumatic experiences, or earlier traumas that may be triggered during end-of-life experiences, including by the dying process itself (Feldman & Periyakoil, 2006). Some symptoms, such as intrusion, are more common at end of life than full-threshold PTSD (Feldman & Periyakoil, 2006). SAMHSA (2014) emphasizes an *event, experience, effect* framework that acknowledges the individual trauma journey. While certain types of events such as abuse, disasters, and accidents can raise the likelihood of trauma-related symptoms, it is someone's experience of that event (how they understand what happened), and the after-effects, or symptoms specific to that person that make it significant, not an official diagnosis (SAMHSA, 2014). Trauma-related symptoms may impact social support networks and communication with healthcare providers. People with PTSD often have stressed social relationships and fewer social supports (King et al., 2006), which can result in fewer informal caregivers available to help at end of life (Glick et al., 2018; Kaiser, Seligowski, Spiro, & Chopra, 2016). They also often have difficulty trusting authority figures, such as medical providers, which can make the difficult conversations that must occur near end of life even harder (Glick et al.). This distrust impacts disclosure of sensitive information (Jeffreys, Leibowitz, Finley, & Arar, 2010), and, combined with avoidance of upsetting situations and stimuli, can adversely impact healthcare decision-making, delaying important end-of-life decisions when time is scarce and precious. This distrust can also lead to nonadherence to medical advice (Feldman, 2011) or incomplete reporting of symptoms to medical providers. Green and colleagues (2016) suggest that with appropriate training of the medical providers this communication can be improved.

Current literature reveals that many older adults and people at end of life are impacted by trauma (Krause et al., 2004; Pietrzak et al., 2012). There is significant overlap between the symptoms and needs of older adults and people at end of life, and specific subgroups, such as veterans, may have some additional specific factors for consideration. Overall, there is a need for greater adoption of trauma-informed approaches by healthcare organizations, including hospice and palliative care providers.

A model for intervention

Interventions for trauma at end of life include both pharmacological and psychosocial options. Social workers are trained to offer the latter. Based on the client's strengths and needs, these interventions fit well with person-centered approaches in long-term care settings, and may include psychoeducation of the client and their loved ones, normalizing end-of-life and trauma-related experiences, and education and training for the staff

(Feldman & Periyakoil, 2006; Glick et al., 2018). Feldman (2011) offers a framework for providing trauma intervention at end of life: the Stepwise Psychosocial Palliative Care Model (see also Feldman, 2017; Feldman et al., 2014). The model moves the practitioner through assessment and intervention across three stages, moving from interventions that require the least effort by the dying person toward those that require more effort, progressing only if the prior phase has not adequately palliated the trauma-related discomfort and the person has sufficient time, stamina, and desire to proceed (Feldman, 2011). This assessment requires communication across the interprofessional team (Feldman, 2017), defined by the Medicare Hospice benefit as minimally including a physician, nurse, social worker, and pastoral/other counselor and often inclusive of care requiring other team members, such as physical, occupational, or speech therapists, home health aide, homemaker, pharmacist, and dietary or additional counselors (SSA, Title 42 section 1861). The model is designed to be flexible and a step that is already underway would likely continue concurrently with subsequent steps. Trauma-informed hospice care is best approached collaboratively, as each team member's observations may be needed in assessment, and Stage I interventions are likely to be applied by all team members (Feldman, 2017).

The first stage in this model focuses on practitioners using interventions to alleviate distress by taking actions on behalf of clients (Feldman, 2017; Feldman et al., 2014). As members of the interdisciplinary team build rapport with a client, they may learn of distressing aspects of a client's situation that they could take collaborative, direct action to ameliorate (Feldman et al., 2014). While this runs counter to typical social work approaches of empowering clients to solve their own problems, it addresses the reality that many hospice clients may have little time and energy to take such actions on their own (Feldman et al., 2014).

During stage II of the model, intervention shifts to offering tools for the patient to use on their own to cope with distress as it arises (Feldman, 2017). Psychoeducation and coping support are interventions that hospice social workers and other members of the team may be already equipped to offer (National Coalition for Hospice and Palliative Care, 2018; NASW, 2004). Providing information about prevalence and potential impacts of trauma can reassure patients and family members about some of the unpleasant symptoms one is experiencing (Feldman, 2017). Social workers may wish to frame this information carefully, normalizing it to minimize any feelings of stigma or shame.

Similar to progression to stage II, before moving to stage III interventions, the hospice team should assess effectiveness of previous interventions (Feldman, 2017). Unlike Stages I and II, Stage III interventions involve

treatment specific to full-threshold PTSD. Qualified personnel, such as a Licensed Clinical Social Worker (LCSW) or Licensed Professional Counselor (LPC), must complete differential diagnosis for PTSD prior to moving to stage III. Interventions in stage III entail thinking and speaking about trauma memories during sessions and should only be used if trauma symptoms are not adequately relieved and if the patient's energy, prognosis, ability, and willingness to continue have been sufficiently assessed (Feldman, 2017). This stage is less likely to be utilized for hospice patients, based on limited prognoses. If indicated, any trauma-focused approach can be used during stage III, with eye movement desensitization and reprocessing (EMDR) therapy as one option (Feldman, 2017; Ganzel, 2018). Some hospices are not equipped to provide this level of intervention themselves and outside referrals may be needed.

Case example

Richard is 82 and has Parkinson's disease. He enrolled in hospice after experiencing significant decline from his disease. Richard and his wife, Helen, married 60 years, live with their daughter, Christine. During initial visits with Richard, it became apparent that he enjoys talking about the life he and his wife had "back home." Per Christine, her parents had been living in the home where they raised their children until 2 years ago, but had moved in with her across the country after the unexpected death of her oldest sister, Katrina. At times Richard enjoys reminiscing about his daughters' childhood and other memories of Katrina. Other times he becomes agitated and angry at the mention of her. Christine and her spouse both work, but she has some flexibility and is gone from the home for around half of the work week.

Richard describes himself as artistic and creative; he loves music, painting, and woodworking. He expresses feeling "old" and "weak" and struggles with not being able to do all he wants. His progressing illness has made it too difficult for him to regularly engage in these activities. Helen also has multiple health challenges, primarily heart disease, and is very hard of hearing making it particularly difficult for Richard and Helen to communicate. Richard and Helen have become involved at their daughter's church, but miss their home community.

Helen and Christine are increasingly worried that Richard will fall, as he does not like to use his walker despite increasing weakness. He has also been getting up at night and even though he and Helen share a bed, she generally does not hear him. He says he has a hard time sleeping, because of distressing dreams and recurring, intrusive thoughts as he lay awake. He is often tired during the day and falls asleep mid-activity but says he "does

not like to take rests.” Richard often becomes agitated while receiving assistance with his activities of daily living, such as using the bathroom, changing clothing, or bathing. He has increasing confusion and forgetfulness and sometimes says that his wife’s collectibles which adorn their bedroom “come to life.”

Case discussion and application of trauma-informed approach

Trauma-informed care is a whole organization approach that considers that everyone (staff, clients, and family members) may have experienced a past traumatic event that needs to be taken into consideration (SAMHSA, 2014). In hospice, where care is provided by an interdisciplinary team, all staff should have knowledge of trauma and be comfortable approaching care through this lens. Feldman’s model, outlined above, provides a road map to guide hospice providers from this whole organization approach through the care of a specific resident, which we apply to Richard here. Though full fidelity to each detail of Feldman’s model may be impractical in some instances in clinical practice, the model allows us to conceptualize approaches to addressing trauma at end of life.

Stage I: Palliate immediate discomfort and provide social supports

Principle of universal precaution. In the case of Richard, the interdisciplinary hospice team might take a trauma-informed approach by using the principle of universal precaution (SAMHSA, 2014), operating under the assumption that any client may have a trauma background and approaches should seek to prevent possible retraumatization. This aligns with the first stage in the Stepwise Psychosocial Palliative Care Model (Feldman, 2011), as a universal precautions approach serves as a preventative measure. Where possible, prevention of distress is preferable to subsequent mitigation of it.

Worsening Parkinson’s disease involves progressive loss of physical function, including not only motor symptoms, but others, such as sleep disturbances and psychosis (Parkinson’s Foundation, n.d.), which may appear similar to those of trauma-related origin. A universal precautions approach recognizes that symptoms could be related to effects of trauma in addition to or in combination with those related to physical disease. For example, Richard’s sleep disturbances or avoidance, visual perceptions (collectibles “come to life”), confusion, and forgetfulness could be related to his Parkinson’s disease, but also to the effects of trauma.

The case example details numerous losses for Richard, along with several clues about potential traumas. Richard is experiencing the physical and cognitive changes that come with Parkinson’s disease, which includes some

loss of control of his body, physical limitations, difficulty communicating with his wife, the secondary loss of his hobbies (which may connect with his sense of identity and his coping skills), and even his sense of self (he describes himself as “old” and “weak”). His move across the country relates to the loss of his community, existing support network, and a familiar setting and sense of what to expect from the world around him. Moving in with his daughter decreased his sense of privacy and independence, with another person’s concern and input into his daily decisions, such as whether to use a walker. The move was also sudden, following his oldest daughter’s unexpected death. Such sudden, unexpected deaths can be traumatic, especially depending on the circumstances surrounding the death. He may not have had an opportunity to say goodbye or make amends with her, the death itself may have been traumatic, and he likely felt little control over any of it. These factors could contribute to an increased likelihood for complicated grief. Complicated grief, which consists of separation distress and grief symptoms (Boelen & Lenferink, 2020) is distinct from PTSD, but shares symptoms such as disruptive thoughts and avoidance (Shear et al., 2011). If complicated grief were to occur, it could interact with trauma from the death experience or other life events and it would be a risk factor for developing symptomatic PTSD (Prigerson et al., 2009). These are only the losses and traumas that Richard and his family have shared; adopting a precautionary approach assumes that there may be additional, as-yet unnamed ones.

Move beyond prevention to active steps. Using empathy, the hospice team can validate Richard’s emotions and experiences and reassure him by providing clear explanations for his physical symptoms. To help relieve environmentally-related discomfort, the team can consider how the physical home environment might contribute to his discomfort (Feldman, 2017). Though Richard has lived with his daughter for two years, the surroundings may still feel unfamiliar, especially during moments of disorientation. Ideas for action may include inquiring about the kind of lighting Richard used at his old house at night when sleeping. Dim night lights might help Richard to reorient himself during periods of wakefulness. Richard may also be comforted to have familiar furniture from “back home” in view from his bed. The use of an audio monitor is also an unobtrusive way for Richard to remain sleeping in his own bed, while allowing his daughter to be alerted if he falls or needs help when his wife does not waken to the noise.

The hospice team can also make efforts to learn more about Richard’s background and experiences, so they can make educated guesses about what things might elicit trauma-related symptoms. For example, after learning about Richard’s agitation when assisted with activities of daily living,

they might guess that Richard is grieving his lost physical abilities, these changes threaten his identity or masculinity, feelings of powerlessness are related to disease-related confusion, or that there is undisclosed past trauma. It is not essential to know the exact reason for these being uncomfortable experiences, but once the team is aware that receiving physical assistance seems to be distressing for Richard, they can develop a plan for action. Coaching aides and team members to ask permission before touching Richard's body and then communicating clearly where and how they will be touching him is one practical approach. Members of the care team can also ask Richard how he would like to be assisted with these activities and then follow his preferences and directions to help him regain a sense of agency during these interactions.

Difficulty in communication between Richard and Helen is another upsetting issue for Richard and could exacerbate other stressors. Though the hospice team is present for Richard's health, they might suggest that Helen have her hearing evaluated, if she has not recently. Other communication strategies might also be helpful, such as a communication board, for Helen to watch Richard's lips as he speaks, and for Christine to repeat Richard's words loudly for Helen when they are together. Though the changes would not fully resolve the issue, improved marital communication would enhance one of Richard's most important social supports.

Reassessment and next steps. Reassessment of Richard's trauma-related symptoms following these interventions is important. Even if there are reduced symptoms, the social worker should evaluate the duration of effects and ongoing reoccurrences and consult with other members of the team. For Richard, the effects may seem brief, and symptoms may recur without continued active palliation efforts. Additionally, he may continue to have challenges based on issues not yet addressed during stage I, particularly his occasional agitation when reminiscing about his deceased daughter and his intrusive thoughts while trying to sleep at night. The team can start by following Richard's lead on conversations about Katrina—listening and engaging when Richard brings her up, but not mentioning her during other conversations of life review. Considerations for continuing to the next stage include assessing Richard's ability and willingness to engage in psychoeducation and sessions to develop coping skills.

Stage II: provide psychoeducation and enhance coping skills

The interprofessional team should confer about Richard's symptoms following implementation of stage I and only proceed to stage II if symptoms are not adequately alleviated (Feldman, 2017). This might mean that the team has identified additional details about past events, such as his daughter's death or

move to a new environment, connecting observed symptoms directly to experiences of trauma and/or PTSD. If the team discovers that the symptoms persist, they can provide psychoeducation about trauma to Richard and his family. Psychoeducation is a useful intervention to normalize reactions to trauma, increase understanding, and to teach coping skills (Whitworth, 2016). Psychoeducation should be offered often, in the context of a supportive relationship, and involve elements of resiliency and recovery including increasing understanding for how trauma impacts an individual's function (Whitworth). Additionally, training Richard on relaxation techniques and mindfulness-based acceptance skills could help him cope with distressing symptoms (Whitworth), regardless of their basis in trauma, grief, or disease progression.

Stage III: treat specific trauma issues

As with the transition from Stages I to II, the interprofessional team should confer about Richard's symptoms before considering a move from Stages II to III and only consider Stage III if Stage II fails to alleviate trauma-related symptoms. However, additional considerations for implementing Stage III include the need for differential diagnosis of PTSD by qualified personnel, such as an LCSW or LPC, and a full evaluation of Richard's energy, remaining time, and interest in pursuing trauma treatment.

Discussion

The focus of hospice is on maximizing quality of life during the time that a person has remaining as they approach death. Since trauma can have such adverse impacts on quality of life and the associated symptoms can complicate care and life review at end of life, trauma deserves clinical attention of interdisciplinary hospice team members, including social workers. Trauma-informed care's universal approach is useful in a setting with an interdisciplinary team because it can be provided by anyone, once they are trained. While all staff should be trained on trauma's impacts and trauma-informed principles, no specific degree or qualifications are required to provide this care. Applying Feldman's model (2017) to Richard's care provides: insight for a universal precautions approach in the consideration of trauma in end-of-life care; structure to guide assessment and interventions at end of life; identification of needed research; and the call for a systems-level approach in addressing trauma at end of life.

Determining the impacts of trauma: differential diagnosis and universal precautions

Trauma researchers and practitioners agree that best practice for trauma treatment involves a thorough assessment of past traumatic experiences

(Muskett, 2014) and diagnosis of trauma-related conditions if applicable. Certainly, in many therapeutic contexts across the lifespan, assessment and differential diagnosis of trauma-related conditions is critical for treatment choices and outcomes. Yet for some patients at end of life, differential diagnosis may not be possible or welcome (Ganzel, 2018). In situations where trauma treatment is not or cannot be the focus, a universal precautions approach minimizes the risk of doing harm. The authors argue that this is the case in end-of-life care, at least for stages I and II of Feldman's (2017) model. Feldman's approach is useful because it provides room to recognize and address trauma without necessarily having to officially diagnose it. Otherwise, potential trauma-related symptoms could go unrecognized and unmitigated, leading to preventable suffering. The case discussion offered here presents instances where trauma could exist, and trauma-informed approaches could mitigate symptoms without requiring differential diagnosis, though diagnosis by a qualified mental health professional, such as a Licensed Clinical Social Worker, would be necessary before proceeding to Stage III interventions.

Reynolds and colleagues (2016) noted that older adults are more likely to present with trauma-related symptoms that are sub-threshold for PTSD, but are clinically relevant, nonetheless. Glick and colleagues (2018) suggested that adjusted diagnostic criteria for people at end of life may be necessary, since the symptom presentation may be so different than the general population. Such adjusted assessment criteria and scales should be developed to aid clinicians in more effective assessment and differential diagnosis of trauma at end of life. Since hospice social workers do not need to make a mental health diagnosis to be compensated for their services, they are well-positioned to move beyond DSM PTSD criteria to use a broader trauma lens to support their clients' well-being wherever they may fall on this trauma spectrum.

Assessments and interventions

While valid and reliable assessments exist for PTSD, none have been tested for use with people at end of life (Glick et al., 2018). This should be remedied with further research. Similarly, research is needed for trauma assessments to use with people with dementia. Like assessments, there is a need for more evidence-based trauma interventions for use with people at end of life. Feldman has taken an important first step with the Stepwise Psychosocial Palliative Care model (2011), which provides a helpful framework, but he offers only minimal details into evidence supported treatment options for the clinician–client team that might require active treatment of the trauma in Phase III. This reflects a lack of specific research in this area,

but other treatments may be appropriate. It may be that modified protocols for existing therapies work for this population, such as trauma-focused cognitive behavioral therapy (TF-CBT), prolonged exposure, and EMDR, however, research is needed to explore these possibilities. Additionally, many people naturally engage in life review during older adulthood and end of life, but the resulting reengagement with traumatic memories can be triggering. A better understanding is needed of the benefits, risks, and potential modifications to clinician-facilitated life review interventions for use in people experiencing trauma at end of life.

Areas for further research

Following SAMHSA's broader definition of trauma begs the question of how to define trauma in order to measure it, if the more limited definition of PTSD is insufficient to capture clinically significant distress. To begin answering this question, further research could investigate what kinds of events and traumatic stressors have the greatest impact on trauma-related symptoms, hospice utilization, pain management, and quality of life at end of life. Additional qualitative research could investigate the reported experiences of dying people with a trauma history to identify other areas for further research exploration.

Because the literature on trauma at end of life is largely based on studies using veteran samples, it may hold a gender bias toward men. Further research should address this by exploring the experiences of women and transgender people. Similarly, more information is needed about the impact of trauma experiences at end of life that are not related to military service or combat, such as Adverse Childhood Events and chronic stressors such as racism (Janssen, *n.d.*). Research in this area could also begin to evaluate whether it is useful to differentiate between traumatic experiences that meet the American Psychiatric Association's Diagnostic and Statistical Manual 5 criterion A for PTSD (2013) and other traumas that do not.

Systems-level approach

SAMHSA's "Concept of Trauma and Guidance for a Trauma-Informed Approach" (2014) calls for adoption of a trauma-informed approach with all people throughout an organization, across all departments. Such comprehensive culture change is challenging and requires buy-in at all levels of the organization. For an example of another field undergoing fundamental changes in approaches to their work with clients, practitioners working to effect change in their organization may look to the culture change efforts toward person-directed care for older adults as spearheaded by the Pioneer

Network (Pioneer Network, n.d.). Hospice organizations that adopt trauma-informed approaches must honestly evaluate their capacity to assess and address trauma. Stage I approaches are universal and can be provided by all staff once properly trained. Stage II assessments, differential diagnosis prior to Stage III interventions, and implementation of specialized trauma interventions in Stage III require the skills of qualified clinical personnel such as licensed clinical social workers, as required by state and federal law. Stage III interventions that directly address trauma require qualified personnel to administer and hospice agencies must be prepared to employ or refer to ensure competence in implementing these approaches. This self-assessment of capacity is essential for organizational level implementation of trauma-informed care.

Trauma is a common experience over the life course (Benjet et al., 2016; Kilpatrick et al., 2013; Strand et al., 2014) and even subsyndromal trauma-related symptoms can cause clinically significant distress for people at end of life (Ganzel, 2018), reducing their quality of life during precious remaining days. Trauma symptoms can be palliated (Feldman, 2011) and the focus of hospice is maximizing a person's quality of life in their remaining time, so it is pertinent that social workers and other members of interdisciplinary hospice and palliative care teams assess for and respond to trauma in people at end of life.

ORCID

Elizabeth S. Ricks-Aherne  <http://orcid.org/0000-0002-2909-0973>

Cara L. Wallace  <http://orcid.org/0000-0002-6739-1910>

Nancy Kusmaul  <http://orcid.org/0000-0003-2278-8495>

References

- Alici, Y., Smith, D., Lu, H. L., Bailey, A., Shreve, S., Rosenfeld, K., ... Casarett, D. J. (2010). Families' perceptions of veterans' distress due to post-traumatic stress disorder-related symptoms at the end of life. *Journal of Pain and Symptom Management*, 39(3), 507–514. doi:10.1016/j.jpainsymman.2009.07.011
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Benjet, C., Bromet, E., Karam, E. G., Kessler, R. C., McLaughlin, K. A., Ruscio, A. M., ... Koenen, K. C. (2016). The epidemiology of traumatic event exposure worldwide: Results from the World Mental Health Survey Consortium. *Psychological Medicine*, 46(2), 327–343. doi:10.1017/S0033291715001981
- Boelen, P. A., & Lenferink, L. I. M. (2020). Comparison of six proposed diagnostic criteria sets for disturbed grief. *Psychiatry Research*, 285, 112786. Online Publication. doi:10.1016/j.psychres.2020.112786
- Davison, E. H., Kaiser, A. P., Spiro, A., Moye, J., King, L. A., & King, D. W. (2016). From late-onset stress symptomatology to later-adulthood trauma reengagement in aging

- combat veterans: Taking a broader view. *The Gerontologist*, 56 (1), 14–21. doi:10.1093/geront/gnv097
- Dinnen, S., Simiola, V., & Cook, J. M. (2015). Post-traumatic stress disorder in older adults: A systematic review of the psychotherapy treatment literature. *Aging & Mental Health*, 19(2), 144–150. doi:10.1080/13607863.2014.920299
- Feldman, D. B. (2011). Posttraumatic stress disorder at the end of life: Extant research and proposed psychosocial treatment approach. *Palliative & Supportive Care*, 9(4), 407–418. doi:10.1017/S1478951511000435
- Feldman, D. B. (2017). Stepwise psychosocial palliative care: A new approach to the treatment of posttraumatic stress disorder at the end of life. *Journal of Social Work in End-of-Life & Palliative Care*, 13(2–3), 113–133. doi:10.1080/15524256.2017.1346543
- Feldman, D. B., & Periyakoil, V. S. (2006). Posttraumatic stress disorder at the end of life. *Journal of Palliative Medicine*, 9(1), 213–217. doi:10.1089/jpm.2006.9.213
- 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. *Palliative & Supportive Care*, 12(3), 233–243. doi:10.1017/S1478951513000370
- Ganzel, B. L. (2018). Trauma-informed hospice and palliative care. *Gerontologist*, 58(3), 409–419. doi:10.1093/geront/gnw146
- Glick, D. M., Cook, J. M., Moye, J., & Kaiser, A. P. (2018). Assessment and treatment considerations for post traumatic stress disorder at end of life. *American Journal of Hospice & Palliative Care*, 35(8), 1133–1139. doi:10.1177/1049909118756656
- Green, B., Saunders, P., Power, E., Dass-Brailsford, P., Schelbert, K.B., Giller, E., ... Mete, M. (2016). Trauma-informed medical care: Patient response to a primary care provider communication training. *Journal of Loss & Trauma*, 21(2), 147–159. doi:10.1080/15325024.2015.1084854
- Hiskey, S., Luckie, M., Davies, S., & Brewin, C. R. (2008). The emergence of posttraumatic distress in later life: A review. *Journal of Geriatric Psychiatry and Neurology*, 21(4), 232–241. doi:10.1177/0891988708324937
- Janssen, S. (n.d.). Considering Racial Trauma in African American Underuse of Hospice/ Palliative Care. *Social Work Today*. Retrieved from https://www.socialworktoday.com/archive/exc_0219.shtml.
- Jeffreys, M., Leibowitz, R., Finley, E., & Arar, N. (2010). Trauma disclosure to health care professionals by veterans: Clinical implications. *Military Medicine*, 175(10), 719–724. doi:10.7205/MILMED-D-10-00054
- Kaiser, A. P., Seligowski, A., Spiro, A., & Chopra, M. (2016). Health status and treatment-seeking stigma in older adults with trauma and posttraumatic stress disorder. *Journal of Rehabilitation Research and Development*, 53(3), 391–402. doi:10.1682/JRRD.2015.03.0039
- Kilpatrick, D. G., Resnick, H. S., Milanak, M. E., Miller, M. W., Keyes, K. M., & Friedman, M. J. (2013). National estimates of exposure to traumatic events and PTSD prevalence using DSM-IV and DSM-5 criteria. *Journal of Traumatic Stress*, 26(5), 537–547. doi:10.1002/jts.21848
- King, D., Taft, C., King, L., Hammond, C., & Stone, E. (2006). Directionality of the association between social support and posttraumatic stress disorder: A longitudinal investigation. *Journal of Applied Social Psychology*, 36(12), 2980–2992. doi:10.1111/j.0021-9029.2006.00138.x
- Krause, N., Shaw, B. A., & Cairney, J. (2004). A descriptive epidemiology of lifetime trauma and the physical health status of older adults. *Psychology and Aging*, 19(4), 637–648. doi:10.1037/0882-7974.19.4.637

- 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. doi:10.1080/00981389.2018.1447531
- Levenson, J. (2017). Trauma-informed social work practice. *Social Work*, 62(2), 105–113. doi:10.1093/sw/swx001
- Maguen, L. (n.d.). *Moral Injury in the Context of War*. Retrieved from the U.S. Department of Veterans Affairs website: https://www.ptsd.va.gov/professional/treat/cooccurring/moral_injury.asp.
- Muskett, C. (2014). Trauma-informed care in inpatient mental health settings: A review of the literature. *International journal of mental health nursing*, 23(1), 51–59.
- National Association of Social Workers (NASW). (2004). *NASW Standards for Palliative and End-of-Life Care*. Retrieved from <https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0>.
- National Coalition for Hospice and Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). Richmond, VA: NCHPC. Retrieved from https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf.
- Osei-Boamah, E., Pilkins, B. J., & Gambert, S. R. (2013). Prevention and screening of post-traumatic stress disorder in older adults. *Clinical Geriatrics*, 21(7). <https://www.consultant360.com/articles/prevention-and-screening-post-traumatic-stress-disorder-older-adults>.
- Parkinson's Foundation. (n.d.). *Hallucinations/delusions*. <https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Hallucinations-Delusions>.
- Pietrzak, R. H., Goldstein, R. B., Southwick, S. M., & Grant, B. F. (2012). Psychiatric comorbidity of full and partial posttraumatic stress disorder among older adults in the United States: Results from wave 2 of the National Epidemiologic Survey on Alcohol and Related Conditions. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 20(5), 380–390. doi:10.1097/JGP.0b013e31820d92e7
- Pioneer Network. (n.d.). *Case studies in person-directed care*. <https://www.pioneernetwork.net/wp-content/uploads/2016/10/Case-Studies-in-Person-Directed-Care.pdf>.
- Prigerson, H., Horowitz, M., Jacobs, S., Parkes, C., Aslan, M., Goodkin, K., ... Maciejewski, P. (2009). Prolonged grief disorder: Psychometric validation of criteria proposed for DSM-V and ICD-11. *PLoS Medicine*, 6(8), e1000121. doi:10.1371/journal.pmed.1000121
- Ramsey-Klawnsnik, H., & Miller, E. (2017). Polyvictimization in later life: Trauma-informed best practices. *Journal of Elder Abuse and Neglect*, 29(5), 339–350. doi:10.1080/08946566.2017.1388017
- Reynolds, K., Pietrzak, R. H., Mackenzie, C. S., Chou, K. L., & Sareen, J. (2016). Post-traumatic stress disorder across the adult lifespan: Findings from a nationally representative survey. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 24(1), 81–93. doi:10.1016/j.jagp.2015.11.001
- Shear, M. K., Simon, N., Wall, M., Zisook, S., Neimeyer, R., Duan, N., ... Keshaviah, (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 28(2), 103–117. doi:10.1002/da.20780.
- Social Security Act. (1982). Section 1861. 42 U.S.C. § 1395x Retrieved from http://www.ssa.gov/OP_Home/ssact/title18/1861.htm.
- Strand, V. C., Abramovitz, R., Layne, C. M., Robinson, H., & Way, I. (2014). Meeting the critical need for trauma education in social work: A problem-based learning approach. *Journal of Social Work Education*, 50(1), 120–135. doi:10.1080/10437797.2014.856235

- Substance Abuse and Mental Health Services Administration (SAMHSA). (2014). *SAMHSA's concept of trauma and guidance for a trauma-informed approach*. <https://store.samhsa.gov/product/SAMHSA-s-Concept-of-Trauma-and-Guidance-for-a-Trauma-Informed-Approach/SMA14-4884.html>.
- Substance Abuse and Mental Health Services Administration (SAMHSA). (2019). *Trauma and violence*. <https://www.samhsa.gov/trauma-violence>.
- Whitworth, J. D. (2016). The role of psychoeducation in trauma recovery: Recommendations for content and delivery. *Journal of Evidence-Informed Social Work*, 13(5), 442–451. doi:10.1080/23761407.2016.1166852
- Woods, A. B. (2003). The terror of the night: Posttraumatic stress disorder at the end of life. *Journal of Hospice and Palliative Nursing*, 5(4), 196–204. doi:10.1097/00129191-200310000-00012