Forum

Trauma-Informed Hospice and Palliative Care

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Abstract

This review highlights the need to integrate trauma-informed practices into hospice and palliative care. The pervasiveness of psychological trauma exposure has been established in the general population and among the elderly adults. Moreover, there is emerging evidence for multiple additional opportunities for exposure to psychological trauma at or near the end of life. For example, many people experience intensive medical interventions prior to their admission to hospice and/or palliative care, and there is increasing recognition that these interventions may be traumatic. These and related opportunities for trauma exposure may combine synergistically at the end of life, particularly in the presence of pain, anxiety, delirium, dementia, or ordinary old age. This, in turn, can negatively affect patient mental health, well-being, behavior, and reported experience of pain. This review closes with suggestions for future research and a call for universal assessment of psychological trauma history and symptoms in hospice and palliative care patients, along with the development of palliative trauma intervention strategies appropriate to these populations.

Keywords: Trauma, Palliative care, Hospice, End of life, Stress, PTSD, Critical care

Hospice and palliative care stand in opposition to pain and fear, particularly as the end of life approaches. Often, however, the implementation of such care is preceded by months or years of escalating illness, health emergencies, intensive care unit (ICU) stays, major medical interventions, and their increasingly intolerable side effects. As the point of admission to palliative or hospice care approaches, these patients often experience the escalating consequences of disease progression and intervention failure. Although the term “suffering” is often used to describe such experiences, the term psychological trauma—along with its clinical implications—is less often applied.

This is demonstrated by the scarcity of information about psychological trauma as it relates to the experiences of hospice and palliative care patients. For example, recent searches in PubMed (National Library of Medicine, Bethesda, MD) using the terms “hospice” and either “psychological trauma” or “PTSD” (the abbreviation for post-traumatic stress disorder) returned only two articles addressing trauma in hospice patients themselves (rather than their caregivers). Significantly, both of these focus on military veterans (Antoni et al., 2012; Feldman & Periyakoil, 2006: discussed later). PubMed searches of “trauma-informed care” combined with “hospice” or “palliative” resulted in no hits. This illustrates the emerging nature of the discussion on trauma-informed hospice and palliative care.

Roadmap

The present review argues that many different types of hospice and palliative care patients (not only veterans) are likely to have histories of psychological trauma, and that skillful awareness of this point improves patient care. In short, there is an overall need for hospice and palliative care to be trauma-informed. This thesis is developed...
in four parts. The Introduction section provides definitions of terms and lays out the reasons that psychological trauma exposure is of clinical concern in hospice and palliative care. The section on Trauma Exposure in Hospice and Palliative Care Populations contains a brief review of the epidemiology of psychological trauma exposure in the general population and discusses the types of psychological trauma that are likely concentrate in hospice and palliative care populations. The section on Why Trauma Matters contains a brief review of the physiological and behavioral impact of psychological trauma, with special emphasis on how it may affect clinical outcomes in hospice and palliative care populations. The review closes in the Directions for Future Research section with suggestions for future research in trauma-informed hospice and palliative care based on ideas that are emerging in the field now, including trauma assessment and trauma-focused interventions that are appropriate to these populations.

The Problem
Psychological trauma exposure and trauma-related symptoms are of clinical concern because they are associated with increases in reported distress and perceived pain in medical patients (Otis, Keane, & Kerns, 2003). In addition, patient–staff collaboration and patient care may be compromised because patients struggling with trauma histories are more likely to be anxious, depressed, distrustful, angry, and/or avoidant of trauma reminders, which may include medical settings and medical personnel (e.g., see Feldman, Sorocco, & Bratkovich, 2014; Kubany, Gino, Denny, & Torigoe, 1994). For these reasons, understanding, assessment, and palliation of patients’ trauma symptoms is a topic of strong relevance in hospice and palliative care.

Definitions
This review argues for a trauma-informed approach to hospice and palliative care. I begin with definitions of the terms involved.

Trauma
For brevity, the terms psychological trauma and trauma will be used interchangeably in this discussion (but should be distinguished from physical traumas, such as contusions of the liver or brain). Psychological traumas are defined as events that threaten death, serious injury, or sexual violence to self or other (e.g., rape, serious accident, or life-threatening illness); these must be directly experienced or personally witnessed, although some indirect experiences may also qualify as traumas (American Psychiatric Association [APA], 2013). Under this updated definition, threat to one’s life or threat of personal injury due to illness is now encompassed within the category of psychological trauma. This means that medical patients can now be evaluated as having illness-related trauma disorders instead of “adjustment” disorders, as was the case in the past (e.g., Derogatis et al., 1983).

Trauma exposure is associated with persistent alterations in brain structure and function (Ganzel & Morris, 2016; Ganzel, Morris, & Wethington, 2010) and immediate and lifetime increases in an array of mental disorders (e.g., anxiety, depression, PTSD: Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). Trauma exposure also predicts negative long-term health outcomes (e.g., increased chronic pain, cardiovascular disease, obesity) and increases in all-cause mortality (McFarlane, 2010).

Trauma-Informed Care
The federally funded National Center for Trauma-Informed Care describes a trauma-informed organization as one that realizes the prevalence and impact of psychological trauma and understands how to assess and treat the signs and symptoms of trauma (SAMHSA: http://www.samhsa.gov/ncti/traustrauma-interventions). A trauma-informed organization would respond to this information by integrating it into its policies and practices in order to prevent client retraumatization and to promote organizational transparency, trustworthiness, safety, collaboration, and client/staff empowerment. Trauma-specific interventions are often an important element of trauma-informed care in any setting (Center for Substance Abuse Treatment [CSAT], 2014).

Hospice Care
Hospice care refers to team-based, patient-oriented supportive services to terminally ill people and their families, including pain management, medical care, and support of social, psychological, and spiritual well-being (http://www.nhpco.org/about/hospice-care). To be eligible for hospice Medicare benefits in the United States, an individual must have a life expectancy of 6 months or less and be willing to forego curative medical treatment (Williams et al., 2010).

Palliative Care
Historically, the terms hospice care and palliative care have both been associated with care of the terminally ill patient, and they are often synonymous outside of the United States (e.g., Williams et al., 2010). That said, palliative care is now a separate and established medical discipline (Risse & Balboni, 2013). Like hospice care, palliative care uses team-based multidisciplinary biopsychosocial–spiritual approaches to provide relief of suffering and support for medical patients and their families. Unlike hospice care, palliative care can be provided in parallel with curative medical treatment at any stage of illness (Risse & Balboni, 2013). In theory, palliative care can be delivered to any medical patient in need of advanced supportive care. In practice, the palliative care patient is characterized as frail, elderly, and in decline due to multisystem disease (Kaasa, Torvik, Cherny, Hanks, & de Conno, 2007), and more than half of palliative consultations are for patients at the end
stages of disease (Morrison et al., 2008). For the purposes of this review, then, the palliative care population will be discussed as a putative hospice precursor population, albeit with considerable actual overlap between the two groups.

This review moves next to a brief survey of the epidemiology of psychological trauma as it applies to hospice and palliative care patients.

### Trauma Exposure in Hospice and Palliative Care Populations

There is robust evidence that exposure to psychological trauma is common in the general population (e.g., Breslau, 2001; Felitti et al., 1998; Kessler et al., 1995). Earlier epidemiological surveys within the United States reported that more than 60% of men and 50% of women (ages 15–54 years) experienced at least one psychological trauma in their lifetime (Breslau, 2001; Kessler et al., 1995). However, recent evidence places the frequency of trauma exposure in the general population at least 10% higher than these early figures (Frissa et al., 2016).

The literature also establishes that significantly higher levels of trauma exposure are present in certain subgroups, such as those who live in unsafe neighborhoods (Boothroyd and Evans, 2001) or who have been exposed to terrorism (Galea et al., 2002) or incarceration (Wolff et al., 2011). Higher prevalence of trauma exposure can also be expected among hospice and palliative care patients for reasons related to old age and serious illness, as discussed below.

### Trauma and Aging

Hospice and palliative care patients tend to be older than the general population—often much older. Approximately 80% of hospice patients are aged 65 and older, and nearly 40% are 85 and older (National Hospice and Palliative Care Organization, 2013). Unfortunately, age itself is a risk for trauma exposure (e.g., Krause, Shaw, & Cairney, 2004; Pietrzak, Goldstein, Southwick, & Grant, 2012), and it is estimated that 70%–90% of adults aged 65 and older have experienced a trauma-level life event (Norris, 1992, also see Pietrzak et al., 2012). Some of the most potent forms of trauma exposure occur in the context of an individual’s closest relationships (e.g., sudden death or serious injury of a loved one or the life-threatening illness or death of a spouse or child). These relationship-based traumas are often endorsed by people as their worst trauma, regardless of their other life experiences (Pietrzak et al., 2012). Notably, research shows that this type of trauma becomes much more likely with increasing age (see Figure 1). For example, one epidemiological study found that almost three quarters of respondents in the oldest-old category (age 85 and older) had experienced the death of a spouse (Krause et al., 2004). As noted earlier, hospice and palliative care populations are heavily biased toward these older age groups and thus are more likely to encompass a larger burden of trauma exposure.

### Medical Trauma

Hospice and palliative care patients, by their nature, are more likely than the general population to have been diagnosed with a life-threatening illness and to have experienced intensive medical intervention. Threat to life is potentially traumatic (APA, 2013); however, there has only recently been recognition of the traumatic impact of having a life-threatening disease or that intensive medical interventions can themselves engender trauma (Hatch et al., 2011; Needham et al., 2012; Wake & Kitchiner, 2013). Patient-oriented studies of medical trauma (psychological traumas due to medical diagnosis and/or medical intervention) are a relatively recent effort (Mundy & Baum, 2004; Wake & Kitchiner, 2013).

Prior to entering hospice care, patients often receive intensive medical interventions such as chemotherapy, ICU care, or extended hemodialysis treatments for their terminal illness(es). Similarly, patients in palliative care are
typically undergoing intensive medical intervention for advanced disease (Kaasa et al., 2007). There are an increasing number of studies of psychological trauma in medical patients approaching the end of life in these clinical settings (e.g., Kaasa et al., 1993; Moye & Rouse, 2014; Tedstone & Tarrier, 2003). As reviewed in the following sections, these data suggest that the impact of medical trauma is high in these populations.

Example: End-Stage Cancer
A palliative care study by Kaasa and colleagues (1993) assessed distress and symptoms of PTSD in 247 terminal cancer patients prior to administration of palliative radiation. This study found that 69% of patients reported high levels of psychological distress and reduced well-being, in addition to PTSD symptoms such as avoidance (72%) and intrusion (67%). Approximately a third of the sample had scores consistent with clinical PTSD. This study did not differentiate between prior trauma and trauma associated specifically with the terminal illness, but it demonstrates that trauma-related distress is likely to be prevalent in the palliative care population (with parallel implications for hospice care).

Example: Hemodialysis
A study of prior and current trauma in dialysis patients found that nearly 80% reported at least one trauma in lifetime and 17% had a lifetime history of PTSD (Tagay, Kribben, Hohenstein, Mewes, & Senci, 2007). Of the different types of traumas reported, more than 66% reported events associated with their current life-threatening illness as a trauma and nearly all of these reported it as their worst trauma, even among those who had experienced other types of traumas (e.g., combat traumas, serious accidents, or assaults). Fifty percent of the entire sample reported feelings of helplessness, and 43% reported feelings of horror/fear regarding dialysis therapy. Approximately 10% of the sample developed clinical-level PTSD in response to dialysis itself. Note that this study included a mix of patients, ranging from those who were new to dialysis and those who had been on dialysis for more than 5 years.

Example: Critical Care
Emergency room admissions and hospitalizations become more common as the end of life approaches, and these are more likely to result in intensive medical intervention in critical/intensive care units (Teno et al., 2013). ICU care can result in patient traumatization (e.g., Parker et al., 2015). A study of critical care in nine hospitals found that 74% of ICU patients recalled having nightmares, severe anxiety or panic, trouble breathing, and/or severe pain during their ICU care (this includes only those patients who reported having any memory of their ICU care: Granja et al., 2008). A recent meta-analysis found that 18%–34% of ICU patients report symptoms consistent with a diagnosis of PTSD within 1–6 months of discharge and 10%–26% of ICU patients remain highly symptomatic 7–12 months after discharge (Parker et al., 2015; also see Granja et al., 2008; Twigg, Humphris, Jones, Bramwell, & Griffiths, 2008). In addition, an even larger subset of patients report symptoms consistent with clinically significant partial PTSD (Parker et al., 2015).

In the literature, PTSD is more often associated with combat exposure and ICU-related PTSD often remains undiagnosed. The British Medical Journal has helped to bring attention to this issue by publishing an account of a medical resident’s experience of ICU-related PTSD (Wake & Kitchiner, 2013):

Endless days and nights filled with strange broken sleep.
A sea of fragmented menacing faces and shadows swimming through erratic beeps and bells… The staring old lady in the bed opposite, her sallow skin disintegrating, eyeballs disappearing to reveal deep dark holes from which cockroaches crawled… Blood seeping through holes and cracks in my skin, forming a puddle of red around me. Small insects scuttling up my arms and legs. My chest locked to the bed with wires and straps, as a plastic mask repeatedly smothered me. (Wake & Kitchiner, 2013, p. 1)

Delirium, prolonged sedation, and physical restraint are principle distressing factors in Wake’s account of her ICU experience, and all three are thought to be related to the development of postintensive care PTSD (Jones et al., 2007). Delirium is commonly observed in ICU patients. Half of ICU patients report at least some periods of delusional thinking (those who have any memory of their ICU stay: Granja et al., 2008) and more than 80% of mechanically vented ICU patients are delirious at some point in their ICU experience (Ely et al., 2004). Notably, delirium predicts post-ICU cognitive declines and 6-month mortality (Ely et al., 2004), as well as PTSD (Jones et al., 2007).

In 2012, a meeting of critical care providers and other stakeholders outlined a new post-intensive care syndrome (PICS) that includes frequently observed psychological consequences of critical care (PTSD, anxiety, depression in patients and their families), along with long-term cognitive and neuromuscular impairments (Needham et al., 2012). This statement also outlines common ICU practices that are likely to contribute to PICS, including frequent use of sedatives, physical restraint, endotracheal intubation, and interruption of the sleep/wake cycle. A growing recognition of the distress and trauma associated with critical care has prompted the American College of Critical Care Medicine to publish new clinical practice guidelines to prevent significant pain and delirium and oversedation or undersedation in ICU patients (Barr et al., 2013). Because many patients transition from critical care settings to hospice or palliative care (Teno et al., 2013), these issues are a crucial consideration in the care of these patients.
Why Trauma Matters
The Body Keeps Score
Many people who experience trauma go on to thrive in personal and/or public domains. Nonetheless, extreme life experiences affect biological functioning, so that traumas from even decades in the past can have significant long-term effects on mental and physical health and mortality (e.g., Boscarino, 1997, 2006; Brown et al., 2009; Chaudieu et al., 2011). To quote one trauma researcher, “the body keeps the score” (Van der Kolk, 2014). For example, a study of 17,000 middle-class Americans (mean age 57 years) found that increased exposure to severe stressors during childhood was related to adult increases in mental disorder, memory impairment, liver disease, chronic obstructive pulmonary disease, and heart disease (Anda et al., 2006; Felitti & Anda, 2010), as well as shortened life span (Brown et al., 2009). (Note: In this study of 17,000 Americans, 64% of respondents reported at least one childhood trauma/severe stressor [e.g., abuse, neglect, domestic violence] and 12.5% of the sample reported four or more; Anda et al., 2006.)

Long-term effects like these are not exclusive to childhood stress and trauma. Studies of military veterans (e.g., Boscarino, 2006) and community-living elderly adults (e.g., Chaudieu et al., 2011) show significant (though somewhat different) relationships between trauma in adulthood and later increases in morbidity and/or mortality. And there is emerging evidence that psychological trauma exposure carries unique risks for older adults (reviewed in Ganzel & Morris, 2016). For example, older adults with a history of trauma exposure in adulthood have a higher likelihood of developing dementia than older peers with no trauma history (Burri, Maercker, Krammer, & Simmen-Janovsky, 2013; Tsolaki et al., 2010; Yaffe et al., 2010). Notably, older adults with a history of childhood trauma do not appear to share this increased risk of dementia (e.g., Burri et al., 2013; Ravona-Springer, Beeri, & Goldbourt, 2011), but they are more at risk for geriatric depression (Kuhlman, Maercker, Bachem, Simmen, & Burri, 2013).

Signs, Symptoms, and Sequelae of Trauma
After trauma exposure, a subset (14%–24%) of people will develop the full range of symptoms needed to meet diagnostic criteria for PTSD (Breslau, 2001; Kessler et al., 1995), including symptoms of hyperarousal, avoidance, re-experiencing, and negative cognitions/mood (APA, 2013). Trauma-related hyperarousal may manifest as difficulties with emotion processing and emotion regulation, inability to concentrate, irritability, jumpiness, distrust, flashbacks, sleeplessness, and/or nightmares. Symptoms of avoidance arise as individuals attempt to protect themselves from sensations of hyperarousal, and for those with medical trauma, this may include avoidance of reminders of medical settings and medical personnel (e.g., see Feldman et al., 2014; Kubany et al., 1994). The PTSD symptoms of cognitive and emotional disorganization may include feelings of numbness and loss of interest, a distorted sense of blame and/or forgetting of important elements of the trauma (e.g., APA, 2013). Importantly, PTSD is often comorbid with anxiety, depression, and/or substance abuse (Kessler et al., 1995).

After trauma exposure, a much larger proportion of individuals will experience some but not all of these symptoms, along with their associated clinical impairments; this has been called subclinical or partial PTSD (e.g., Lai, Chang, Connor, Lee, & Davidson, 2004; Pietrzak et al., 2012; Stein, Walker, Hazen, & Forde, 1997). Subclinical/partial PTSD is clinically significant, as outlined below.

Even in the absence of full-criteria PTSD, trauma exposure predicts lifetime increases in mental disorder (Kessler et al., 1995), decreased life satisfaction (Krause, 2004), long-term cognitive declines (Stein, Kennedy, & Twamley, 2002), more chronic illness later in life, and decreased mean life expectancy (Krause, 1998; McFarlane, 2010). Subclinical trauma-exposed individuals are also observed to have reduced volume in brain areas significant to emotion regulation, even though years may have passed since the precipitating trauma (e.g., Ganzel, Kim, Glover, & Temple, 2008). Although smaller in volume, these brain regions may continue to show a hyperactive response to trauma-related (Sharot, Martorella, Delgado, & Phelps, 2007) and standardized emotional stimuli (Ganzel, Casey, Glover, Voss, & Temple, 2007). Trauma exposure in subclinical samples is also associated with long-term increases in cardiovascular reactivity to trauma reminders (Tucker et al., 2007), altered catecholamine levels (dopamine, epinephrine, and norepinephrine: Young & Breslau, 2004), and a greater vulnerability to PTSD with subsequent trauma exposure (Bremner, Southwick, Johnson, Yehuda, & Charney, 1993). The takeaway message here is that trauma exposure can have significant negative effects on individual health and well-being through to the end of life, making it a topic of relevance for hospice and palliative care.

Clinical Implications
To summarize, increased stress and trauma may accumulate in hospice and palliative care populations due to normal aging and the increased likelihood of prior intensive medical intervention. Moreover, evidence suggests that memories of old traumas and symptoms of PTSD may be reactivated in normal aging, and these may be exacerbated by illness and life stress.

What might this look like in clinical practice? For example, a hospice patient with a history of rape may become combative, anxious, and/or depressed if she or he is not adequately prepared for a switch from oral medication to suppository-based medication (this change in modality of medication delivery is standard hospice clinical practice when swallowing becomes difficult; Lau et al., 2012). Notably, it is not uncommon for older clients to have histories of rape. A study of community-dwelling older women...
found that 72% reported experiencing interpersonal trauma such as physical or sexual abuse or rape (Higgins & Follette, 2002; also see Sachs-Ericsson et al., 2014).

As another example, an aging military veteran may demonstrate symptoms of PTSD that intensify with increasing medical intervention, even though he reports no combat history. However, he may have been one of the tens of thousands of draftees with conscientious objector status (e.g., Mennonites, Quakers) who were used in military medical experiments between 1942 and 1975; rates of PTSD are reported to be high in this population (Department of Veterans Affairs, 2003).

Israel, with its substantial population of aging Holocaust survivors, provides a third clinical example. Staff in Israeli eldercare facilities are cautioned that these clients may respond strongly and negatively to being helped to the shower, which can trigger associations with Nazi gas chambers (O’Rourke et al., 2015). O’Rourke and colleagues note that “Understanding the meaning and symbolism of survivors’ memories can enable care providers to make small changes in procedures to prevent reactivation of trauma” (p. 9).

It is important to note that the basis for trauma-related reactions may be difficult for individual patients to articulate or even understand, particularly in the presence of delirium or dementia. The care provider must be aware of the originating events in order to understand patients’ needs in a nuanced way, in order to flexibly accommodate agency practice and policy to meet those needs and to avoid retraumatization.

Directions for Future Research

Trauma Assessment in Hospice and Palliative Care

Trauma assessment is at the heart of competent trauma-informed care (CSAT, 2014). Understanding a patient’s trauma history is a critical step toward providing quality patient care. Because of this, there is national initiative calling for universal screening for psychological trauma in all behavioral health services (CSAT, 2014) and primary care settings (Kaiser et al., 2016; Reeves, 2015). Screenings should assess an individual’s history of trauma and the presence of any current trauma symptoms. Measures should be “minimally intrusive,” yet evidence-based and clear (e.g., Stamm, 1997). Care providers should be trauma-informed and trained to provide education, reassurance, and support to ensure that the patient feels safe during and after trauma assessment, and to prevent retraumatization (CSAT, 2014; Kaiser et al., 2016).

The development of trauma assessment protocols for hospice and palliative care patients must also take into consideration issues such as patient age and likely ill health. There are significant differences in how younger and older adults report trauma-related symptoms, with older adults being more likely to report somatic symptoms such as insomnia, poor appetite, and problems with memory rather than “psychological” symptoms such as anxiety (e.g., Davidson, Kudler, Saunders, & Smith, 1990). Older trauma-exposed adults are also likely to report more symptoms of hyperarousal and fewer symptoms of intrusion than younger adults (Goenjian et al., 1994). Nevertheless, studies suggest that current validated measures remain useful for assessing symptoms of PTSD in older adults (e.g., Hyer et al., 1992) and thus are likely to be helpful for assessing these symptoms in hospice and palliative care patients who are alert and oriented.

But what are the assessment options when a hospice or palliative care patient is overwhelmed, confused, demented, or minimally conscious? In these cases, the default source of behavioral health information becomes the primary caregiver or other responsible party (e.g., Centers for Medicare and Medicaid Services, 2015). There appear to be no validated assessments of trauma history or symptoms designed to be filled out by a caregiver on behalf of an elderly patient who is unable to report independently. There are, however, validated parent-report measures of children’s trauma exposure and PTSD symptoms (http://www.ptsd.va.gov/PTSD/professional/assessment/child/index.asp), and these might function as templates for future caregiver-report measures for hospice and palliative care patients who are unable to respond for themselves. Trauma assessment is an important area for future research in hospice and palliative care.

The effectiveness of these secondary sources of information would be substantially supplemented if primary health care providers routinely screened their patients for history of trauma prior to their becoming gravely ill (Kaiser et al., 2016; Reeves, 2015). There is a successful precedent for this in the Kaiser Permanente Healthcare studies of adverse childhood experiences described previously (e.g., Anda et al., 2006; Brown et al., 2009; Felitti & Anda, 2010). It remains to future research to adapt this model for life-span trauma assessment in primary care settings, with particular emphasis on assessment of trauma histories in the elderly adults before the end of life.

Developing Trauma-Focused Interventions in Palliative Care

In palliative care settings, palliation and treatment are integrated and there is a range of possibilities for pharmacological and/or psychosocial interventions to reduce trauma-related symptomatology. As discussed earlier, patients in palliative care may have a broader time window for intervention than patients in a hospice setting. This could allow implementation of medications that are helpful in reducing symptoms of trauma-related disorders, which can take six or more weeks to relieve symptoms (Feldman & Periyakoil, 2006). There may also be sufficient time for lengthier evidence-based interventions that are targeted specifically toward ameliorating PTSD, such
as trauma-focused cognitive behavior therapy (TF-CBT) or extended exposure therapy (these treatments are delivered across 8–16 weeks: e.g., Rothbaum, Foa, & Hembree, 2007). These approaches may be feasible with an extended prognostic window, with the caveat that the patient must be alert, oriented, able to participate in these therapies—and able to tolerate the short-term increases in symptom severity that are typically associated with these treatment modalities. If not, then the approaches in the following section may be more appropriate.

Developing Trauma-Focused Interventions in Hospice Care

The interventions discussed earlier may not be practical in hospice care, which is often constrained to a limited time window (the average hospice stay is less than 3 weeks: National Hospice and Palliative Care Organization, 2013). For hospice patients, the prognostic window must be included in the selection of the intervention. To do so, Feldman and colleagues developed a stepwise approach to hospice care for PTSD that delivers trauma-focused intervention according to each patient's needs and capabilities (Feldman, 2011; Feldman et al., 2014). For patients with the least time and fewest emotional resources, this includes trauma-focused emotional/social support and environmental change (e.g., education of the medical team to avoid trauma triggers). For patients with more time and emotional resources, Feldman's intervention also incorporates patient education (e.g., teaching coping skills). For patients with a prognosis of months to years, Feldman suggested evidence-based treatments that provide remission of trauma symptoms (e.g., TF-CBT), although he makes the caveat that this requires the patient to have robust cognitive and emotional capacities (Feldman, 2011).

Feldman's work brings needed attention to the issue of mental health treatment/palliation of psychological trauma at end of life, and he proposes a viable model for incorporating prognostic time limits for intervention. Although not yet empirically tested, this titrated approach to palliation of trauma symptoms represents an important “next step” in the palliative care of trauma-exposed hospice patients. That said, it may be too early to discard evidence-based trauma treatments as inappropriate for shorter-term hospice patients.

In particular, eye movement desensitization and reprocessing (EMDR) therapy offers brief, evidence-based trauma treatment/palliation that can be modified to be appropriate to a wide range of hospice patients. The aim of EMDR is to correct incomplete and/or maladaptive encoding of adverse life experiences (Shapiro, 2001). EMDR therapy is delivered in a brief manualized protocol that uses bilateral stimulation (visual, tactile, or auditory) to generate a dual focus of attention that fosters adaptive memory integration (http://www.emdria.org/). The manualized protocol is modifiable to be situation appropriate and developmentally appropriate (Shapiro, 2001). Research indicates that EMDR therapy helps to relieve symptoms of all types of psychological trauma, including medical trauma (e.g., Arabia, Manca, & Solomon, 2011; Bisson et al., 2014; Capezzani et al., 2013).

Within the past decade, EMDR has become a frontline treatment for PTSD with a strong evidence base (e.g., Bisson et al., 2014). For hospice care, it is useful that EMDR therapy is brief (Nijdam, Gersons, Reitsma, de Jongh, & Olff, 2012), there is no homework and no need for detailed description of the trauma, and EMDR is documented to also reduce symptoms of depression, anxiety, physical pain, and anger (e.g., Shapiro, 2001; Silver, Rogers, & Russell, 2008). Moreover, evidence suggests that EMDR may be modified for use with individuals with cognitive impairments (Mevissen, Lievegoed, & de Jongh, 2011; Mevissen, Lievegoed, Seubert, & de Jongh, 2012), and with mildly (Hyer et al., 1992) and clients who are floridly demented (Amano & Toichi, 2014). This places EMDR at the forefront of possible strategies for mental health palliation/treatment of trauma symptoms at or near the end of life.

Conclusion

This review delineates the need for trauma-informed hospice and palliative care. Trauma-informed care does not replace other approaches to hospice and palliative care—rather it provides a new lens through which to view all patients in all approaches to care. The argument here is that psychological trauma is commonplace and often unacknowledged in hospice and palliative care populations. There is sufficient evidence right now to be sure that exposure to psychological trauma is frequent in the general population. And as detailed earlier, those who are old and/or very ill are likely to carry an even larger burden of trauma exposure. Trauma exposure, in turn, can negatively affect patient mental health, well-being, and pain experience, particularly in the presence of confusion, delirium, or dementia. Assessment of trauma history and trauma-related symptoms is an important element for compassionate patient care, along with the development of trauma-specific intervention strategies appropriate to these populations.

References


