June 2018

SWHPN Voice

Curated News for Psychosocial Professionals in Hospice and Palliative Care

SAVE THE DATE FOR SWHPN 2019 IN ORLANDO, MARCH 17-19

The SWHPN General Assembly, now in its seventh year, is being held March 17-19, 2019 at the beautiful Hilton Lake Buena Vista at Disney Springs, a wonderful retreat to learn and recharge during our signature three-day conference.

This annual event showcases leading psychosocial research, innovative practices, educational strategies, policy initiatives, and case narratives from leaders in the field of hospice and palliative care – and this year will feature even more opportunities to network, engage, and connect with your colleagues! Also new to the 2019 event: educational sessions to prepare for the new APHSW-C Certification.

Earlier this year, our 2018 General Assembly in Boston welcomed over 350 leaders, practitioners, and researchers in hospice and palliative social work – and kept them there! A late-winter Noreaster delayed the travel plans of many attendees, but we took it in stride, grateful for the additional time to network and share with one another.

Sign up for our mailing list to be the first to get 2019 conference updates.

SWHPN 2019 | ORLANDO

ADVANCED PALLIATIVE HOSPICE SOCIAL WORKER CERTIFICATION (APHSW-C) PROGRAM

Late last month, SWHPN announced the Advanced Palliative Hospice Social Worker Certification (APHSW-C) Program, the first evidence-based specialty certification program for hospice and palliative social workers.

Led by Dr. Barbara Head, and an advisory committee of educators, administrators, and practitioners, the APHSW-C program requires verification of knowledge and competency based on passing an exam specifically constructed to reflect the essential knowledge and skills required for specialty practice. While both nurses and physicians practicing in palliative and/or hospice care have had evidence-based competency certification programs for many years, this is the first such program for social workers in this field.

Now established, social workers practicing in this specialty can apply for certification. The first administration of the test is scheduled for January 2019, with the application opening on November 1, 2018. SWHPN will offer a webinar over the summer with more information for those who are interested in learning more about this exciting new program.

SWHPN BOARD MEMBER TRACY SCHROEPFER, PhD, LEADS EFFORT ON DEVELOPMENT OF NCP'S 2018 GUIDELINES

SWHPN recently approved the first draft of the National Consensus Project's (NCP) Clinical Practice Guidelines for Quality Palliative Care, 4th Edition (2018). The goal of the NCP Guidelines, 4th edition, is to improve access to quality palliative care for all people with serious illness, regardless of setting diagnosis, prognosis, or age.

We are grateful to SWHPN Board Member Dr. Tracy Schroepfer, NCP Writing Workgroup Co-Chair, for her valuable contributions to this important effort! Publication of the final guidelines is scheduled for October 31, 2018.

Policy Notes

Medicare is Cracking Down on Opioids

CreditEamon Queeney for The New York Times

The New York Times takes a comprehensive look at the struggle to regulate opioid analgesics when so many depend on these prescriptions as treatment. For those who have been treated with opioids for decades, aggressive tapering or immediate discontinuation of their prescriptions can be detrimental to their lives and hope for recovery. More >

Practice Update

Trauma-informed Hospice and End-of-Life Care

By Nancy Kusmaul, PhD, MSW

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,

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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 the 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)

Making Trauma Work Sustainable

By Amanda Moment, MSW, LICSW and Catherine Arnold, MSW, LICSW

The Issue: As hospice and palliative care social workers, our work can be intense and traumatic. Concepts like *burnout* and *vicarious traumatization* imply that we are passive recipients of this suffering. However, based on work in Laura Van Dernoot Lipsky's book Trauma Stewardship, we understand that we choose to practice in this difficult field and, importantly, we can decide to actively work towards our own health and longevity. By shifting the locus of control from external to internal, we are often able to create a work experience that is fulfilling yet containable.

The Evidence: Concepts like burnout, compassion fatigue, and vicarious trauma are often used to characterize the impact of our work on us personally. Studies estimate that anywhere between 21 - 61% of mental health practitioners experience signs of burnout (Morse et al., 2012). However, research has focused less on identifying effective means of preventing vicarious trauma from occurring, often offering disappointing "band-aids" at best. In her groundbreaking book Trauma Stewardship (2009), van Dernoot Lipsky encourages us to pro-actively approach work-related stress, reminding us that "we have options at every step of our lives,"

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and that "we can make a difference without suffering." Importantly, we are reminded that "we can do meaningful work in a way that works for us and for those we serve." She and others like author Babette Rothschild in Help for the Helper (2006) encourage us to be stewards of other's stories while maintaining firm but healthy boundaries. By doing so, we are able to protect ourselves from internalizing others' traumas while offering compassion and support.

Practical Implications/Recommendations: In order to incorporate work sustainability into our daily practice, it is important to first build insight into our motivations, goals, and needs and, then, to assess and develop a plan for managing them. As a starting point, we encourage colleagues to explore *insight* and *management* in three separate and unique categories: personal dynamics, work trauma, and professional circumstances.

- **Personal dynamics**: It is important to ask ourselves why we chose our work paths: Are we trying to repair our own trauma, and, if so, is this the best context in which to do so? For many of us, we are compelled to "give back" in an area that has touched our personal lives (such as illness or loss), though we may soon discover that our work too frequently puts us into contact with triggers that require too much psychic energy. To protect ourselves from these heightened associations, we can choose to reflect honestly about our triggers and anticipate them. We can also forgive ourselves for being "good enough." These strategies help us move from being passive recipients to active participants in our work.
- **Work trauma:** It is important to assess how we process the grief and trauma of our daily work, how we regroup after a difficult clinical encounter, and if we have ways to transition from our professional lives to our personal lives. To address this, we encourage colleagues to explore how guilt impacts our professional coping, such as believing that we can never do enough for our clients or that if we say "no," others suffer insurmountably. To acknowledge and accept these feelings, we encourage clinicians to develop rituals for containing the trauma of their work, and to develop a meaning-making narrative that encourages us to thrive. We differentiate between holding people's trauma and creating a "holding space" for our clients, thereby separating ourselves from our work. To this end, we encourage people to "unmirror" their experiences from their clients.
- **Professional circumstances:** We ask clinicians to assess their environments, focusing on supports and resources. We suggest that colleagues assess their caseloads and reflect on their stress/satisfaction balance. Importantly, we encourage reflection about the benefits of advocating for structural change. We ask people to explore the gap between how we want to practice and how we are able to practice, considering the costs and benefits to both. We encourage colleagues to develop allies, thereby creating opportunities for fun and professional connection, and reframing the value of stressful work.
- **Taking this to your teams:** Our hope is to not only help clinicians strengthen their own work sustainability, but to also find ways to bring these questions back to their teams. We respect that we all approach this work from different starting points, and, as the social workers in this field, we are often called upon to support our colleagues, whether formally or informally.

Research Spotlight

Maintaining Records Helps Honor Patient Wishes

Advance Care Planning Documentation Practices and Accessibility in the Electronic Health Record: Implications for Patient Safety

By Evan Walker, MD, Ryan McMahan, Deborah Barnes, PhD, Mary Katen, Daniela Lamas, MD, and Rebecca Sudore, MD

- This research, presented at the American Academy of Hospice and Palliative Medicine (AAHPM) annual assembly, supports the importance of advance care planning while highlighting the need for documentation of explanatory discussions that accompany the completion of related documents. By surveying a sample of records from primary care clinics at the San Francisco Veterans Affairs Medical Center, the authors discovered that half of older, chronically ill participants had their wishes documented, while one-third had discussions captured as well. Half of patients with completed legal forms and orders had no accompanying explanatory discussions, setting a clear path for improvement. More >

Research Spotlight

Are Hospice Social Workers Satisfied at Work?

Social Workers' Perceptions of Job Satisfaction, Interdisciplinary Collaboration, and Organizational Leadership

By Suzanne Marmo, PhD, LCSW
and Cathy Berkman, PhD, MSW

This study surveyed more than 200 hospice social workers in three states on their relationships with other members of the interdisciplinary hospice team and their perceptions of hospice leadership and examined how their responses may be linked to overall job satisfaction. Researchers found that interdisciplinary collaboration, feeling valued by the hospice physician, and interdisciplinary collaboration are significant. Results support previous research that found that leadership style of the hospice director and relationships with colleagues are important to social workers' job satisfaction. Read more >

Post-Traumatic Growth in Youth

Adding Trauma-Informed Care at a Bereavement Camp to Facilitate Post-traumatic Growth: A Controlled Outcome Study

By Irene Searles McClatchy, LCSW, PhD
and Rachel *Francis Raven, MSW*

This study examined the experience of children experiencing bereavement and their who participated in a weekend-long bereavement camp that focused on facilitating post-traumatic growth.

Method: A total of 105 participants completed standardized measures of posttraumatic growth and posttraumatic stress disorder after which 52 of the participants took part in a camp session. Ninety-five of the participants from both groups were post-tested four weeks after the camp session. **Results**: Multiple Regression showed that PTG scores were significantly greater at posttest for the treatment group. No significant changes in PTSD were found in either group, although the presence of dissociative symptoms decreased significantly among campers in the treatment group. Conclusions: Findings suggest trauma-informed care may increase posttraumatic growth among youth coping with loss. Implications for future studies and clinical practice are discussed. Read more >

In the News

What Does It Mean to Die? In the *New Yorker*, reporter Rachel Aviv explores questions surrounding the circumstances of the life of Jahi McMath, who remains notably interactive after being declared dead by numerous physicians and legal authorities. Her mother Nailah continues to care for her at home and fight for her personhood. More >

Alfie Evans Stirs a National Conversation Alfie Evans, from Liverpool, England, suffered from a neurodegenerative disease that severely affected his brain. Prior to his death at 23 months, Alfie was removed from life support by medical professionals. His case stirred much conversation from medical professionals and conservative groups over his so-called "right to life" or "death with dignity." In a Guardian op-ed, Rachel Clarke, a palliative care physician with the NHS, made a case for Alfie's peaceful death. More >

Comfort care, palliative care, and hospice care explained after Barbara Bush's death Former First Lady Barbara Bush died on April 17 at age 92. Prior to her death, news coverage highlighted her shift to "comfort care," prompting the need for clarification from hospice professionals on nuances in the definitions of hospice and palliative care. Many subsequent news articles focused on illuminating these definitions and providing information pertinent to advance care planning. More >

NHPCO #MyHospice Campaign The NHPCO has launched the #MyHospice campaign on social media to bring stories of the benefits of hospice to the forefront. Check out the hashtag for stories from practitioners, healthcare policy implications, and advocacy opportunities. More >

Safety Violations Compound Painkiller Shortages As healthcare providers and patients nationwide grapple with shortages of Dilaudid, morphine and fentanyl, safety violations at a major compounding pharmacy are exacerbating the problem. In the past few months, the Food

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and Drug Administration has found major violations at a number of plants belonging to PharMEDium, which mass produces ready-to-use IV bags, prefilled syringes, and other medical needs. Read more >

Palliative Prison *The New York Times* covers a prison-based hospice in California where inmates become caregivers to their peers. Pastoral Care Service Workers are primarily convicted murderers serving life sentences, and they provide those who are dying with the support needed for a dignified end of life. "All I wanted was kindness and to be held as a boy. Now I get to do that for somebody else," said one participant. More >

Wishing to Die at 104 Dave Goodall followed up a celebration of his 104th birthday with a trip to Switzerland, where he ended his own life. "I greatly regret having reached that age," he said. For twenty years prior to his death, Dave was a member of Exit International, an Australia-based nonprofit organization that advocates for legalized euthanasia. Read more >

Palliative Care Shortens Hospital Stays U.S. News and World Report covers a recent study published in *JAMA Internal Medicine* that shows palliative care treatment results in shorter hospital stays and increased savings for hospitals. More >

Educational Opportunities and Resources

AAHPM's Pedi-Innovate

Join the American Academy of Hospice and Palliative Medicine for their summer pediatrics course, Pediatric Hospice and Palliative Care: Advances and Innovations (Pedi-Innovate). This learning experience for all disciplines takes place August 9-11 in Minneapolis. More >

End Game on Netflix

Netflix recently premiered End Game, a short documentary about hospice care and the clinicians who are hoping to change thinking and conversations around life and death. Watch the trailer >

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SWHPN 2018 General Assembly

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