

## E-News for Professional Social Workers in Hospice and Palliative Care

### A Message from Our Chair



SWHPN is pleased to bring you this first edition of the SWHPN Quarterly Newsletter. Edited by SWHPN Board Member John Cagle, the newsletter is designed to provide specific and current curated news on literature, education, research,

policy, and practices in social work and psychosocial palliative care. Our goal is for this newsletter to be an important tool for social workers and other psychosocial

professionals that will inform, update, inspire, and empower readers to appreciate, value, and expand this critical knowledge and skill base that is so essential to quality palliative care. This joins the outstanding Journal of Social Work in Hospice and Palliative Care (requires login), edited by Ellen Csikai, to which members also enjoy complimentary readership.

Grace Christ, DSW, PhD  
Chair, SWHPN

### SWHPN 2016 - Meet Leading Experts in Palliative and Hospice Care

The 2016 SWHPN General Assembly is shaping up to be an outstanding and expansive program that includes: pre-conference workshops offering hands on practice experiences and opportunities for extended dialogue with other colleagues; social work and interdisciplinary plenary presentations, workshops, as well as paper and poster presentations. Register for [2016 SWHPN General Assembly](#) >

### SWHPN Uses Survey Results on Advance Care Planning for Advocacy

Palliative social workers play vital roles on hospice and palliative care teams performing advance care planning services—whether facilitating communication among patients, families, and the health care team; assisting with the preparation of formal directives; training professional staff or educating consumers; or leading programs to promote more thoughtful planning. Unfortunately, when advocating for our profession among policymakers or members of other



*continued on page 2...*



#### SWHPN GENERAL ASSEMBLY

PROMOTING INTEGRATED CARE FOR SERIOUS ILLNESS:  
*Improving Access, Coordination and Psychosocial Outcomes*

MARCH 6-8, 2016//CHICAGO

...continued from page 1

disciplines on the team, information on these efforts has been limited to anecdotes of known social work leaders or programs, acquired from colleagues, articles, conference presentations, and our palliative social work list servs. We needed data.

Last summer, SWHPN was presented with the opportunity to advocate for social work reimbursement of advance care planning services, in response to what was then a proposal Center for Medicare and Medicaid Services's (CMS) to [reimburse physician time](#) for counseling patients about end-of-life options. Recognizing the need to document social work activities, SWHPN conducted a survey of hospice and palliative social workers who are members of our organization and of a listserv of palliative social workers. The results have been incorporated into our comments to CMS, as well as comments of the National Coalition for Hospice and Palliative Care, of which SWHPN is a member.

Among the approximately 500 responding social workers are many years in hospice and palliative care; work in community hospices, inpatient palliative care, or oncology settings; and high rates of masters-level and advanced training, licenses, and credentials. Among our social work respondents:

- 97% report that social workers in their facilities were conducting advance care planning discussions with patients and families;

- 70% of respondents personally participated in advance care planning discussions more than 5 times in a typical month (half participated more than 10 times);
- 60% of respondents personally led advance care planning discussions with patients and families more than 5 times in a typical month;
- 2/3 of respondents rated themselves as very competent or expertly competent in facilitating advance care planning discussions;
- 65% reported that social workers in their settings were primarily responsible for documenting patient/family advance care planning preferences;
- 77% reported that social workers in their settings were responsible for informing patients about options for advance care planning;
- More than half reported teaching other social workers about conducting advance care planning.

These results document that licensed and experienced social workers are facilitating and conducting advance care planning activities with their patients and families, frequently leading the team effort; and frequently teaching colleagues on how to conduct these activities. Our data offer compelling support for our call to reimburse qualified social work professionals for their professional services, alongside their physician, nurse practitioner, and physician assistant colleagues. Our findings will be submitted for publication in a palliative care journal early next year.

## Health Literacy in Palliative Care

SWHPN Board Member Dr. John Cagle recently [presented the social work perspective to the Roundtable on Health Literacy](#), a day-long series of discussions and workshops hosted by the Institute of Medicine. When aligned, health literacy, palliative care, and social work can succeed in providing expert pain and symptom management; attention to quality of life and dignity; help in mobilizing an array of supports; and strength in relationships. The presentation explained how an interdisciplinary group of integrated social and medical care provides greater support to patients through careful attention to language; addressing myths and misperceptions; advocating for social justice; facilitating coping; and acknowledging uncertainty and change. [See the presentation.](#)

## Practice Update

### Sexuality and Intimacy in Palliative Care

by Anne Kelemen, MSW, LICSW, ACHP-SW

**The Issue:** Sexuality and intimacy should be included in a comprehensive palliative care consultation, but they are rarely assessed. Get tips for how to identify and address concerns about sexuality/intimacy for patients receiving palliative care.

**The Evidence:** Sexuality and intimacy have been identified as important components of a psychosocial assessment for palliative care (PC) patients (Cagle & Bolte, 2009). Specifically, an assessment of patient concerns related to sexuality and intimacy should be included in a

*continued on page 3...*

## Practice Update

comprehensive PC consultation. However, these concerns are rarely assessed. Barriers to these conversations include inadequate clinical training in these discussions, lack of time, fear of being intrusive, misconceptions about the importance of sexuality/intimacy in the seriously ill, and the assumptions that patients will raise the topic (Cagle & Bolte, 2009; Gallo-Silver, 2011; Barsky Reese et al., 2009). Patients are often uncomfortable raising the issues themselves, yet there is evidence that many patients want to discuss issues around sexuality and illness (Gallo-Silver, 2011; Barsky Reese et al., 2009). Lack of privacy in the acute hospital setting also poses a barrier for assessment and interventions of sexuality and intimacy. Below are some evidence informed suggestions to help social work professionals become more comfortable initiating these conversations.

### Practice Implications/Recommendations:

- Review your own comfort level with sexuality/intimacy before broaching the topic with patients.
- Before assessment, normalize the conversation and create a safe space for patients/families to discuss their concerns.
- Ask one or two simple questions:
  - *Has sexuality or intimacy been affected by your illness?*
  - *How has your illness affected your relationships?* (Nyatanga, 2014)
- Allow for discussion and ask clarifying questions:
- What is important for your healthcare team to know regarding sexuality or intimacy?
- Is it helpful if I discuss some of these issues with your doctor/nurse and ask them to bring this up next time you see him/her?
- Consider using one of the available models for assessing sexuality (PLISSIT, Ex-PLSSIT, CARESS, BETTER) (Cagle & Bolte, 2009; Gallo-Silver 2011).

### Opportunities:

- NASW's (2004) current Standards for Social Work Practices in Palliative and End of Life care do not mention sexuality or intimacy. These standards could be updated to include this important domain.
- More research is needed to better identify specific needs and possible interventions for sexuality/intimacy related to palliative care patients.

## Substance Use Screening in Hospice Care

by Paul Sacco, PhD, MSW

**The Issue:** Hospice care providers have the challenging task of providing care to individuals, many of whom are coping with severe pain that has the potential to curtail their quality of life. The task of pain management is more complex when the patient has a history of at-risk substance use or a substance use disorder, yet the quality of assessment of individuals in hospice may be inadequate.

**The Evidence:** Current hospice quality guidelines do not mention substance use specifically, but call for interdisciplinary treatment of psychiatric diagnoses and training of staff regarding “common psychological and psychiatric syndromes” (National Consensus Project for Quality Palliative Care, 2013, p. 22). Additionally, hospice guidelines suggest the measurement and documentation of psychological symptoms using standardized scales.

Even though standards apply to the assessment of substance abuse in hospice care, it is unclear whether current practices reflect quality indicators. Research by Blackhall and colleagues (2011) focused on hospices programs in Virginia found that only 43.5% of agencies had policies focused on screening for substance abuse in patients, and 30.4% had a policy in place for screening of substance abuse in family members. In a study of palliative care fellowship programs (Tan, Barclay, & Blackhall, 2015), only 40.5% had written policies for screening patients, 16.2% had a policy for screening family members, and 27% had a policy for screening for diversion. In addition to low prevalence of screening, these studies also reported low levels of education and training in substance abuse. Similarly, a survey of palliative medicine fellows found that less than half (47.2%) reported having a “working knowledge of addiction” (Childers & Arnold, 2012).

In a current study (Sacco, Cagle, & Camlin, 2015), we reviewed random sample of social work assessments from hospice providers nationwide. Although two-thirds (66.7%) of providers included substance use in their assessments, the majority (55.7%) were in the form of check-boxes and text entry. This is not consistent with current best practices in the area of substance abuse screening.

*continued on page 4...*

### Practice Implications/Recommendations:

- Assessment of substance use including alcohol, tobacco, and other drug use should be incorporated into hospice assessment -- for both patients and their caregivers.
- Policies and practices designed to stem drug diversion should not impede efforts to manage pain and symptom.

- Whenever feasible, validated screening measures should be used to improve the quality of information gathered during an overall assessment.
- At the agency level, providers should consider development of specific policies for screening and prevention of diversion.

## Research Spotlight

### Evaluating Formal Mentorship Programs

#### Mentoring the Next Generation of Social Workers in Palliative and End-of-Life Care: The Zelda Foster Studies Program

by Daniel S. Gardner PhD, LCSW, Susan Gerbino PhD, LCSW, Jocelyn Warner Walls LCSW, Esther Chachkes DSW & Meredith J. Doherty LCSW in *Journal of Social Work in End-of-Life & Palliative Care*

Social workers play a vital role on interdisciplinary palliative care teams, promoting understanding in difficult conversations between physicians and patients, guiding patients and families through the course of their illnesses, and providing the link to hospice at the appropriate time. In an effort to enhance social worker capacity in the field, the Zelda Foster Studies Program in Palliative and End-of-Life Care provides formal mentorship and training to promote professional and leadership development. This study examines mentorship as an approach to gaining competency in the field and findings from the first six years of the program, which demonstrate the feasibility, benefits, and challenges of formal mentorship programs. [Read more >](#)



### The Impact of Caregiver Expectations

#### Caregiver Expectations: Predictors of a Worse Than Expected Caregiving Experience at the End of Life

by David C. Currow in *Journal of Pain and Symptom Management*

We know from many areas of health and social care that a patient's expectations are a major determinant of their perception of experience and outcomes. But how does experience compare to expectations? Ultimately, one in two report their expectations were not met when looking back on the experience. How do we incorporate this finding into thinking about ways to support people as they provide care at the end of life? [Read more >](#)

### The ACE Study and Palliative Care

#### The Relationship of Adverse Childhood Experience to Adult Health: Turning Gold into Lead

by Vincent J. Felitti, MD in *The Permanente Journal*

The [Adverse Childhood Experiences \(ACE\) Study](#) supports a groundbreaking link between childhood trauma and adult health. Years of research on more than 50,000 adult patients supports a distinct relation between these experiences and major causes of mortality, depression, and the use of coping mechanisms. A new book by science journalist Donna Jackson Nakazawa, *Childhood Disrupted: How Your Biography Becomes Your Biology, and How You Can Heal*, examines the body of research comprising the ACE study by linking findings to individual patient accounts and experiences. It is important for social workers who provide palliative and hospice care to maintain an awareness of these findings when evaluating and recommending support to patients. [Read more >](#)

### CMS Final Rule Covers End-of-Life Counseling

The Centers for Medicare and Medicaid Services (CMS) has finalized a rule to reimburse physicians for holding advance care planning conversations with patients. Under the new rule, which will take effect on January 1, 2016, providers, including doctors, physicians, and nurse practitioners, will receive payment for in-person meetings to discuss patient wishes for end-of-life care. The counseling is voluntary and will take place during regular office visits. [Full story >](#)

### Palliative Care: A State-by-State Report Card

The latest release of a [joint report](#) by the Center to Advance Palliative Care and the National Palliative Care Research Center offers a state-by-state analysis of whether seriously ill patients receive equitable access to palliative care services in hospitals. Notable findings include service gaps, the number of hospitals reporting palliative care teams, and regional availability of services. [See the report card >](#)

### California Passes Physician-Assisted Suicide

In October, [California became the fifth state](#) to allow doctors to aid terminally ill patients in dying by prescribing life-ending medication. “I do not know what I would do if I were dying in prolonged and excruciating pain,” Governor Jerry Brown wrote in his signing message. “I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn’t deny that right to others.” The state joins Oregon, Vermont, Washington, and Montana in legalizing this practice. [Full story >](#)

### A Racial Gap in the Conception of Hospice

Recent statistics exhibit the racial divide between those who receive hospice care and possess advance care directives. As hospice use grows and Medicare moves to cover physician payment for advance care planning, increased attention must be paid to supporting access for African Americans, a demographic group that has historically resisted the concept. At the root of this resistance, according to researchers and Black physicians, is a pervasive and harmful distrust of a historically racist health care system. [Full story >](#)

### Rest in Peace, Oliver Sacks

Dr. Oliver Sacks, a neurologist, researcher, and acclaimed writer, [died in August at the age of 82](#). The cause was cancer. Dr. Sacks showed great commitment to the dignity and worth of his patients throughout his career, describing their struggles and strengths through accurate depictions of diagnoses not previously discussed with mainstream audiences. Upon receiving his prognosis earlier this year, Dr. Sacks illustrated his gratitude and perspective in [a beautiful piece for the New York Times](#). [Full obituary >](#)

### Ain’t the Way to Die

To illuminate the necessity of conversations at the end of life, Dr. Zubin Damania, a physician, comedian, and rapper otherwise known as ZDoggMD, recorded a cover—and accompanying music video—of a popular song by Eminem and Rihanna. “Ain’t the Way to Die” takes a fresh look at the hazards of the current state of end-of-life care in the United States, including patient and family communication and discussions of treatment and palliative care options.

[See the video >](#)

### How to Talk About Dying

When Ellen Goodman’s father was dying, her mother bought him a suitcase as a birthday present. This denial resurfaced decades later as her mother’s health began to fail, when the author again struggled in conversations about the reality of the situation at hand. Here she shares how talking about her personal experiences with others helped her to solidify the idea behind the essentiality of a good death: whether a patient’s wishes were expressed and respected. [Full column >](#)

## Educational Opportunities and Resources

### Interprofessional Palliative Care Webinar Series

In collaboration with the National Hospice and Palliative Care Organization, the MJHS Institute for Innovation in Palliative Care is offering a number of regular and accessible opportunities for practitioners and researchers to advance knowledge in best practices in the field. Upcoming topics include palliative care and neurodegenerative diseases; assessment and management of fatigue; and an examination of breakthrough pain. [Learn more and register >](#)

### Continuing Education

Fordham University regularly offers numerous opportunities for continued education through its Lincoln Center Campus and online. Topics include psychopharmacology, eating disorders, and grief, loss, and bereavement. [Learn more >](#)

### Call for Papers

For this special thematic issue of The Journal of Social Work in End-of-Life and Palliative Care, manuscripts are sought that relate specifically to palliative and/or end-of-life care topics in pain and symptom management for serious illness. Manuscripts that report on original research, including systematic literature reviews and meta-analyses, policy analysis, program evaluation, innovative educational programs, and evaluated community interventions. Possible topics include the role of the social worker in pain assessments and interventions; issues related to specific populations; and ethical challenges in decision-making. Deadline for submissions is January 15, 2016. [Submission details >](#)

## Jobs

### NYU LANGONE MEDICAL CENTER

We are interviewing for the position of full time senior social worker position covering the Neonatal Intensive Care Unit at NYU Langone Medical Center. This inpatient position will consist of covering the 30 isolettes in the NICU, Tisch Hospital. The social worker is an integral member of the interdisciplinary staff who will be working inclusively with families whose infants are receiving care in this area. The patient population consists of premature or full term infants who are either born at Tisch or transferred from an outside hospital for specialized care. Many of these infants may also have complex medical issues that require extended admissions to the inpatient setting and/or require multiple surgeries. It is an emotionally intense and demanding environment due to the infants' precarious medical conditions. These families require ongoing counseling, crisis intervention, and working with siblings and other family members around the emotional impact of having a baby in the NICU. The social worker will also be responsible for psychosocial assessments, family education, and discharge planning, and developing dynamic partnerships with families to maximize supportive experiences. The social worker will be involved with end of life discussions with families and the coordination of services with the

Pediatric Palliative Care Team and other staff when needed. This will also involve bereavement counseling and follow up. In addition to direct practice with families, the social worker will be involved with interdisciplinary family program development to expand and enhance the family centered and engagement culture on the unit. There will also be an opportunity to facilitate support groups, work with a Family Advisory Council, be involved with parent networking, and interface with various community based resources. The social worker who covers this unit should be prepared to take a leadership role in providing psychosocial services and programming to parents. Knowledge of developmental issues, the bonding process, domestic violence and child protection issues, end of life issues involving infants, and strong clinical skills are important.

The position requires 4 years of practice as an LMSW and requires an LCSW before conclusion of probationary period. If you are interested in this position, please email your resume to [socialwork@nyumc.org](mailto:socialwork@nyumc.org).

### The Children's Hospital at Montefiore

The Children's Hospital at Montefiore is seeking a part-time clinical Pediatric Chaplain to work as part of a multi-disciplinary Quality in Life team dedicated to the care of

*continued on page 7...*

*...continued from page 6*

children needing palliative and hospice support. The Children's Hospital at Montefiore is consistently recognized among the top hospitals nationally by *U.S. News & World Report*. Our academic affiliation with Albert Einstein College of Medicine, a National Cancer Institute-funded cancer center, results in the availability of unique treatment options for our patients.

Successful candidates should have a Bachelor's Degree and a Masters of Divinity degree or its equivalent; also official recognition of ministry, such as ordination or certification in Religious Vocation that is acceptable to The Association of Professional Chaplains (APC), The Association of Catholic Chaplains (NACC), or The Association of Jewish Chaplains (NAJC) or comparable national chaplain certification agencies; also endorsement for institutional ministry by ecclesiastical authority; in addition four (4) units (1600 hours) of ACPE, Inc. accredited Clinical Pastoral Education; with certification or in the process of certification by APC, NACC or NAJC. Such certification requires graduate theological education, formal clinical pastoral education and demonstrated pastoral and conceptual competence.

Responsibilities include providing for all aspects of ministry including: spiritual assessment and the provision of pastoral care, administration of the sacraments, pastoral visitation and counseling on own initiative and in response to referrals, with particular attention to ministry to persons in crisis, with life-threatening illness, near end-of-life and at the time of death, and to their families and friends. Review of candidates will begin immediately and will continue until the position is filled. A competitive compensation package and potential for academic appointment within Albert Einstein College of Medicine commensurate with training and experience are available. Interested candidates should send their C.V. and a brief statement of interest to:

Sarah Norris, MD  
Director of Pediatric Palliative Care  
The Children's Hospital at Montefiore  
3415 Bainbridge Avenue, Rosenthal Room 100  
Bronx, New York 10467  
sanorri@montefiore.org

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### Compassionate Care Hospice

FT/PT LMSW/LCSW Hospice Position Available – Brooklyn  
Compassionate Care Hospice is seeking a FT or PT LMSW/ LCSW for its Brooklyn hospice program. Patients reside in their own homes, assisted living facilities and skilled nursing facilities across the borough. Please send resume to robert.aberman@cchnet.net.

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### NYU Langone Medical Center

We are currently interviewing for the position of Manager of Social Services-Palliative Care. This important position provides leadership with the Directors of Social Work and Palliative Care to coordinate the development and implementation of the Palliative Care Program at NYU Langone Medical Center. The position functions collaboratively with multidisciplinary leadership across the institution to integrate palliative and end of life care for appropriate patients in all settings. A primary area of focus is supporting a patient's primary care team social worker to intervene when appropriate on issues surrounding palliative and hospice care. This position also is instrumental in developing, reviewing and revising structure standards and other policies to ensure consistency with all regulatory requirements and to promote excellent patient care.

The position requires a Master's Degree in social work (a PhD is preferred), an LCSW, a minimum of five years of progressive clinical experience in social work which includes one year in an administrative, supervisory or social work teaching position and previous experience in an end-of-life setting such as hospice, oncology, palliative care or other related experiences. Advanced training in end of life care, ethics consultation/mediation, and family treatment is also preferred. This position has a dual reporting to the Director of social work and to the Director of palliative care. If you are interested in this position, please email your resume to socialwork@nyumc.org.

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### Queens, VNSNY Hospice and Palliative Care

The Visiting Nurse Service of New York Hospice is currently seeking a full time Social Worker for one of our Queens teams. The position will provide the social work services to hospice patients in both community and nursing home

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## Jobs

*...continued from page 7*

settings, and be a member of the Queens interdisciplinary team. Our ideal candidate will be responsible for delivering core social work services, including psycho social counseling, advocacy, education, and case management for hospice patients and families.

We are seeking a NYS LMSW or LCSW with a preferred minimum of 1 year hospice/palliative care or health related

experience. Spanish language ability is preferred as well. Drivers license and car required to complete home visits in Queens.

VNSNY Hospice is a dynamic program which supports social work professionalism and interdisciplinary collaboration and offers excellent benefits, compensation and clinical supervision.

For further information or to forward a resume for consideration, please contact: Rivkah.Brenenson@VNSNY.org

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