June 2016  Issue No. 11

We hope that you find this complimentary monthly e-newsletter informative. Below are short summaries of each selected item with links to the entire pieces.

Please feel free to send any questions or comments to comm@healthcarechaplaincy.org.

Sincerely,

Rev. Eric J. Hall
President & CEO
HealthCare Chaplaincy Network & Spiritual Care Association

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**Spiritual Care Research Update**

**Members of HealthCare Chaplaincy Network’s (HCCN) Research Advisory Board** met by conference call last week to discuss the state of research in spiritual care and the field of professional chaplaincy. It was agreed that much has been accomplished in the past decade to affirm and validate the impact of spiritual care and the contribution of chaplains. While the research has been formidable, significant gaps still remain. HCCN is committed to contributing resources and creating the infrastructure to drive the research agenda forward. Next steps include identifying:

- Other organizations and researchers in the field to involve in this important effort.
- An agenda of research topics to initiate data collection pilot projects

If you are interested in participating, please send an email and some detail to comm@healthcarechaplaincy.org with the word "Research" in the subject line.
A recent study on nurses' definitions of spirituality and their comfort-levels with providing patients spiritual care has led a Cleveland Clinic research team to create a working definition for spirituality in healthcare.

The article "Critical Care Nurses' Perceived Need for Guidance in Addressing Spirituality in Critically Ill Patients," was published in the May 2 edition of the American Journal of Critical Care.

"Without a clear definition, each nurse must reconcile his or her own beliefs within a framework mutually suitable for both nurse and patient," said lead author Christina M. Canfield, RN, MSN, ACNS-BC, CCRN-E, in a media release.

"Nurses who seek to give whole-person care to their patients' sense that something beyond the technical aspects of their job is needed."

She is a program manager, Cleveland Clinic Hospital and clinical nurse specialist at Cleveland Clinic's main campus.

Through interviews with 30 nurses, researchers found that even though nurses report they are ready to offer direct spiritual support if they sensed it was needed, they had trepidation about initiating spiritual support for fear of potentially offending the patient or the patient's family.

Nurses also said they were eager for resources and guidance on how to address their patients' spiritual care needs.

Read more here and here.

A Patient Writes

10 indispensables for those with chronic pain and illness (KevinMD.com)

1. Email.
2. Being nice to yourself.
3. Pacing.
4. Earplugs.
5. The proper pillow arrangement.
6. Not sweating the small stuff.
7. Slowing down.
8. Amazon's Subscribe and Save (or its equivalent).
10. Saying "no."

**A Family Caregiver Writes**

**This Is What I Learned, Living in an Intensive Care Unit (Huffington Post)**

Recently I had the rare and shocking privilege of living in an Intensive Care Unit, or ICU, for three months. I was not a patient, nor a member of staff. I was there because my teenaged son became critically ill. Tim's learning difficulties meant that he needed his dad or me to be with him virtually all the time. I stayed every night for the first month, and then around five nights a week thereafter. ...

During those three months, I learned that crisis means looking after yourself as well as doing your best to help others. Specifically, I learned the following five insights.

1. Appreciate and care for your body.
2. Pause, breathe. Sit still in silence every day.
3. Give healing when you are drawn to do so.
4. Choose uplifting language.
5. Adopt a mindset of wellness.

**Physicians Write**

**Here are the lessons I learned from caring for my ailing father (KevinMD.com)**

My father's illness taught me to be a more humanistic and compassionate physician. Our patients and their families are scared and confused. It is not only our job to know anatomy in the operating room, clinical guidelines, or how to manage fluids and antibiotics; to truly heal a patient, we must understand what they're dealing with along the entire course of an illness. I know that my father's situation was not unique, but it forced me to confront the way that I practice medicine and forever shaped the way that I treat my patients.
A physician's view on when to get more information from your doctor (The Guardian)

Diagnoses are often just educated guesses, and prognoses less certain still. Based on data collected about cancer patients over the past four decades, doctors can talk about the odds of survival. For example, we know that a patient who has localised bladder cancer has about a 70% chance of being alive at five years. But oncologists telling patients that they have a 70% chance of survival at five years is a very different thing from predicting that they have about four years left of life, as some patients with bladder cancer will decline very quickly and others will live for many years.

Such discussions entail an honest admission by clinicians that they cannot look into the crystal ball, and such statements are only meant for patients and families to weigh the risks and benefits as they make decisions about their care, because cancer treatment can often make patients very sick and reduce their quality of life.

The key to good health might lie in the ability to recognise the hype created by medical reports and how the media treats health stories and health scares. It is important to sense when to push a physician for more testing or to resist a physician's enthusiasm when unnecessary tests or treatments are offered.

With polite but firm insistence, we got the doctors to understand that this was not about their plan but my father's. We can learn from this that embracing uncertainty - and asking the right questions - allows for more humane treatment, less anxiety and better care. But to do that we need to confront some sobering realities of our modern medical system.

Read more

Listening to Patients at the End of Their Lives is Crucial - So Why Don't Doctors Do It? (The Conversation Project & The Guardian)

For many physicians around the world, end-of-life care conversations test the limits of their ability to communicate with patients. In a recent opinion piece published in The Guardian, Australian oncologist Dr. Ranjana Srivastava discusses the need to provide physicians with the training and tools that will help them have better conversations with patients about their end-of-life wishes.

"Such training in medicine, especially when it pertains to end of life care, is patchy, undervalued and considered an optional extra rather than a clinical imperative. In an era where we have mapped the human genome and talk about cancer moonshots we have consistently failed to provide not just physicians, but all doctors, with the tools to be effective communicators."
Researchers Write

Just 5% of terminally ill cancer patients understood their prognosis, researchers say (e-hospice International, Center for Research on End-of-Life Care at Weill Cornell Medicine, Journal of Clinical Oncology)

Too many advanced cancer patients lack basic understanding about their disease, researchers report.

Only a small consortium of advanced cancer patients were able to show that they could identify and fully understand their prognosis according to a study led by faculty members from Memorial Sloan Kettering and Weill Cornell Medicine, which aimed to uncover the influence of prognostic discussions on the accuracy of illness understanding.

The open access study, published in the Journal of Clinical Oncology, compared patients' understanding of their illness before and after scans that staged their cancer, and before and after discussing results with their oncologist. Before the restaging scan visit, just nine (5%) of 178 patients acknowledged being at the end stage of incurable cancer with just months to live.

Find out what our contributing faculty members at the Center for Research on End-of-Life Care at Weill Cornell Medical College had to say about this issue.

Read more here and here

Palliative, End-of-Life, Hospice Care

Early Palliative Care Improves Outcomes for Family Caregivers of Cancer Patients (Oncology Times)

Introducing palliative care shortly after a cancer diagnosis results in better quality of life and fewer depression symptoms for family caregivers, according to a new study.

The study (Abstract 10131) was featured in a press briefing and will be presented at the 2016 American Society of Clinical Oncology (ASCO) Annual Meeting.

"The benefits of early palliative care extend beyond patient outcomes and positively impacts family caregivers. Early integration of palliative care for patients with newly diagnosed lung and GI incurable cancers leads to improvement in family caregivers'
depression and aspects of quality of life," said lead author Areej El-Jawahri, MD, Director of Bone Marrow Transplant Survivorship Program at Massachusetts General Hospital Cancer Center, Boston.

"This study suggests that early palliative care creates a powerful positive feedback loop in families facing cancer. While patients receive a direct benefit from early palliative care, their caregivers experience a positive downstream effect, which may make it easier for them to care for their loved ones."

This is the first study to show that early palliative care alone for a patient with cancer can have a strong impact on family caregivers, she said.

Read more

### End-of-Life Care in Hospitals Has a Long Way to Go (Health Leaders Media)

Many doctors and patients don't talk about how to handle the pain, disability, or despair that may accompany a serious illness or imminent death. Hospital leaders can push for greater competency in advanced planning among clinicians.

Medicare may reimburse primary care physicians for end-of-life talks with patients, but those conversations between seriously ill patients and their doctors often don't occur, even when patients are being treated for serious illnesses.

A survey by the Massachusetts Coalition for Serious Illness Care shows that 85% of Massachusetts residents believe that physicians and their patients should talk about end-of-life care, but only 15% have actually had such conversations.

Working with healthcare delivery systems will be one of the coalition's most important tasks, according to Atul Gawande, the coalition's co-chair and a surgeon at Brigham and Women's Hospital in Boston.

Read more

### Palliative, hospice care lacking among dying cancer patients, researcher finds (Science Daily, Stanford University Medical Center & Journal of Palliative Medicine.)

Medical societies, including the American Society of Clinical Oncology, recommend that patients with advanced cancer receive palliative care soon after diagnosis and receive hospice care for at least the last three days of their life. Yet major gaps persist between these recommendations and real-life practice, a new study shows.

Risha Gidwani, DrPH, a health economist at Veterans Affairs Palo Alto Health Economics Resource Center and a consulting assistant professor of medicine at the Stanford University School of Medicine, and her colleagues examined care received by all veterans over the age of 65 with cancer who died in 2012, a total of 11,896
individuals.

The researchers found that 71 percent of veterans received hospice care, but only 52 percent received palliative care. They also found that exposure to hospice care differed significantly between patients treated by the U.S. Department of Veterans Affairs and those enrolled in Medicare. In addition, many patients who received palliative care received it late in their disease's progression rather than immediately following diagnosis, as recommended by ASCO.

Read more

**What You (i.e. Palliative Care Team Members) Can Do To Improve Quality Right Now (Palliative in Practice blog from Center to Advance Palliative Care)**

*Post written by Diane E. Meier, MD, Director, Center to Advance Palliative Care*

I had the privilege of visiting palliative care colleagues in Melbourne, Australia in February of this year. Not only did they share some great book recommendations (*Songlines* by Bruce Chatwin - which includes this quote comparing western to Australian aboriginal culture: "We give our children computer games and guns...they give their children the land.") and fantastic wine and food that rivals that in my hometown of New York City, but also a breathtakingly simple way to monitor quality of palliative care during your weekly team meeting.

I observed the weekly palliative care team meeting during my visit. After "running the list" and discussing each patient on service with the whole team, Dr. Jenny Philip pulled out the spread sheet (at link) and asked everyone if they had observed any of the following among the patients they had cared for:

- Uncontrolled pain and symptoms for >24 hours
- Fecal impaction
- Dissatisfaction with the team's care on the part of patients, family members, colleagues
- Occurrence of requests for a hastened death
- Emergency room "crash" admissions
- Team distress
- And others

If such an occurrence was noted, specifics were recorded and the team leader then developed a plan of inquiry, root cause analysis and remediation.

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**Podcast with Substantial Content about a Successful Palliative Care Program Operated by UCLA Health for the Motion Picture and Television Fund (Palliative in Practice blog from Center to Advance Palliative Care)**
Interviewed are Nurse Practitioner Linda Healy and Chaplain Rabbi Arthur Rosenberg. The program was set up to help the entertainment community - inpatient, in residence care, and outpatient - get proper care when facing serious illness and comprises geriatricians, nurse practitioners, nurses, chaplains, licensed clinical social workers, dietitians and activity coordinators. Guidance and counseling is also provided for those struggling with complex decision making about medical issues.

Rabbi Rosenberg completed the Palliative Care Chaplaincy Specialty Certificate course offered jointly by Health Care Chaplaincy Network and the California State University Institute for Palliative Care. Rabbi Rosenberg emphasizes that delivering effective spiritual care requires the professional chaplain as the specialist and the other members of the interdisciplinary team as generalists.

Listen here

Caring for the Human Spirit

Emotional, spiritual needs can affect health outcomes and how a chaplain helps (The Union Democrat - Sonora, California)

A Joint Commission Study found that health outcomes can be positively affected by attempts to address emotional and psychosocial needs.

To that end, Chaplain Mario DeLise at Sonora (California) Regional Medical Centersaid he works with staff to give them the tools to try to help patients on a personal level.

"It's not just chaplains that can have a calming experience (with a patient)," he said. "We want to give specific tools to everybody to talk about spirituality that builds up community. Just to give them the ability to engage people in a way that works for everyone."

When DeLise talks about spirituality, it's about noticing the spiritual experience a fellow human being is going through when they are sick.

"Spirituality is often seen to include how we make meaning of life, what we find to be our purpose in life, and how we connect in meaningful ways - with ourselves and with that which is outside ourselves. Also, chaplains and others who join a sick person as a support person help remove them from isolation as we participate in what they are going through and provide compassion and empathy," DeLise said.

"One of our things is to set people at ease. Let them know they are not going through it alone. That is typically appreciated," he said. "It would probably be disingenuous to say everyone we leave is beaming in joy, but typically we have a calming effect on people."
However, there's only so much spiritual care can do, he allowed.

One patient DeLise met was "suspicious of everyone who came in."

DeLise spent some time with him, just visiting and talking for a while.

"His wife later told me that really changed things for him. He was able to feel more trust for the whole hospital team," DeLise said. "That was a noticeable, positive thing."

DeLise said another former patient had a long history of health issues.

"I just kind of gave her space to talk. She shared her story. ... Finally she just kind of paused. She said, 'You know, I think God is using this to draw me closer to himself.' I didn't say that to her," DeLise said. "When she explored her experience in the greater context of meaning, she discovered through talking. It doesn't take away her health struggles, but for her it gave her a more positive outlook."

Read more

**Keeping Our Spirit in Mind (Huffington Post)**

"Spirit is the essence of being human," said the late Joseph Fabry, who wrote Guideposts to Meaning and Pursuit of Meaning, based on Viktor Frankl's existential humanistic theory known as Logotherapy. "You have a body that may become ill; you have a psyche that may become disturbed. But the spirit is what you are. It is your health core."

That health core - our life force, needs to be cared for. When someone is ill or suffering physically, it is imperative that the person's spirit is also cared for. This is why the Spiritual Care Association came into being earlier this year. When we see all that the spirit does for us, is it any wonder that we emphasize the importance of keeping it healthy?

Should you ever feel that your spirit is not in prime condition or temporarily "out to lunch," heed the words of the well-known physician, spiritualist and author Deepak Chopra. "Ultimately spiritual awareness unfolds when you're flexible, when you're spontaneous, when you're detached, when you're easy on yourself and easy on others."

Read more

**New York-Area Alzheimer's Home Care Agency to Offer "Virtual" Spiritual Care by Connecting With Chaplains via Phone, Email, Video**

For individuals with Alzheimer's disease and related dementias, and their family caregivers, isolation, anxiety, and existential questions often accompany this terminal brain disorder. Now, a New York-area home care agency is collaborating with
HealthCare Chaplaincy Network (HCCN) to offer its clients a direct connection to professional health care chaplains who can help with the emotional and spiritual distress surrounding this disease and other illnesses.

ACS Home Care LLC (Alzheimer's Care Specialists), based in Northport, NY and servicing Nassau, Queens, Suffolk, and Westchester counties, is introducing "virtual" professional chaplaincy as a value-added service to new and existing clients. The service, Chat with a Chaplain, enables patients and family members to confidentially speak to a professional multi-faith chaplain via phone, email, or video chat.

The announcement coincides with Alzheimer's & Brain Awareness Month in June. ACS specializes in Alzheimer's disease, and also serves clients with other illnesses and needs.

This is the first home care agency HCCN is collaborating with to provide the unique service, which is staffed by HCCN's professional multi-faith chaplains. Chaplains are the spiritual care specialists on health care teams; they listen without judgment and provide comfort and meaning.

Chat with a Chaplain is available to anyone, regardless of religion or beliefs, or no religion or beliefs. Clients can obtain emotional and spiritual support as well as submit prayer requests. In the face of illness, common questions include, "Why me?" or "Has God abandoned me?"

Robert Macedonio, RN, president, director of patient care services at ACS Home Care, said he expects people facing Alzheimer's disease and related dementias to especially benefit from this service.

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