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Palliative Medicine Physicians: Adjuncts to Comprehensive Patient Care

Middlestate Palliative & Hospice CareCenter is a resource for physicians caring for patients with serious, even terminal, illnesses. The CareCenter's staff helps the physician attend to their patient's physical needs, as well as the mental, emotional, and spiritual needs of both the patient and their family.

Over the last three decades, there has been a growing awareness that truly comprehensive patient care goes beyond the needs of the physical body; it also requires treating the patient as a whole person and not simply as a disease process. It includes acknowledging the patient's psychosocial background and how that relates to their understanding and views of their own disease process. It also involves identifying and supporting the mental, emotional, and spiritual needs of both the patient and their family. This holistic approach, called palliative care, is a concept dating back millennia and has been practiced in Australia, Canada, and Western Europe for thirty years; however, it has only been two years since Palliative and Hospice Medicine has been a recognized subspecialty in the United States.

Middlestate Palliative & Hospice CareCenter is a community-based, not-for-profit practice providing palliative care services to many different healthcare systems in the area. The CareCenter's physicians, like palliative medicine physicians nationwide, work to perpetuate, strive for, and uphold excellent quality standards for patient care throughout the healthcare industry, not just within the palliative medicine specialty.

Although knowledge of palliative care within the medical community is growing, it has yet to fully eclipse a common misconception; namely, that palliative care equates to hospice care—that is, end-of-life care. While there is some truth in that description, it's more accurate to say that palliative care and hospice care are variations of the same concept.

"Palliative care *is* hospice care," says Maureen Johnson, MD, FACP, FAAHPM, who is board certified in both Internal Medicine and Palliative and Hospice Medicine, and is one of the acknowledged pioneers in the subspecialty of Palliative and Hospice Medicine. She is chief medical officer of the CareCenter.

"If you look at the continuum, hospice care is holistic, team-based care that focuses on a patient and family in the very end stages of illness," she says. "Death is a known outcome within a perceived, limited amount of time defined in weeks to months.

"That same approach of holistic, team-based care can extend far upstream to any patient who has a significant, life-changing diagnosis that doesn’t have to be terminal, such as Multiple Sclerosis, ALS, severe rheumatoid arthritis, or lupus. So palliative care is what begins when we become a patient. In a palliative care model, we may interface with palliative care for years, even decades."

By contrast, she continues, there are people who don't have a chronic disease but have a life-threatening illness that completely disrupts their lives. The palliative care approach, says Dr. Johnson, very much supports those patients, as well. "I look at life-limiting, life-defining, and life-threatening illnesses as all being very well supported by palliative care."

Dr. Johnson is a strong believer in a holistic, balanced approach and she found that perspective supported in the palliative care model. Palliative care, she says, is what medicine was intended to be.

"Plato talked about holistic care six thousand years ago, but we've gotten seduced by technology and diagnosis and treatment, and we've lost our center as far as why are we doing what we're doing. I think most physicians who spend any time in palliative care find that they are very affirmed by it and it is a very, very satisfying career."

Andrew Ruskin, MD, is one of those physicians who are pursuing a medical career that will include palliative care. The board-eligible internist recently began a Fellowship in Palliative and Hospice Medicine at the CareCenter. He says he first became aware of this subspecialty during a geriatrics rotation in his fourth year of medical school. He remembered that experience as he was entering his residency at Pasco University Medical Center.

"My first month as an intern was on the oncology ward," he says, "and I came to realize there were an incredible number of patients who didn't have a good grasp of their own illnesses and the depths of their illnesses, nor did their families. They also had a lot of symptomatic complaints that weren't necessarily being addressed. I thought back to my one-week exposure as a medical student and decided I'd pursue palliative care some more."

Once Dr. Ruskin has completed his fellowship, he plans to incorporate palliative care into his primary care practice, dividing his time between seeing his patients in the office and in the hospital, and also serving as a palliative care consultant with the hospital or doing in-patient and home-based hospice care.

COMMUNICATION IS KEY

Dr. Johnson says a palliative care physician must have communication as their number one skill set. "We have to be able to communicate with families, and the number one procedure we do is the family meeting—bringing together a group of people and helping them to get their heads around what is happening and make some decisions.

"We have to then do the same thing with the team that's caring for the patient because what we experience in the hospital model is that care becomes parallel. I call it the 'disintegration of the person,' and nowhere is it more evident than in the ICU."

She says the typical ICU patient is separated into body systems, with a specialist assigned to each system. Each specialist reports regularly on how the body system under his or her care is working, yet there is no one to integrate all of those separate reports.

"So the daughter at the bedside asks, 'How is my mother?' and, depending on which specialist she's asking, the answer she gets is, 'Her lungs are working well' or 'She's producing urine' or 'Her cardiac output is fine.' But nobody is answering the question," explains Dr. Johnson.

"Palliative care's competency is to say, 'All these organ systems are working, but your mother does not seem to be doing well. What would be your mom's goals? How can we help you and your mother? What's the chance of meaningful recovery as opposed to physiologic recovery?' Those types of conversations pull it all together."

Dr. Johnson says physicians today have the capability to sustain patients beyond what their own ability to sustain their life would be. What physicians aren't doing, she adds, is asking a tough question: Should we do that?

"If the patient says, 'I never want to be in a nursing home,' then why would we do all these things where the only potential outcome is a nursing home? We just set ourselves up for these horrible ethical dilemmas because we haven't asked questions early on."

When palliative care services are initiated and substantiated in the hospital, states Dr. Johnson, the number of ethics consults typically drops by over fifty percent. "You're focusing on communication, you're establishing goals of care, you're making sure people have advanced directives, you're getting people to talk to each other. There is no ethical dilemma after a while because we've done all the work."

AN ONCOLOGIST'S PERSPECTIVE

Joseph Banner, MD, a board-certified Oncologist-Hematologist at County General Hospital, is one of the physicians who has seen first-hand the benefits that palliative care brings to both his patients and his practice.

"Palliative care is an important adjunct to the overall care we provide," says Dr. Banner. "With palliative care, the focus is on supportive care, pain management, and management of potential complications that may be therapy-related.

"Palliative care is taking the knowledge base that's been learned in the hospice population about how to care for chronic pain, chronic nausea, and fatigue and placing this type of management in a setting where patients are still receiving some form of active care.

"We have people at the CareCenter who have a great deal of expertise in the management of chronic symptoms that accompany malignancies, and I think from an overall patient management standpoint, it's highly complementary to what I do in terms

of providing care. Even in the setting of someone who may not have a curative outcome, it's an important adjunct in care delivery."

AWARENESS AMONG PHYSICIANS

Partnering with physicians on cases is the most effective way Dr. Johnson convinces them of the benefits palliative care can provide to their patients. Her efforts have made an impression.

"Despite this, I still have physicians who say, 'This patient isn't ready for palliative care,'" says Dr. Johnson. "*Any* patient could benefit from palliative care if they perceive they need it. Even if they don't continue, a palliative care consult for anybody who's ill could be beneficial because we're talking about the psychological ramifications of being ill. How could that not benefit *everybody*?"

The bottom line, she says, is that a palliative care physician can make a primary care physician's job easier. "An office-based physician's patient is in a hospital that they don't go to, or their patient is at home and they don't go there. How does that physician case-manage a complicated illness if they can't get to the patient? Only if they have a team that goes to the patient: a social worker, a physical therapist, a physician.

"The docs will tell you they feel like they're taking better care of their patients. Some physicians worry they'll lose control. My personal experience is that they *gain* control because they have a better sense of what's happening with their patient than before."

KEEPING PERSPECTIVE

One of the most difficult aspects of practicing palliative medicine is caring about and empathizing with a terminally ill patient while still maintaining the distance and

objectivity necessary to assist the patient and his or her family in making the best decisions.

"As a physician, I can very much love them and care for them and practice compassion," says Dr. Johnson, "but I am first and foremost a physician in their life, and I have to be really attentive to that.

"You are getting down to the nitty gritty of what people value and what they live for. There are heavy emotions and discussions about death and its approach and what that means to a family. The teamwork is what really keeps you in the therapeutic relationship as opposed to crossing the line.

"What I've noticed over the years as a consultant is that in some ways myself and my colleagues and my practice represent a safe harbor for other physicians," observes Dr. Johnson. "We're the people to whom they can say, 'This is really tough,' or they can acknowledge the grief of losing a patient for whom they've cared for twenty-five years. They're able to give that a voice and say, 'I need to grieve this as a human being,' whereas many physicians often aren't attentive to that."

Finding that line between caring about a patient and remaining objective is a boundary Dr. Ruskin is continuing to identify. "Dr. Johnson has told me that you are who you are wherever you happen to be, so if I'm with a patient and their family then I do allow myself to feel some of the emotion they're going through. You have to be able to do that. If you can't do that then you can't be compassionate and if you can't be compassionate, then you can't understand what they're going through."

JOANN'S STORY

Joann South, RN, MSN, is Vice President for Patient Care Services at a hospital in the area. In March 2008, she became very ill with a severe case of shingles and was hospitalized twice. When she was nearing discharge from her second hospitalization, she was asked what home healthcare agency she wanted to use. She chose Middlestate Palliative & Hospice CareCenter based on their stellar reputation and the recommendation of a friend.

At the same time, Joann says her primary care physician was really struggling with how to treat her intense pain. "It seemed like every time I started a new medication, I would have a reaction to it or develop allergies to it. My physician was looking for a colleague to talk to about chronic pain and what ideas they had about dealing with it." Her physician found colleagues to consult at the CareCenter.

Joann says the staff of the CareCenter provides care in a way that keeps the focus on her and her family. "They're looking at my whole person, and they've been very supportive, whether my family and I need support psychologically or spiritually. They're always willing to talk to my family members and allay their fears or answer their questions."

Joann says her pain is now under better control through the use of IV pain medication, as well as physical therapy and proper nutrition, and she and the physicians at the CareCenter are working to transition her to oral medication. That will be a major step toward allowing her to return to work. "That's my goal and that's their goal with me—to get me back to work and to be healthier than I was before this all started."

WHY DO WE NEED IT?

Dr. Johnson cites three reasons why the Palliative and Hospice Medicine subspecialty is so valuable: "From an outcome standpoint, the evidence is highly suggestive that patients do better in terms of survival, comfort, symptom management, achieving goals of care, and care concordant with values.

"From a financial point of view, the involvement of palliative care has actually cut patient care costs significantly, predominantly in pharmacy and procedures, because we're very intentional about what we're doing and why we're doing it."

The third reason, she says, is that palliative care is really the affirmation of the art and science by which physicians care for their patients. "Palliative care affirms for them that there is benefit in the compassionate, humanistic things they do for their patients, which in our traditional system are not affirmed. There is also a science in that caring that has not been affirmed. Physicians will say to me, 'This is why I'm a doctor, and palliative care gives my compassion a voice and a platform to be validated.'"

While palliative care physicians have established their area of specialty, says Dr. Johnson, their long-term goal is that there will be primary palliative care so that any physician, particularly anyone who practices in primary care, would have primary palliative care training to incorporate into their practices. The specialty level of palliative care will still be available for those patients in situations requiring more expertise.

TRULY MEANINGFUL TIME

"Palliative care is the most satisfying work in medicine I've ever experienced," says Dr. Johnson, "and, at the end of the day, to feel like you really helped someone is what gets you home when you're running out of gas."

Dr. Johnson relates the story of a patient who had metastatic colon cancer and was in a nursing home. The prognosis was that he had days to live, and his pain was not well controlled. "I sat with his wife," recalls Dr. Johnson, "and I said, 'You know, I understand we've only got a few days, and I know you don't want to prolong this dying phase, but I really feel like your husband is not comfortable. If it would be okay, I'd like to give him some IV fluids and give him his pain meds intravenously because I think he would feel a lot better.' Lo and behold, the guy perked up like crazy!

"With his pain under control and a little bit of steroids, he really started to regain some strength, and I got him home twice. He said to me, 'You know what? I had to work two jobs to support my family. The hardest part of being at this phase of my life is feeling like I regret that I haven't been able to be with my family. Not that it makes up for it but I've been able to have two days where I have talked to my kids about what's important.' He grabbed my hand and said, 'I cannot thank you enough.' I was moved to tears.

"For his kids, for his wife, for his grandkids, there is nothing better," says Dr. Johnson. "In the circumstances, for him to be able to have that truly quality, meaningful time was just incredible. I love it. It makes me so excited."

Middlestate Palliative & Hospice CareCenter is located at 789 Oak Court, Treasure Island, FL 63447. For more information, call (800) 555-9999. Additional information about the CareCenter is available at www.website.com.

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Maureen Johnson, MD, FACP, FAAHPM, received her Medical degree from the University of Pinellas School of Medicine and completed a residency in Internal Medicine through Northsouth College Crest School of Medicine at Bloom Hospital, where she was also chief resident. She is board certified by the American Board of Internal Medicine and the American Board of Hospice and Palliative Medicine. Dr. Johnson is active in research, speaks regularly to local and national groups, and has been published extensively in peer-reviewed articles and other publications on the importance and benefits of hospice and palliative care.

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