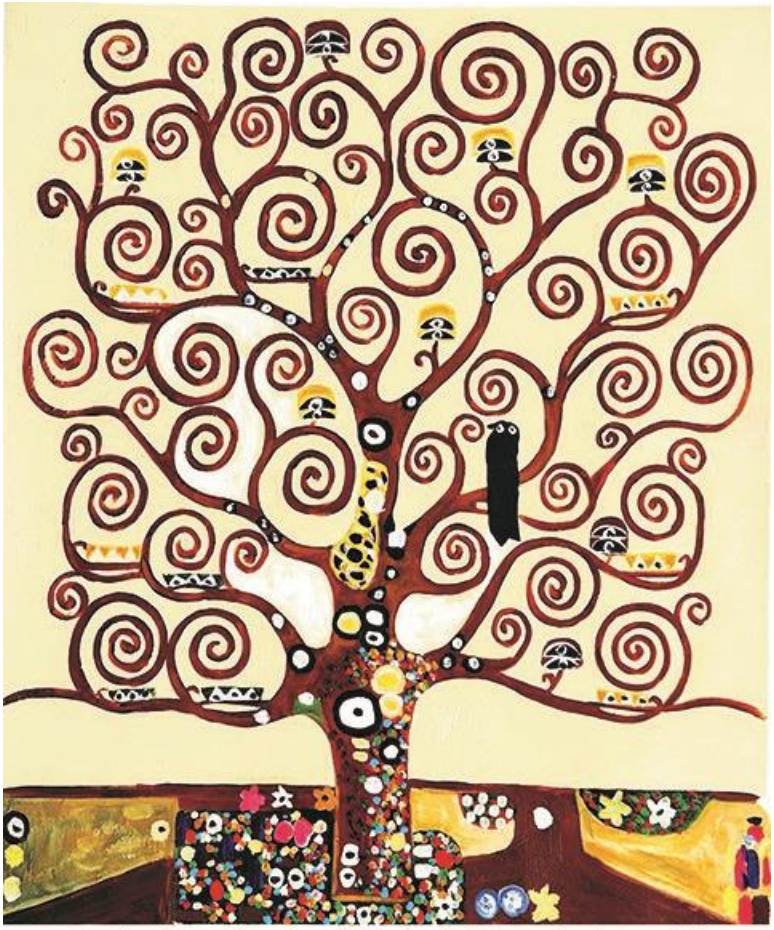
Delivering the Right Care at the Right Time in the Right Setting

Interview with Diane E. Meier, MD



Based on Gustav Klimt, Tree of Life, Stoclet Frieze, Lebensbaum, 1905

By Jean Galiana
ACCESS Health International

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Background

Palliative care prioritizes quality of life for people with serious illness. Palliative care teams provide an added layer of support during disease treatment for patients, families, and treating clinicians by helping to manage the pain, stress, and complexity associated with serious illnesses. The New York City based Center to Advance Palliative Care was established in 1999 as a National Program Office of the Robert Wood Johnson Foundation. Since 2006, a number of charitable foundations and private philanthropies have funded the Center. In 2015, the Center also became a membership organization for healthcare entities. Today the Center has over nine hundred organizational members, including hospitals, health systems, hospices, nursing homes, and office practices.

The mission of the Center to Advance Palliative Care is to increase the availability and quality of palliative care services to those living with serious illness.

The Center works toward six key strategic goals:

Scaling access to high quality palliative care in all hospital and community healthcare and home settings through provision of tools, training, and technical assistance;

Provision of clinical skills training (such as pain and symptom management and communication) to all frontline clinicians across disciplines;

Improving access to payment for high quality palliative care through payer provider partnership initiatives;

Public and professional awareness of what palliative care is and when to demand it;

Policy supportive of standardized access to high quality palliative care;

Quality and standardization via the National Palliative Care Registry and periodic State by State Report Cards on geographic variation in access to palliative care.

The Center to Advance Palliative Care seeks to change the healthcare delivery system to serve the forty six million people in the United States in need of palliative care. They partner with policymakers and healthcare systems to address gaps in access to palliative care by supporting the creation of high quality accessible palliative care in community and hospital settings.

The Center convenes palliative care thought leaders in joint learning activities and disseminates knowledge of best practices in all aspects of palliative care. Members of the Center to Advance Palliative Care have access to extensive online resources, including online Continuing Medical Education and Continuing Educational Unit Training

courses, webinars, Virtual Office Hours with national leaders, national annual seminars, toolkits, training, and technical assistance.

The Center uses online media to build awareness of palliative care for the general public through social media including the Get Palliative Care website to educate and support the general public in understanding and finding palliative care services. The website is open to the public and houses a directory of palliative care providers in the United States.

In this interview, Dr. Diane E. Meier discusses the urgent, global need to fill the palliative care gap to care for the growing population of those living with chronic and serious medical conditions and to support their families. Dr. Meier details the efforts of the Center to Advance Palliative Care to address this need.

About Dr. Diane E. Meier

Dr. Diane E. Meier is Director of the Center to Advance Palliative Care, a national organization devoted to increasing the number and quality of palliative care programs in the United States. Under her leadership, the number of hospital based palliative care programs in the United States has more than tripled in the last ten years. She is also Vice Chair for Public Policy, Professor of Geriatrics and Palliative Medicine, and the Catherine Gaisman Professor of Medical Ethics. She also was the founder and Director of the Hertzberg Palliative Care Institute from 1997–2011, all at the Icahn School of Medicine at Mount Sinai in New York City.

Dr. Meier is the recipient of numerous awards, including the 2008 MacArthur Fellowship for individuals who have shown exceptional creativity in their work and the promise to do more. She was named one of twenty People Who Make Healthcare Better in the United States by HealthLeaders Media in 2010. She also received an Honorary Doctorate of Science from Oberlin College in 2010. In 2012, Dr. Meier was awarded the Medal of Honor for Cancer Control by the American Cancer Society in recognition of her pioneering leadership to bring non hospice palliative care into mainstream medicine. She received the American Geriatrics Society Edward Henderson State of the Art Lecture Award in 2013. Dr. Meier's honors include the Open Society Institute Faculty Scholar Award for the Project on Death in America, the Founders Award of the National Hospice and Palliative Care Organization 2007, AARP Fiftieth Anniversary Social Impact Award 2008, Castle Connelly's Physician of the Year Award 2009, and the American Academy of Hospice and Palliative Medicine Lifetime Achievement Award 2009. She is currently the Principal Investigator of a National Cancer Institute funded five year multisite study on the outcomes of hospital palliative care services in cancer patients. Dr. Meier served as a Columbia University Health and Aging Policy Fellow in Washington DC during the 2009–10 academic year, working both on the Senate Health Education Labor and Pensions (HELP) Committee and at the Department of Health and Human Services.

Dr. Meier has published more than two hundred original peer reviewed papers and several books (Appendix A). Her most recent book, *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform*, was published by Humana in 2014. She edited the first textbook on geriatric palliative care, as well as four editions on geriatric medicine. As one of the leading figures in the field of palliative medicine, Dr. Meier has appeared numerous times on television and in print, including *ABC World News Tonight*, *Open Mind with Richard Hefner*, the *New York Times*, the *Los Angeles Times*, *USA Today*, the *New Yorker*, *AARP*, and

Newsweek. She figured prominently in the Bill Moyers series "On Our Own Terms," a four part documentary aired on PBS.

Dr. Meier received her BA from Oberlin College and her MD from Northwestern University Medical School. She completed her residency and fellowship training at Oregon Health Sciences University in Portland. She has been on the faculty of the Department of Geriatrics and Palliative Medicine and the Department of Medicine at Mount Sinai since 1983. She lives in New York City.

Interview

Jean Galiana (JG): Please describe the activities of the Center to Advance Palliative Care.

Diane Meier (DM): The Center to Advance Palliative Care is an international non profit organization located within the Icahn School of Medicine at Mount Sinai in New York City. Our mission is to improve access to high quality palliative care for anyone living with a serious illness and to support their family. Our vision is *palliative care everywhere*. One should not need to be lucky to access palliative care when living with a serious illness. High quality palliative care should become the reliable and consistent standard of care for serious and complex chronic illness.

Today, in a hospital, we can take for granted that there will be nurses who have a certain minimum of training. There will be an intensive care unit. There will be an emergency department most of the time. Each of those components must meet a certain quality standard. Access to palliative care should be equally standardized and routine wherever patients and families with serious illness receive care.

People who are well and healthy might see their primary care doctor once or twice a year to get their annual checkup. The people who use the healthcare system the most are those with serious chronic illnesses, most of which are not curable. The majority of people with serious illness have chronic diseases like diabetes, hypertension, heart failure, emphysema, kidney problems, dementia, or cancer, with which people live for many years and sometimes decades. We have a healthcare system that was designed fifty years ago around curable, fixable, and surgical problems. It fails to address the whole person care needs of the tens of millions of people with serious and often multiple chronic illnesses who are living a long time. The goal of palliative care is to help people living with serious illness to have the best possible quality of life. That means giving expert attention to communication about what to expect, family and social support needs, and skilled management of pain and other symptoms like fatigue, depression, loss of appetite, and difficulty sleeping.

Stress is an important aspect of care that is often overlooked. Receiving the news of a serious illness is a spiritual and existential blow. A serious illness changes how a person lives, how their future will unfold, and their roles at work and at home. The diagnosis can make a person question how to be a father or mother, or how to be a spouse or a professional living with a disease. It is a profound shock for people. Palliative care clinicians are trained to help people come to terms with their diagnosis and adjust to living with the new reality.

The “informal” caregivers—often close family members—also experience stress. Our current healthcare system measures only what is paid for. We do not measure what is not paid for because it is not a government entitlement. The taxpayer does not pay for informal or personal care except when the tax payer is the patient or the caregiver themselves. The out of pocket costs to families for being caregivers are staggering, amounting to over half a trillion dollars per year worth of care. This cost is not visible on the Medicare or the Medicaid budget. The cost of informal care delivered by loved ones is a serious issue physically, emotionally, and economically, and needs to be addressed.

Caregiving often draws women (and men) out of the workforce, which leaves them less financially secure at the time of retirement. Some families lose their home or deplete the college funds of their children. The cycle of poverty repeats itself because those in the lower socioeconomic strata are the ones who are most likely to be seriously and permanently hurt by the costs of family caregiving. They will not be able to pass on any resources to the next generation. The healthcare system is full of inequities that hurt those who are the most ill and poor.

JG: When you refer to palliative care, do you mean palliative care in the hospital setting?

DM: Palliative care principles and practices need to be everywhere that patients and families in need receive care. This includes hospice, and also nursing homes, home care, and office practices. That is the point. Palliative care is now widely available in hospitals because of ten to fifteen years of work to make it so. Palliative care is also widely available as hospice if you are very close (within a few months) to death. The big care gap that we are trying to fill is for those who are not hospitalized or dying soon, such as people in nursing homes, assisted living facilities, and at home with their families caring for them. They have basically been abandoned to handle life with the burdens imposed by serious chronic illnesses on their own. They have been abandoned financially. They have been abandoned in terms of a workforce trained to address their needs and honor the things that matter the most to them. We do not train doctors and nurses to manage symptoms. We do not train doctors and nurses to communicate with patients and families to understand how an illness may affect their life. Rarely are physicians trained to understand what is most important for the patient and family. When I ask patients and families what is most important, I will hear answers such as, “I want to leave the hospital and go home to my garden.” Patients also say, “I want to see my youngest grandson graduate from college,” or “I want to connect with my brother who I have not spoken to in thirty years.” I have never had someone say to me, “I want to live forever.” Yet, the entire healthcare system is designed as if everyone wants to live forever. The factors that matter most to patients and families are completely ignored because we

don't ask. How could we possibly design a person centered care plan without the key concerns of the patient in the forefront?

Our mission is to make palliative care accessible wherever people need it, which is predominantly in the community and at home. It is also our mission to make sure that every clinician, such as oncologists, other specialists, homecare nurses, nursing home directors, and family practitioners, has the basic core knowledge and skills to deliver palliative care. These are skills that should be taught in medical and nursing school and in residency and graduate education programs, but are not. We have a patient population whose dominant need is for palliative care and a workforce that is not equipped to meet that need. The Center to Advance Palliative Care is leaping into the chasm between what people receive and what they need, and trying to close it.

JG: Do people confuse palliative care with hospice?

DM: There is much misunderstanding about palliative care because many people, especially physicians, hold to the myth that palliative care is the same as hospice care. It is not the same as hospice care. All hospice care is palliative care, but not all palliative care is hospice care. Hospice care is focused on quality of life, symptom relief, support for families, and understanding and honoring what matters most to patients and families. Because of the Medicare statute that governs hospice, a person cannot receive hospice care unless two doctors say the person is likely to die in a short period of time. The policymakers who designed the statute were concerned that everyone would want this kind of care because it is great care. They were thinking it would be too costly, so they restricted hospice to people who are predictably dying. We have no idea who is dying in six months. We are lucky to be able to predict the timing of death accurately when it is weeks away. The result of laws restricting access to hospice is that the median length of stay in hospice in the United States is seventeen days. Thirty percent of people who receive hospice receive it for less than a week.

JG: How were the hospice patients being cared for before the last weeks of life?

DM: They were on their own. They were very likely traveling back and forth to the hospital in an ambulance. Ambulance transport and emergency department visits are reimbursed. Patients are being hospitalized for concerns such as a dyspnea crisis or a pain crisis that the primary doctor should have been able to prevent and identify as a high risk. They were not identified as high risk because the clinicians were never trained to do so. The doctors throw their hands up and say, "He was in terrible pain, what could I do? It was after 5 pm in the afternoon, my office was closed." In the United States, when someone with a serious chronic illness has a significant problem after 5 pm, they call their doctor. They hear a recorded message that says, "If this is an emergency, hang up now and dial 911." If you are an eighty seven year old woman and your eighty nine

year old husband, who has dementia and low back pain from arthritis, is unable to stand up from the couch because his back is in spasm, you cannot pull him up. There is no one around to help you, you call your doctor, and it is 6 pm on a Thursday night. You are connected to the "call 911" recording. 911 is the only safety net in the system.

JG: What is a better scenario for these types of events?

DM: The above scenarios should be a "never event." There should be a higher standard of care for seriously ill patients who are predictably going to experience a health crisis. It is easy to identify those patients. They have severe recurrent low back pain, an eighty seven year old family caregiver, no other family in town, and significant cognitive impairment. It is predictable that they are going to have needs after 5 pm, yet there is no system set up to support them.

Going to the emergency department and hospitals is the worst place for the oldest and frailest patients. Research shows that the hospital is the third leading cause of death in the United States. Think about that. This does not happen because people working in hospitals are trying to do harm. The reason for this startling statistic is that the people in the hospitals are extremely vulnerable. They are often frail and cognitively vulnerable to confusion and disorientation. Someone with cancer is immunologically fragile because of chemotherapy and radiation. A person could go to the hospital for a pain crisis, catch a resistant bug, and die. A person might fall and then be tied to the bed, and then become incontinent. This can lead to agitation and delirium. They may never go home again. Hospitals should be the place of last resort, not the only resort. They are often harmful to the patient population in need of palliative care. Palliative care should be available in the community. This is a fixable problem.

One *New York Times* article gives a heart breaking account of how the state of South Dakota deals with their frail elderly. The state does not have the ability to care for those with multiple chronic conditions, so they put them all in nursing homes whether they need that level of care or not. They do not have systems in place to manage this patient population. It is completely unacceptable. It is cruel, and it is neither cost effective nor sustainable.

JG: Is the Center to Advance Palliative Care a think tank?

DM: Yes, in some respects we are a think tank. We find the people doing the best work, translate what they are doing into transferrable skill sets, and then disseminate the information. We identify initiatives that work, boil them down to their essence, and publish them for others to adopt in their own settings. We facilitate the diffusion of innovation. For example, Dr. Kristofer Smith's program is a center of excellence. We have eleven centers of excellence around the country that were identified because they

are delivering cutting edge, state of the art, palliative care in various settings, including nursing homes, private homes, offices, and hospitals. We have recognized these centers of excellence so that teams from other organizations can visit and become trained.

JG: Are they the Palliative Care Leadership Centers?

DM: Yes. Dr. Smith and his team are among our four newest Palliative Care Leadership Centers because of their pioneering leadership and delivery of homebased palliative care. He calls it homebased primary care, but the patients who need homebased primary care are all palliative care patients. The primary care teams of nurses, nurse practitioners, and doctors all have palliative care skills. If the clinician does not know how to manage pain, they cannot treat people at home. If they do not know how to talk to patients and families about what matters the most to them, the patient will end up in the emergency room.

If a primary care practice does not provide reliable, meaningful, twenty four hour a day, seven days a week coverage, people will call 911. If someone has trouble breathing and they call the doctor and leave a message but do not receive a call back within ten minutes, they call 911. There must be an access safety net, including a phone number that is well staffed every day and all night. That is what Dr. Smith is building. He is not alone. There are many others across the country doing this. We are identifying them, convening them, and working to make their model of care well known and widely replicable.

JG: Is the shift toward value based care reimbursements making it possible for primary care practices to create and sustain the service delivery programs that fill the care gap of the frailest and the elderly?

DM: Without question.

JG: Will these practices drive future reimbursement policy?

DM: It is difficult to know. In theory, Medicare can decide that any of the models funded by the Center for Medicare and Medicaid Innovation should be folded into the regular Medicare program. Thus far, six or seven years into the innovation grants initiative, none of the models have led to a reimbursement change. It critically depends on who wins the next presidential election. It also depends on the willingness of the House and Senate leadership to resist lobbying by entities that will lose money under the newer and better models.

The motion toward capitation and global budgets means that the fee for service money faucet is being turned off in healthcare. Providers are realizing at different rates that the

party is over. The adaptation to new payment models depends on the caliber of leadership in a healthcare system or the payer. There are some payers that are far ahead.

Many insurers are now focusing on what they can do as a payer to arrange the right care for patients needing palliative care in partnership with clinicians in the community. Insurers are moving toward paying for the right care, including providing reimbursement for homebased primary and palliative care, for Hospital at Home, and for other programs that meet the needs of the patients and help them to avoid 911 calls, emergency rooms, and hospitals.

We are realizing that there is a lot of interaction now between the major payers in this country and the providers and healthcare systems. We are starting to understand how best to pay for the right care and stop paying for redundant and unnecessary care. That makes me hopeful. What is happening in this country, that many people are not aware of, is that the whole healthcare system is moving toward privatization.

While roughly seventy percent of Medicare beneficiaries are still in the old fee for service system, the growth of Medicare Advantage, which is managed care, is a striking thirty percent and rising. In some states, eighty percent of Medicare is Medicare Advantage. In other states, it is much lower, like Alaska, where there is none. That thirty percent overall statistic hides the great variation from state to state. Some states, particularly in the West, have much higher rates of managed care than other states. The United States is a big country, and each health system moves at a different pace, depending on many factors.

We are increasingly moving away from fee for service because of the recognition that it is bankrupting our society, and it is not meeting the healthcare needs of patients and families. The transformation will not be simple. Healthcare represents roughly one fifth of the economy of the United States. Any disruption in how healthcare is delivered is highly disruptive to jobs, the tax base, and the political system. That is the reason that the change is so difficult. But the change is coming.

People will need to be retrained. I am waiting to see big health systems reduce their hospital footprint and expand their community footprint. They will need to train their workforce to be able to do that. That investment in retraining is the piece still largely missing.

JG: What is your definition of community within the palliative care context?

DM: Community includes any setting that is not the hospital—it includes office practices, cancer centers, dialysis centers, nursing homes, assisted living facilities, and care in the home. Today, the great majority of homecare is delivered formally through Medicare certified home health agencies. These agencies are not delivering primary or

palliative care. We are working toward convincing payers that they should reimburse for personal care workers and palliative care in the home setting. They should reimburse family caregiver counseling and support. They should reimburse transportation for patients to travel to see their doctor. If they do not pay for that kind of support they will pay for emergency department visits and hospitalizations. Payers are skeptical, which is why the Independence at Home demonstration is so important. The demonstration found that Medicare beneficiaries with one or more serious illnesses, functional dependency, and one or more prior hospitalizations or nursing facility stays were able get better quality care and avoid hospitalization and institutionalization when they received comprehensive primary and palliative care in their own homes from physician led interdisciplinary teams.

JG: Do reimbursement models vary from state to state?

DM: Yes. They also vary from payer to payer. Just as in every other aspect of life, it depends on how effective and visionary the leadership is. There is a bell curve on leadership. Imagine an S curve for the diffusion of innovation. First you have the innovators, then the early adopters, then the middle stage adopters, then the late adopters, then the laggards. We are on the steep limb of that S curve toward change, where we have now passed the early adopters stage. More organizations are aware that they need to change, and they are looking for help with incorporating an integrated palliative care program that better serves their highest risk, highest cost populations into their business model. This is a big change from five years ago.

We have and always will have laggards who will not adapt until it is a requirement. If the Joint Commission changed the accreditation requirements for hospitals and said, "You will not be accredited if you are not delivering palliative care in your hospital that meets certain quality guidelines," overnight everyone would adjust accordingly, including the laggards. Regulatory requirements that drive this kind of care are the way to make the laggards change.

We are at a point now where approximately seventy percent of all hospitals in the United States with more than fifty beds have a palliative care team. It is still not a Joint Commission requirement. Must we be at one hundred percent before it becomes an accreditation requirement? This is true for nursing homes and homecare agencies also. They are regulated. Let us change those regulations to include services and programs that are proven to make a positive difference in quality and efficiency.

JG: Please describe some of your palliative care guides.

DM: We have a home palliative care work group, which has eleven or twelve programs participating. They have been meeting for about a year and a half. They share their best

practices, tools, technical assistance, financing models, and quality measurement instruments. Based on the diverse experience of these innovators, we are building a Guide to Homebased Palliative Care that will be available to members of the Center to Advance Palliative Care. We have already constructed a Guide to Building Hospital Based Palliative Care Program. We are planning next to write a guide for creating a palliative care program in the nursing home setting. Our guides contain clear step by step instruction. We advise every organization to begin with a comprehensive needs assessment involving interviews with a broad range of key stakeholders.

Many organizations have launched new programs without first conducting a needs assessment. A year later, they are receiving few referrals, they are not seeing enough patients, and they are going bankrupt. They worked diligently in the wrong direction. The guides to developing a new palliative care program teaches what every businessperson knows, which is to do a market assessment before you start a new business. Healthcare providers need to create financially sustainable models like any other business sector. Just because a provider is on the side of the angels does not mean that someone is going to pay them. If the provider is not reimbursed for their services, they will go out of business. An organization will only have a successful financing model if someone else values their services and thinks the model is worth investing in. Who are the people ultimately financing the palliative care teams? The answer is the people accepting risk, such as the payers, the Accountable Care Organizations, the Patient Centered Medical Homes, and the hospital that is financially penalized for thirty day readmissions and hospital mortality. Providers must engage the people whose priorities align with their mission, because they are the funders. Essentially, we help clinicians who have been clinically trained in nursing or medicine and give them a functional masters in business administration (MBA). They need to know how to write a business plan. They need to know how to communicate with multiple audiences that have different concerns. They need to understand social marketing. They need to understand healthcare financing. They need to understand how to conduct a needs assessment, synthesize that information, and then test their proposal with their key partners and funders. We did not learn any of that in medical school.

JG: This guide and education is available through the Center to Advance Palliative Care website?

DM: Yes. The guides and courses are available to our member organizations. We have given free memberships to anyone in resource poor nations who requests it. We have about thirty courses now. There are fourteen on safe and effective pain management, five on communications skills including advance care planning, and several on distressing symptoms like nausea, depression, anxiety, shortness of breath, and fatigue. We have a course on preventing crises through whole patient care, which includes

assessing and supporting the family caregiver and care coordination. We offer operational skills training in community based program design, hospital program design, and leadership training. We give an introduction to palliative care to help people understand what it is and what it is not. We also teach how to create a business plan and conduct a needs assessment.

JG: Each course has pages of research and tools.

DM: There is a lot of valuable information and links to technical assistance resources within each course. Each course has continuing medical unit credits (CMU) for doctors and nurses and continuing educational units (CEU) for social workers, care managers, and licensed professional counselors. The other nice thing about these courses is they work just as well by smart phone as on a laptop, tablet, or desktop computer. People are busy. They can take the course while waiting for the subway or the bus. This is the course order: introduction to palliative care in the community, followed by needs assessment. The needs assessment then determines the program design. The next step is writing a business plan. One question we ask is, how do they define the current gaps in care and how likely is it they will be able to obtain resources to fill those gaps. This helps providers understand the importance of the needs assessment in determining where they should start their community based palliative care program. The program could be based in the home setting, a nursing home, or in an office. Providers must synthesize information collected from their stakeholders and collaborators to design a program that is the best fit for their community.

JG: Are you finding additional points of entry for your training such as colleges and medical schools?

DM: Medical schools are difficult to penetrate. Some medical schools are using our curriculum and doing what we call a flipped classroom. The students study our online courses and use the classroom time to go through case studies, to talk about things that did not make sense to them, to role play and practice communication skills, to practice complex opioid conversions, and other subjects that arise based on the course. This reinforces the learning through conversation, practice, repetition, and coaching. There are nursing schools that are also using our curriculum in the flipped classroom style.

JG: Do many medical schools and schools of nursing use your online palliative care training?

DM: No, not nearly enough. Most of the medical schools, residencies, and nursing schools are still teaching how and what they taught thirty years ago. They are not preparing their students to thrive in the new era. That is a big problem. We need to see major changes in the graduate and undergraduate health professions training. There are

a few shining light medical schools like Hofstra Northwell School of Medicine. The school curriculum was designed with an eye toward preparing their graduates for the world of medicine that exists today with more emphasis on an aging society and moving resources and care out of hospitals and into the community.

JG: Now that Medicare reimburses doctors for having the advance care planning discussion, does the Center to Advance Palliative Care offer courses in advance care planning?

DM: We have a workforce who have had no training in advance care planning conversations with their patients. The fact that providers are now reimbursed for having advance care planning conversations helps, but it does not does not close the training gap.

My concern is that reimbursing for advance care planning conversations could do more harm than good because people are untrained in how to introduce the conversation and elicit the hopes and concerns of their patients. We are working with Bud Hammes at Respecting Choices, who has established a very successful community based model of advance care planning and support. We are also working with Tony Back of Vital Talk. Tony and his team have developed online communication training for advance care planning discussions. This education is urgently needed.

JG: Are clinicians able to honor the care plan of the patient?

DM: That is another problem. Why ask people what they want if we cannot honor their wishes? Our healthcare system overwhelmingly promotes more interventions, more scans, more surgery, and more drug treatment. Patients at a vulnerable stage of their lives are encouraged to see specialists, have tests and procedures, and visit the emergency department after hours.

There was an article this month, *Dying in the Hospital Means More Procedures, Tests, and Costs*, that paints a sobering picture. Atul Gawande gives a YouTube talk in which he tells the audience that the most likely time for someone to have surgery is in the last week of their life. The procedures may be profitable for the hospitals, but it is likely that they do not align with the best interests of most patients.

It does not matter that we know that most older people want to stay home and receive their care at home. Until we can honor that wish by providing reliable access twenty four hours a day, seven days a week, with teams that visit patients and their families at home, I feel it is somewhat disingenuous to tell the public that we will honor their care plan. I hope the movement to prompt the public to seek control and engage with their care plan also creates public demand and pressure not only on their elected representatives but also their health systems.

Read Nina Bernstein's *New York Times* front page article, *Fighting to Honor a Father's Last Wish: To Die at Home*. It is a painful example of the inability of the healthcare system, as it is structured today, to honor people's preferences. The article is about a ninety year old man who had clear life goals and planning. He wanted to receive healthcare at his own home until he died. Instead he spent the last two years of his life cycling between nursing homes, hospitals, and emergency departments because neither Medicare nor Medicaid would pay for the care that he needed at home and he could not afford to pay himself.

What I liked about this article, in addition to it conveying this reality in the way only a great investigative journalist can do, is the comment section. The comments reflect the frustration and the rage of the public. Here is one comment: *"This is exactly what happened to my mother. I promised her I would not let this happen to her. I will be guilty for the rest of my days because I could not stop them."*

People cannot access the right care because it only exists for the wealthy. Here is another quote, *"My heart broke reading this story. It brought me to tears. Why can we not fix this?" "This is horrific. The entire time I was reading this I was thinking, this is America? This is freedom?"*

The power for change is going to come from public outrage over how completely unresponsive the healthcare system is to the needs of a ninety year old person with multiple chronic conditions who was cognitively intact, had clear and often repeated wishes to stay home, and instead was bounced between hospitals and nursing homes at very high cost for the last two years of his life.

JG: Is the Center to Advance Palliative Care trying to reach the public directly?

DM: Yes. Getpalliativecare.org is our consumer microsite. When someone is sick, they do not Google palliative care. They Google their diagnosis. When we Googled lung cancer, the Wikipedia page had nothing on palliative care for lung cancer. So we edited the Wikipedia page and put in a section defining palliative care. We have done this for the top thirty diseases. This is how we educate the public. We are trying to reach the public where they go for information.

We also work with large disease advocacy societies like the American Cancer Society to help ensure accurate understanding of palliative care. We explain that palliative care is an added layer of support that helps people live longer and live better. We give them the right language. They add palliative care resources into their website. Since we began using these strategies, we went from four thousand to seventy thousand unique visitors per month to our getpalliativecare.org website and its palliative care program directory. Visitors can find programs in their city that are delivering palliative care.

JG: How do you determine which palliative care programs to include on the Center to Advance Palliative Care website?

DM: The American Hospital Association does an annual survey of every hospital in the country including those that are not its members. One of the one hundred questions the survey asks is whether the hospitals have a palliative care program or not. That is our denominator. We then confirm the yes or no answer by checking the website of every hospital surveyed. If we do not find anything on the website, we call the hospitals to assure the accuracy of our program directory.

JG: Do organizations approach you to be included in the palliative care provider list?

DM: Yes. Any provider can submit their data to be included in our palliative care registry. They do not need to be a Center to Advance Palliative Care member. There is no charge to be placed in the registry. It is the only national registry of palliative care in the country. The great thing about this site is that one can read aggregate reports for the whole country. Providers can look at a report on their hospital as compared to other hospitals of their size. It is a valuable comparison resource. A provider can compare their performance over time. We make both longitudinal data and peer comparison data available. We have shown that programs that are better staffed have higher impact. They reach more patients, and they reach them earlier in the hospital stay.

JG: Please discuss how reaching a patient earlier results in cost savings.

DM: Often people with serious complex illness are in the hospital because of symptoms such as a pain or dyspnea crisis. They are not in the hospital for elective procedures. They are referred to as crisis admissions. If the palliative care physician is involved early in the hospital stay, we can determine the root cause for the admission. For example, if a person with end stage chronic obstructive pulmonary disease develops recurrent breathlessness and associated fear and anxiety. The more anxious the person becomes, the more difficult it becomes to breath. Typically that situation results in a 911 call and a trip to the emergency department and usually a hospital admission. There are studies that show that when you provide chronic obstructive pulmonary disease patients and their families with a very specific stepwise algorithm, up to and including low dose opioids, you can reduce 911 calls and hospitalizations of those patients by eighty percent. If doctors are not familiar with that protocol and therefore do not develop a plan for handling predictable breathlessness crises at home, the patient and family will call 911 with every incident.

JG: Who is conducting this research?

DM: Graeme Rocker. The initiative is called INSPIRED COPD outreach. We included the INSPIRED model in our courses on treatment for shortness of breath. We sent the

courses to be reviewed by pulmonologists and cardiologists. They said, “We would never use opioids for shortness of breath.” They never had any training in the use of opioids for shortness of breath. Because of this, their patients keep frequenting the emergency department and hospitals. The INSPIRED model is rapidly expanding across Canada, and we are hoping to bring the initiative to the United States. The Canadian Foundation for Healthcare Improvement has a wonderful resource page about the INSPIRED initiative and the outcomes, if you are interested.

JG: Are there examples of good palliative care in other countries?

DM: The United Kingdom has accessible hospice care thanks to Dame Cicely Saunders and others. Their palliative care focus has been largely restricted to cancer, although I think that is changing. If you do not have cancer, access to palliative care is difficult. Many developed countries are beginning to realize that the most profound care gap is not at the end of life care because we have hospice care for that. The gap in care is for patients with one or more serious or chronic illnesses, who need for help from another person to get through the day, and who have an indeterminate prognosis. For example, patients with heart failure, emphysema, dementia, end stage renal disease, or geriatric frailty, who live for many years with the burden of disease, but are not dying anytime soon are therefore are ineligible for hospice.

There will never be enough specialists to deliver the amount of palliative care that is needed. With the increasing elder population, health systems around the world are facing the necessity to train every clinician in the core knowledge, skills, and competencies of palliative care.

JG: Thank you for this insightful conversation.

DM: Thank you for your interest in the Center to Advance Palliative Care.

END

Additional Information

Appendix A

Publications by Dr. Diane Meier

Books:

Cassel, C.K., Leipzig, R.M., Cohen, H.J., Larson, E.B., & Meier, D.E. (Eds.). (2003). *Geriatric medicine*. 4th ed. New York: Oxford University Press.

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