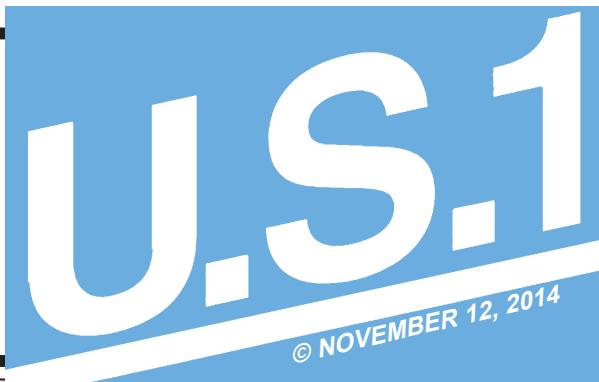




**ART AT RUTGERS:**  
Grimanesa Amorós' work is part  
of the Women/Art/Technology  
series. See story, page 28.

Diversity Is Power, page 5; Tritel's Feel-Good Tunes, 39;  
A Brass Band & the Beatles, 43; Crowdfunding For All, 44.



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# Senior Living 2014

## LISTEN FIRST, THEN PRESCRIBE

Geriatrician  
David Barile  
urges doctors  
to weigh all  
options when  
providing  
end-of-life care.

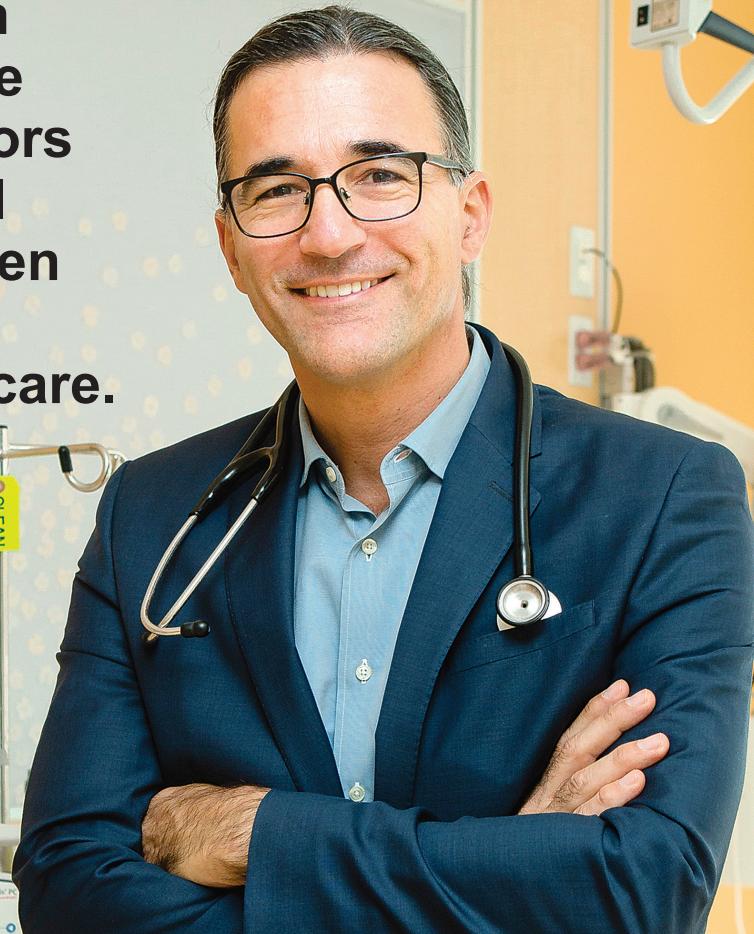


Photo by SUZETTE LUCAS

BARBARA FIGGE FOX REPORTS, PAGE 8

# Online Guide For Better Care

**D**avid Brown believes that palliative care — management of symptoms — will be the new model of care for all chronic disease. “Today’s palliative care does not write the patient off who suffers from pain and symptoms but has 20 years left to live,” says Brown.

His firm, Vox Telehealth, based at the Straube Center, is developing a mobile health solution for palliative care. It will help patients in the end-of-life stage to connect with their own physician plus other means of support, including a chaplain. “Our program is an intentional walk alongside the patients and their caregivers, providing resource on resource, says Brown. “We try to engage the patient and the family to take a role in decision making, to determine his or her own level of action and involvement.”

Dr. David Barile developed the content for Vox Telehealth’s palliative program, and the chaplain service will be provided through the Healthcare Chaplaincy of New York and their seasoned palliative consultant, Linda Emmanuel, Buehler Professor of Geriatric Medicine at Northwestern University.

Brown, 43 and a graduate of Vanderbilt University, established Vox Telehealth based on his observation that patients need more support than doctors usually have time to give them. He’s betting that patients who are educated and prepared by his web-based solutions will get much better care and have better outcomes. “Our internal motto: the wiring of technology will always evolve, but the wiring of humanity generally will not,” says Brown. “We are building our programs on technology-based platforms that are a fantastic complement to the clinical process.”

The palliative care program will be the second one Brown has launched. Vox Telehealth’s first solution, OrthoCare, is for orthopedic surgery. It educates and prepares patients before orthopedic surgery and continues to monitor them remotely for up

to 90 days after discharge (U.S. 1, June 25, 2014). OrthoCare finished its preclinical review and its pilot was rolled out in partnership with Bon Secours Healthcare System of Virginia last month. A number of hospital contracts for OrthoCare are forthcoming.

Brown claims that his platform is so flexible that it can accommodate both knee surgery and end-of-life decisions. Orthopods operate and heal. Palliative care physicians manage pain and symptoms and help people adjust to the reality of their diagnosis.

With \$2.4 million raised so far, and having closed a second angel round of \$1.1 million in

**‘We try to engage the patient and the family to take a role in decision making, to determine his or her own level of action and involvement.’**

June, Brown is not looking for funding now. He wants to sidestep the demands of institutional investors and venture capitalists who would likely push to cash out. “They would want you to go to market ASAP,” says Brown.

Instead he will focus on rolling out more programs in other treatment areas. He also wants to hold on to as much equity as possible and alludes to how the valuation might change dramatically soon. “We have a number of customer contracts and industry peer relationships that we are extremely confident about,” says Brown. “We are raising just what’s needed now.”

He has decided who pays for the orthopedic program (the hospital) and how much it costs but has yet to work out the payment model for the palliative program. It will be available to any hospital and will likely be popular among the 4,500 hospi-

tals in the nation who already have palliative care physicians, counselors, or chaplains.

The program depends on a lot of engagement with the caregivers. The first tier of the two-tiered program is based on the four-step pathway that is being patented by Barile (see main story, page 8). The caregivers are referred to information modules about each step — diagnosis, prognosis, goals of care, and treatment plan. If they are struggling with accepting the diagnosis, it offers support content for patient and caregiver, such as suggesting ways to prepare for their next visit to the physician.

“It takes a long while for the patient and caregiver to realize that they can be in control, that they can ask for more time in the doctor’s office,” says Brown, “Much discussion is needed. This is a huge factor in getting the type and level of care they want.”

Once the patients and caregivers get the prognosis and move to goals of care, the program gives them the tools to decide on their Advanced Care Directives and to help their doctors fill out their POLST form.

The palliative care program will not zero in on hospice, though it will offer hospice as a choice. A hospice patient needs a higher level of care than can be accomplished with a web-based program. “By the time the patient goes into hospice mode, our level will taper off,” says Brown.

Patients or caregivers will be able turn to a chaplain for help in decision making. Chaplains are specifically trained to engage patients of any religion or those who have no religion. In fact, one study showed that it is not typically helpful for someone to consult with a pastor who has no expertise in the healthcare field because some of them say that giving up on treatment translates to “giving up on God.” This leads to the patient asking for a higher level of care.

Even the term “giving up” is fraught. It may evoke the so-



**Care on the Go:**  
**David Brown of Vox Telehealth is developing a mobile health solution for palliative care.**

called “death panels” that haunted the debates over managed care. Brown denies this is a big problem. “Discussion has moved away from the hyper political witch hunt of the death panels. People are realizing the cost of care is unbearably high and patient satisfaction is unbearably low,” says Brown, quoting research studies. “We are not advocating death. We are advocating decisions. Patients get dissatisfied with their care pathway but are not educated about the likelihood of success or the potential side effects.”

A better idea: to reintroduce the reality of death as a part of life and start to have the discussions that few physicians are prepared for or are willing to have. Doctors typically see medicine only through a curative lens, says Brown. “It is amazing that the default mode is the absolute most aggressive care.”

“We have a certain amount of confidence that palliative care will become the model for all chronic disease. We will focus on empowering the patient for action,” says Brown.

— **Barbara Figge Fox**  
**VOX Telehealth** 100 Straube Center Boulevard, Suite 205, Pennington 08534; 888-360-4869. David Brown, founder and CEO. [www.voxtelehealth.com](http://www.voxtelehealth.com).



## Evangelist for Palliative Care: Listen, Then Prescribe

by Barbara Figge Fox

**D**eath in the abstract is OK with me. I am perfectly clear headed when death comes for fictional people, like the victims in a detective story, or real people, if it is somebody I don't know. But when it gets close to home, when someone near and dear is involved, clear thinking rapidly deteriorates to muddled. When a close relative faced death this year, I was plenty muddled.

Suffering from terminal cancer, she was in what they call "the end of life stage." Dr. David Barile came to her hospital room. I figured he was just making rounds. But this was different. He didn't prescribe, he merely explained what was going to happen — outlined the prognosis — and asked about her goals. He listened carefully.

Then he gave her some choices. He offered what is known as "palliative care," a term new to me.

Palliative care is specialized medical care for anyone living with a serious illness. It can be given to those who hope to live for decades, or it can offer hospice to those who have less than six months. But palliative care is also appropriate for anyone with a serious chronic disease, like failure of the kidney, liver, heart, respiratory system — even Alzheimer's. Palliative care treats symptoms such as pain, swelling, and nausea. It does not include curative treatments (medicines, chemotherapy, radiation)

but neither does it preclude them. For instance, you can get palliative care and still be on chemo.

Not very many people know about palliative care, and not many doctors are comfortable talking about "end of life" issues with their patients. Barile, a medical doctor who received his training as a geriatrician at Mount Sinai in New York and is now on the staff of the Princeton Healthcare System and Princeton Care Center, is an evangelist for reform in this arena. He founded Goals of Care, a non-profit start-up, to change this, to improve medical decision making for New Jersey seniors. Just announced: His four-step Goals of Care process will be incorporated into an online mobile platform developed by Vox Tele-

health based in the Straube Center (see sidebar, page 46). This supportive tool for physicians, patients, and family members will, Barile hopes, effect a culture change in med-

icine.

Here are the four steps:

What is the diagnosis?

What is the prognosis?

What are the patient's goals of care within the context of this prognosis?

What plan will the medical team develop to achieve the patient's goals of care?

This approach seems simple enough, but most doctors omit



steps two and three. As Barile points out, "We doctors are all pretty good at two things: Nine times out of ten we get the correct diagnosis, and, more often than not, we can tell you how to treat that problem." What doctors are not good at, he says, is stepping back to look at what the future holds — the prognosis, like how long the patient will live even with the most aggressive treatment. Nor do they ask about the patient's long-

**The Doctor Who Listens:** Dr. David Barile specializes in palliative care for those living with serious illnesses.

term goals.

Susan Hoskins, executive director of Princeton Senior Resource Center, applauds Barile's approach: "The Goals of Care

process helps us focus on the difficult but necessary conversations that need to happen between physician and patient and among family members,” she says. “Chatter about ‘patient-centered care’ often seems driven by other forces, such as what insurance will cover, how treatment is paid for, what the facility’s policies are, or what is most efficient for the staff. It makes so much sense, to switch the focus from treatment to goals and quality of life, and to make the treatment fit the patient’s goals.”

Even after going through the four steps, the doctor has another major hurdle: to break the usually unwelcome news. It’s hard to tell a family, in a compassionate way, with empathy, that grandma is entering her final months.

Doctor-patient communication is especially difficult in New Jersey because, among doctors, it leads the nation in diversity, and overall it is the third most culturally diverse state. Different cultures approach death differently, so a doctor from Argentina will have a different attitude toward death than a family from Egypt. Confronted with potential misunderstandings, it can be easier to just avoid the D word than to figure out how to communicate that message with appropriate sensitivity.

There’s another reason why New Jersey seniors are less likely to have their goals met —

they don’t have effective family doctors in tune with their needs. When Barile moved here from New York in 2007, he was taken aback by the discord at the bedside — what the doctors were doing versus what the patients wanted. Many families tell about how a dying relative endured unnecessary tests that served no other purpose than to

## Weighing Their Options: Dr. Barile, left, consults with Dr. Craig Gronczewski.

increase the bill for the hospital or doctor. Indeed, studies show that a New Jersey senior will, in the last two years of life, spend more days in the intensive care unit and see more sub-specialty doctors than in any other state.

Without a “quarterback” or effective primary care doctor in charge, the specialty physicians can be influenced by ageism or by the habit of providing burdensome care. “They were either withholding interventions because of the patient’s age or ordering unnecessary tests,” says Barile. “It was a mismatch, with no attention paid to patient requests.”

So, starting in this state and then expanding nationwide, Barile hopes the four-step model will change how medical decisions are made at the bedside, in the hospital, or the nursing home setting. He wants to inculcate young doctors with his goals: “I hope that these four steps will penetrate the residency training programs to change how hospitals interact with pa-

tients and their decision makers.”

Barile began his hoped-for revolution by taking an important role in the creation of the New Jersey forms for Physicians Orders for Life Sustaining Treatment (POLST). The POLST bill was signed into law in 2011, and doctors were required to take two hours of training on it. The form is on the website of the New Jersey Hospital Association.

POLST forms are filled out



by doctors to establish guidelines for current treatment. They should not be confused with advanced directives, which are filled out by patients to express preferences for future treatment. (When you check in to a hospital, you are always asked about your advanced directive).

Doctors fill out POLST forms for every “end-of-life stage” patient. The form is supposed to reflect the patient’s current preferences on a variety of issues, from choosing a surrogate decision maker to tube feeding. It is an actual medical order and is the first page in the patient’s file. All medical staff are supposed to abide by it.

Using a \$300,000 grant from New Jersey Health Initiatives, a program of the Robert Wood Johnson Foundation, Barile worked with the University Medical Center of Princeton to survey POLST forms for other states. He strenuously objected

to how these forms focus on “Do Not Resuscitate” codes, rather than taking the opportunity to explore other opportunities for care. “When the form opens with ‘Resuscitate or Do Not Resuscitate,’ that encourages spending way too much time talking about what to do when the heart stops,” says Barile. “Often that is the only topic in an end-of-life discussion.”

In his version of the POLST, Barile dropped the DNR question to the bottom, and he put the four Goals of Care at the top. To ensure that the patient can have useful input to how the doctor or nurse practitioner fills out the POLST form, he put a patient tool on the Goals of Care website. “We created a script that can model the conversation between patient and doctor, and to, symbolically, de-emphasize the DNR decision,” says Barile. The form is posted at the New

## Doctors are good at diagnosis and treatment, not at asking about the prognosis and long-term goals.

Jersey Hospital Association website ([www.njha.org](http://www.njha.org)) as well as his own.

(As for the Do Not Resuscitate question itself, Barile says more people would use that code if they knew what it involved. Most doctors opt for DNR because they know it involves a violent process, a possible caved-in sternum, and a potential vegetative state.)

Along with improving the official forms that doctors use to decide end-of-life intervention, Barile aims to solve this problem at the source, in medical school. He questions why it is even necessary to create a subspecialty that focuses on treating symptoms and talking with patients. "When did we stop training young doctors in communication skills? We have splintered off the dying process. We have reinforced silo systems."

His favorite New Yorker cartoon shows a doctor, saying to a patient in his final months, "There is no easy way I can tell you this so I am sending you to somebody who can."

"On one hand it is alarming, even absurd, that this is farmed out to a specialty," says Barile. "On the other hand, as in the feminist movement and the civil rights movement, we need to form a community of trained physicians to turn on the lights in the room, so government and academe pay attention."

Insurance companies are indeed paying attention. "New Jersey ranks at the top of the list of states for most aggressive care, most expensive care, and most patients dying in the ICU, adjusted for population," says Steven R. Peskin MD, senior medical director for clinical innovations, Horizon Blue Cross Blue Shield of New Jersey. Horizon insures more than half of New Jersey's population, and Horizon Healthcare Innovations contributed \$50,000 for Barile's nonprofit firm to train doctors in South Jersey; its logo graces the lower banner of his website.

### **Comfort Zone: Dr. David Barile offers a palliative care consultation. Patients' views can change with time.**

The American Medical Association has asked Medicare to pay for end-of-life consultations with physicians, and the Institute of Medicine, the research arm of the National Academy of Sciences, reports that end-of-life care needs a complete overhaul. Nevertheless, conservatives continue to oppose change. "Government payment for counseling would lead to even more regulation and oversight of all facets of these very personal decisions," wrote John R. Graham in an online September column for Forbes. "The AMA is a business that profits from its monopoly over the billing codes that physicians use when they submit claims to Medicare. The more billing codes there are, the better it is for the AMA."

In contrast, social workers, who are on the front line when patients and caregivers are battling with end-of-life decisions, strongly support change. "We desperately need for doctors to be more comfortable with palliative care," says Hoskins of the Princeton Senior Resource Center.

Doctors may claim that they say, "You can stop aggressive treatment at any time." But few patients and families have the knowledge or perspective to make that decision. People die only once," wrote Atul Gawande MD, author of the current best-seller "Being Mortal." "They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come."

"Palliative care effectively



relieves physical and emotional suffering, strengthens patient-family-physician communication and decision making, and ensures well-coordinated care across health care settings," says Lisa Morgan, acting chief communications officer at the Center to Advance Palliative Care (CAPC) at Mount Sinai in New York.

"It's a huge need," says Morgan. Six million people could benefit from palliative care today, so making palliative care policy changes would not only be good for patients, it could also help insurance companies, hospitals, and governments, Morgan claims.

Discussion of palliative care is likely to come up only in conjunction with hospice — because, before 2000, it was available only through hospice. So now, says Morgan. "If you are not ready for hospice, then you

might not know to ask for a palliative care team." She cautions against confusing palliative care with pain management centers. These centers treat patients with arthritis and back problems. Palliative care also treats, for instance, nausea, shortness of breath, or any unwanted symptom.

It's important for the medical community to make it clear that the palliative care team is available early, starting at the point of diagnosis, says Morgan. Primary doctors may be able to treat some pain and some symptoms, but the side effects of chronic disease are likely more complex. "All frontline clinicians should have basic skills in palliative care, however, the pain and symptom management needs of seriously ill patients can become very complex. That's when the palliative care team of specialists should be

brought in," she says. "If you need it, the earlier you get it, the better."

The earlier the better, indeed. By the time my relative had gone to the hospital and had her palliative care conversations with Dr. Barile, she had been through five months of curative treatments by a half-dozen different specialty doctors (two or three visits a week, some in blizzard conditions), long hours in offices and emergency rooms, blood draws, biopsies, scans, and tracking a changing array of pills — some to cope with symptoms of the disease, some to cope with the symptoms caused by the medications.

No one had pinpointed what quality of life she desired for her remaining days. We can't turn back the clock to find what would have happened if she had had those conversations earlier. But now that I know what I know, I believe that her end-of-life experience could have been more tranquil and productive.

Barile knew early on that he wanted his medical career to focus on the elderly. He had a close relationship with his grandfather, Domenick Fazio. "Like a lot of people with an interest in geriatrics, I grew up with my grandfather in the household, and I spent a lot of time with him. Maybe I feel re-united with him when I am with older adults. In retrospect, my grandfather was a character from the old world. He loved life and embraced every person he encountered, from the mailman to the doctor."

Both parents were Italian immigrants. His father came here as a teenager and made his living doing auto body and fender repair. After raising three children in the Bronx, his mother did secretarial work. She influenced his education, says Barile. He had wanted to take some

time off after high school, but his mother and his older sister (who now teaches English literature) filled out his college application. At that time his only interest was art. "I figured I could pick up my financial aid money and go traveling, then come back and crank out the work, and I did pretty well the first year. Then I took an anatomy elective. The slides went up — and, whoa! I knew this is what I was going to do."

Transferring from the art program at State University of New York at Purchase to graduate as a biology major at UCC Santa Cruz, he went to Eastern Virginia Medical School in Norfolk.

He did an internship at Beth Israel and a geriatric fellowship at the Center to Advance Palliative Care at Mount Sinai, working with Rosanne Leipzig MD and MacArthur Foundation recipient Diane Meier MD. He is married to Nicole Schrader, a facial plastic surgeon with a practice on Route 206, and they have two school-aged children.

Board certified in internal medicine, geriatric medicine, and palliative care/hospice medicine, he has a private practice. In addition to being founder and medical director of NJ Goals of Care, he is medical director of the Acute Care for the Elderly Unit at Princeton Healthcare System, and medical director at Princeton Care Center, and he does "palliative consults" at both places. He was also nominated to join the newly

formed New Jersey Advisory Council on End-of-Life Care.

Barile sees his Vox Tele-health partnership as "a huge opportunity to influence decision making, to create — not just a platform that is all things palliative medicine — but also a website that encourages better decision making using the four steps. Vox is building a supportive tool for physicians, patients, and family members that could effect a culture change. Once set up, it encourages the doctor and the patient to keep circling back to the four steps."

His next tasks: to get a volunteer coordinator for his non-profit startup, and to assemble vol-

unteers for various skills, including fundraising. (His smooth bedside manner does not, unfortunately, translate into an ability to ask for money.)

Barile is thinking about scaling down his practice in order to focus on launching

this project. With all the attention being paid to end-of-life issues, attention spurred by the best-seller "Being Mortal," Atul Gawande's book about the end-of-life experience, there is money to be made, and other for-profit and not-for-profit firms will enter the arena. Without a big push now his startup might have to go to the end of the line.

Barile is a gerontologist and Gawande an oncologist, but they are on the same page. "People who had substantive discussions with their doctor about their end-of-life preferences were far more likely to die

at peace and in control of their situation, and to spare their family anguish," wrote Gawande in the New Yorker magazine (August 2, 2010). "Given how prolonged some of these conversations have to be, many people argue that the key problem has been the financial incentives: we pay doctors to give chemotherapy and to do surgery, but not to take the time required to sort out when doing so is unwise."

"The simple view is that medicine exists to fight death and disease, and that is, of course, its most basic task. Death is the enemy. But the enemy has superior forces. Eventually, it wins," wrote Gawande. "And, in a war that you cannot win, you don't want Custer. You want Robert E. Lee, someone who knew how to fight for territory when he could and how to surrender when he couldn't, someone who understood that the damage is greatest if all you do is fight to the bitter end."

The first time my gravely ill relative talked to Barile, she wanted to continue treatment. He supported her decision. After the second consultation, she had the same outlook, and he continued to support it. But he also pointed out that the treatment seemed burdensome, that "you might actually live longer if we focus only on palliation of symptoms."

The days wore on. Then she changed her mind and opted to stop curative treatment. I was surprised, but Barile was not. "Hope changes," he explained. "At first, hope is for a cure, then it is for remission, then it is for being comfortable for the final time."

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