

This special section, a bonus issue of the university's Ezra magazine, highlights ways Cornell initiatives intersect with philanthropy and engagement of Cornell alumni, parents and friends.

RESEARCHERS EXPLORE THE 'GIST' OF DOCTOR-PATIENT COMMUNICATION

Holly Prigerson, left, a sociologist, is the Irving Sherwood Wright Professor in Geriatrics and co-director of the Cornell Center for Research on End-of-Life Care at Weill Cornell Medicine. **Valerie Reyna** is the Lois and Melvin Tukman Professor of Human Development in the College of Human Ecology and is director of Cornell's Human Neuroscience Institute and co-director of the Center for Behavioral Economics and Decision Research.

Together, they have combined forces to study end-of-life communication between patients and their physicians and clinicians, with the goal of improved prognostic understanding and decision-making and, ultimately, better end-of-life decisions. They have received a Cornell intercampus seed grant that has sparked additional collaborations and applications for new NIH-funded studies.

The full conversation is available at news.cornell.edu/PrigersonReynaQA.

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“IF YOU DON’T KNOW, BASED ON A NUMBER, WHETHER YOU SHOULD BE ECSTATIC OR FEARFUL – YOU HAVEN’T GOT THE GIST.”

– Valerie Reyna

How did you begin working together?

Prigerson: My husband, Paul Maciejewski, and I had moved from Boston to Weill Cornell Medicine to co-direct the new center for research on end-of-life care. Our results demonstrated that patients and family members had little understanding of their prognoses – the course of their illnesses, how sick they were and, bluntly, how close to death they were. It pointed to the need for a new approach to improve medical communication. We were searching for a theoretical basis for our empirical approach, and Paul found one of Valerie’s articles. We thought there might be insights from psychology for medical decision-making, so we sought Valerie out.

Reyna: And I’m so glad you did.

Valuable resources are expended for health care during the end of life, sometimes to achieve goals that patients would not want if they understood their options. And what we’re about, really, is not constraining those resources; what we’re taking is a decision-making approach, so that patients have the ability to make informed choices about their own lives. That’s why the decision-making component is so important, empowering people to have the information to make those informed decisions.

Prigerson: Applying what Valerie’s done in her work and her insights could transform medical communication. For example, in oncology programs we have been looking at ways for physicians to improve empathic communication.

Reyna: The key way to do that is to focus on “getting the gist,” and it’s not an accident that “gist” also works perfectly as an acronym for “get information strategically and transparently.”

Prigerson: It’s not just about using simple words [or] responding to emotion. For the patient, it’s “What is the meaning of this for me and for my values and preferences?” Everyone wants a cure, and we understand

that. But within the realm of real, pragmatic expectations, we want patients to be dealing with realities.

We’re not trying to disparage hope. But most patients we’ve studied want to know their prognosis, they want to hear it from their oncologists, and they want their oncologists to talk to them in ways that they understand.

How does your approach play out?

Reyna: So doctors are trying to give a lot of detail, and ... lost in the detail is that really important bottom line – for example, that your latest scans suggest that you have metastasized cancer, and your prognosis is months, not years.

“Months, not years” came out of a conversation we had about, say, a stage 4 diagnosis with scans that show metastasis. So, that’s the essence of it. It’s literally a phrase to capture where the patient is.

Often, people feel you need to give the numbers to the patient so that the patient can decide. I think that’s probably a good idea. But numbers, just like words, are not meaningful by themselves. Statistics about outcomes and probabilities are important, but they have to be interpreted, just like words have to be interpreted.

Say, for example, I said you had a 20% chance of prostate cancer. Do you feel informed? What does that 20% mean? Should you be relieved? Or, should you be really, really worried? If you don’t know, based on a number, whether you should be ecstatic or fearful – you haven’t got the gist.

Prigerson: We published some studies showing how well advanced cancer patients understood four basic facts: one, that they had incurable cancer; two, that they were terminally ill; three, that they were at a late-end stage of their illness; and four, that they had months, not years, to live. The studies showed that following a discussion of scan results with their oncologists, only 5% of the patients had an accurate understanding of their prognoses.



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We suggested that, rather than talk at length about tumor sizes and growth rates, oncologists should describe scan results as indicating whether their cancer is “better,” “worse” or “the same.” No numbers. They can add numbers later, and a lot of patients want detail and should get it. But we’re concerned that details can get in the way of comprehension and that the way these details are presented can be misleading. What patients really need to know is, is the cancer growing on treatment, remaining stable or shrinking (getting better)?

Reyna: Physicians don’t want to tell someone something that’s overly pessimistic, that removes hope, and then it later turns out that it was wrong. And that is an admirable motivation.

So the whole point of risk and uncertainty has to be taken into account. That’s one of the reasons why hyper precision about prognosis is not favored by physicians – they realize that treatment outcomes are uncertain. On the other hand, they do feel compelled to accurately inform patients so that they and their families can make plans about treatment and about the rest of their lives. So this “gist” approach allows you to do both of those things.

We just received funding from the National Institutes of Health to train oncologists in communicating the gist to advanced cancer patients. Our Oncolo-GIST study instructs oncologists to focus on basic bottom-line points related to the meaning of scan results for the patient (better, worse or stable), what those results mean for their prognosis based on data, and last, what this prognosis might mean for medical decision-making.

There have been many attempts to improve end-of-life communication with patients, but what makes this approach different is the grounding in evidence-based theory, which is about emphasizing meaning.

You’ve had several published studies already; what are some of the findings?

Prigerson: We found a few interesting things. One, which confirmed a vast literature on what is called depressive realism, was that depressed people can hear bad news pretty well. They’re almost anticipating it, and it’s almost validating and confirming. Depressed advanced cancer patients more accurately heard that their scan results were worse than the nondepressed. Those who were anxious heard it significantly less well, and they heard good news better than they heard bad news.

Strong religious beliefs can also influence information processing because the patient might say, “My doctors are great, I trust them. They’re very educated, they treat me well; I respect them. But it’s really not up to them. It’s



Patricia Kunic/Provided

up to God when I go.” We respect that, and our theoretical approach actually makes it easier for people to connect medical information to their values.

Reyna: We also have an additional part of our theory that has to do with moral and social values: What’s important to you? For example, if someone says, “The most important thing to me is to be able to take care of my family,” that would be a gist-based value. Or, “The most important thing for me is to be in this trial so that I can leave a legacy of hope, because I know that I’m going to die. But this is my contribution, and it matters to me to help others.”

What have you learned personally through this work together and from each other?

Reyna: Instead of doing more work on things that I’ve done in the past, it helps me really think in new ways and form new partnerships. Our work and this whole new crop of collaborations that are leading to new studies are connected to the seed funding we received from the Office of the Vice Provost for Academic Integration.

Holly is an inspiration, and I think we’re very complementary in our approaches. It is good to be reminded, in such an evidence-based way, and in such an empathetic way, of some of the downsides of being aggressive in treatment, and I think that’s important.

Prigerson: To the limited extent that medical researchers apply psychological science to clinical care, it is often without the direct involvement of the scholar who developed those ideas. But we have been able to work from the conception of our approach with Valerie from the outset; we have remained true to her conceptual framework, applied it, and now we are eager to see its impact.

Opposite page:

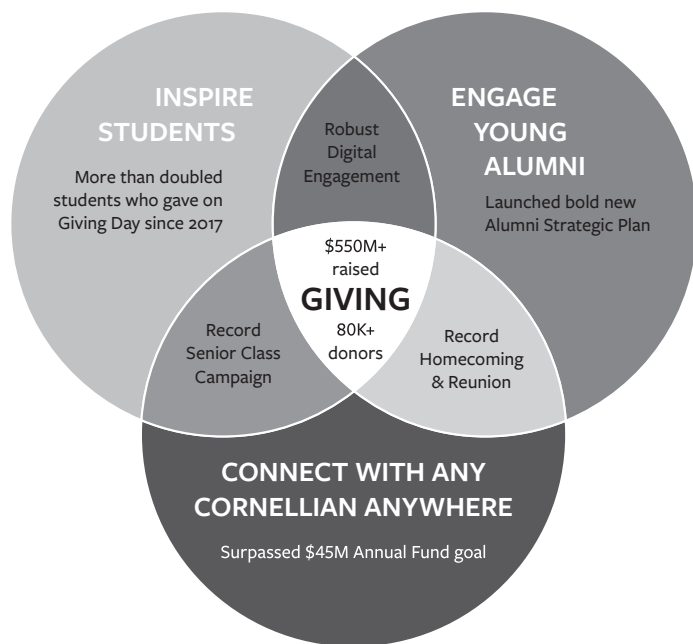
Professor Valerie Reyna works with a graduate student.

Above: Professor Holly Prigerson, left, with two members of her research team at Weill Cornell Medicine.

At the end of the year, every contribution counts

The university received just over \$550 million in new gifts and commitments in fiscal year 2019, including \$340 million raised for the Ithaca and Cornell Tech campuses and \$210 million for Weill Cornell Medicine. More than 80,000 donors contributed to these results.

“With incredible teamwork across our three main campuses, Cornell raised \$550 million in new gifts and commitments – an 8% increase over 2018,” said Fred Van Sickle, vice president for Alumni Affairs and Development, thanking the donors, volunteer leaders and staff who came together to make these results possible.



Gifts to Cornell Annual Funds totaled \$45.8 million – surpassing the FY18 record of \$44.4 million. “Of the last 17 years, 16 have been record-breaking,” said Tom LaFalce ’94, acting director of Annual Giving Programs. “We are fortunate to have such loyal support from our alumni, parents and friends.”

Over 60 percent of Cornell undergraduates receive financial aid, and all students benefit from gifts to the university’s Annual Funds.

Giving Day, March 14, 2019, recorded the highest number of gifts received on any day in Cornell history, with 13,803 donors contributing \$7,866,014 to Cornell.

The number of students who gave on Giving Day has more than doubled, from 933 in 2017 to 1,985 in 2019; and nearly one-third of all graduating seniors made a gift to the Senior Class Campaign in 2019, a significant increase in participation over the past few years.

Nearly 85,000 Cornellians engaged with the university in FY19, including a record number of alumni who returned with their friends and families to attend Homecoming and Reunion. Thousands of others participated in Cornell alumni events based in communities around the world, and more than 10,000 alumni engaged in online event experiences.

In May, the Board of Trustees Committee on Alumni Affairs endorsed a five-year Alumni Engagement Strategic Plan with three engagement imperatives: inspiring more students to embrace the alumni network, increasing young alumni engagement, and developing flexible, lifelong journeys for all alumni.

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