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A Search for Meaning

The StoryListening Study

Parses Words

and Silences

to Find Moments of Connection

By Erin Post

Bob Gramling, M.D., D.Sc., has witnessed grief in its many forms. As the inaugural Holly and Bob Miller Chair in Palliative Medicine and a professor of family medicine, he counsels seriously ill patients and their families while they navigate the challenging terrain between life and death. During the COVID-19 pandemic, Gramling worked with a UVM Medical Center team to provide critical support at a Burlington nursing home experiencing an outbreak. He sat with patients, often holding a phone or iPad, so they could say goodbye to loved ones who, because of safety precautions, couldn't be present. The forced distancing was difficult, but moments of connection still emerged.

These moments—as brief as they may be—deserve attention, says Gramling. He wants to find the communicative patterns that develop. If his team can uncover a clearer picture of the exchanges that bring humans together in empathy and compassion, then perhaps medical professionals can collectively create end-of-life journeys that are a little less lonely and fraught with fear, and maybe even a little more joyful.



Bob Gramling, M.D.,
D.Sc., pictured in a
Vermont Conversation
Lab t-shirt

In their Vermont Conversation Lab in the Given Building at the UVM Larner College of Medicine, Gramling and his team have assembled a breadth of research expertise focused on parsing the sentences we use, the words we choose—and the silent spaces in between—to understand how conversations bring meaning and comfort to patients and their loved ones.

Although the work has been ongoing for over four years, the COVID-19 pandemic has infused it with a new sense of urgency.

“Whether it’s just the potential energy of this year or where our work has naturally evolved, we’re becoming more and more interested in this one fundamental question: What is human connection?” says Gramling. “What does it look like in different types of conversations? And then how do we foster that?”

The StoryListening Study is the newest project for his team. Funded through the Holly and Bob Miller Endowed Chair Fund in Palliative Medicine, UVM Continuing and

Distance Education, and a generous donation from UVM Medical Center Foundation board member Kate Laud, the goal is to enroll 150 to 200 family members, friends or clinicians who experienced the death of a loved one or patient during the COVID-19 pandemic. These people are invited to tell their story—with no stipulations on how they tell it, or for how long, or what specifically they talk about. End-of-life doulas trained in UVM’s certificate program serve as the “listeners.” The exchanges between participants and end-of-life doulas happen via televideo—a key aspect of the study, says Gramling. He’s excited to discover more about how video affects human connection between participants.

Participants receive 15 questions before and after the exchange, designed to measure “the acceptability of the televideo StoryListening visit” and to understand “the aspects of the storytelling experience that are most beneficial to quality-of-life.” →

The recordings of the exchanges between participants and end-of-life doulas tell their own stories, says Gramling. Researchers are listening to each conversation, analyzing the language, the silences, even the frequency of “turns” the speakers take, that may uncover when and how moments of connection are created. Once patterns emerge, machine learning can help scale the analysis across thousands of conversations, helping to home in on when barriers fall away.

“One way or another, we’re hovering around this concept of loneliness or feeling disconnected,” says Gramling. “And the converse of that: what does connection look like and how do we make it happen?”

Analyzing Silence

A UVM undergraduate majoring in biology with a minor in gender studies, Ann Wong has been a researcher on Gramling’s team since the spring of 2020. She has spent many hours in the Conversation Lab—headphones perched on her head—listening to some of the intimate moments in the lives of patients facing the end of life. The gravity is not lost on her.

“They were definitely very difficult, heavy conversations, but it was a really enriching experience to be able to hear that vulnerability and to have the honor of being able to listen to those words,” she says.

Wong has been focused specifically on silences. When they appear in a conversation, she’s tasked with noting their presence and categorizing them based on what they signify. Two fellow researchers in the lab—Cailin Gramling and Brigitte Durieux—created a code book and a 1-3 scale to help guide the process. A “one” is an “invitational connective silence,” where “there’s a question and [the speaker] is trying to invite a conversation,” says Wong. A “two” is an “emotional connective silence,” characterized by a silence of a couple of seconds or more following a moment of gravity, whether it is an unfavorable diagnosis or a difficult decision point. The “three” indicates a deeper exchange that invites further dialogue.

“Immediately following an emotional connective silence, there’s an acknowledgement of the moment of gravity. Quotes that we’d hear are: ‘That’s a lot to take in,’ or ‘Can you tell me more?’” Wong says.

Sometimes, the work is more art than science, reliant on a team of people willing to parse slivers of a conversation—quite literally the absence of words in two- to three-second intervals—for what may be happening in that space.

“If there was ever conflict, then we’d have a group listen and determine what we thought the code was,” says Wong. “And sometimes someone would say, ‘I thought that was a moment of gravity,’ and then another coder could be like ‘Oh, I didn’t really think so.’ It was interesting to see how our different brains worked with what we identified.”

These exchanges are critical to a process that hinges on context and culture. Each member of the team brings a unique viewpoint that taken together helps to arrive at a common understanding.

“We’re just starting to publish on some important ways of developing a taxonomy of silences,” says Gramling. “What are they? And can we find them in ways that are reliable and valid and that are not overly culturally defined? Because what counts, what looks like connection in one setting, in one context, in one person’s experience, may not be in another. We have to make

sure that we’re open to all different definitions of what human connection can be.”

This summer, Wong is applying what she’s learned to the StoryListening Study, parsing the exchanges between participants and doulas for silences and other communication patterns that may help to identify moments of connection.

Silences are just one piece of the puzzle. Previous publications from Gramling and his team— dating back more than a decade— have explored a variety of language patterns in serious illness conversations. One study published in the *Journal of Pain and Symptom Management* focused on correlations between expressions of anger and clinical outcomes. Another in the *Journal of Palliative Medicine* describes a tandem human and machine coding method to identify connective silences. Most recently, the team, led by a recent graduate of UVM’s Computer Science doctoral program, Larry Clarfeld, Ph.D., and former chair of computer science, Maggie Eppstein, Ph.D., published a paper in *PLOS One* detailing a “computational model of conversation flow in serious illness conversations,” which stands to serve as a “fundamental tool in conversational epidemiology.”

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The Conversation Lab’s database contains over one million words of conversation—more than ten thousand minutes of patients, family members and health professionals talking—all of which has been poured over to understand what defines moments of connection. In collaboration with his brother, David, Gramling has written what is perhaps the definitive book in the field, titled *Palliative Care Conversations: Clinical and Applied Linguistic Perspectives*.

For the StoryListening Study, Gramling is excited to see how the work unfolds, leaving open the possibility for entirely new lines of inquiry to emerge.

“There’s going to be some sense of discovery,” he says. “We know we’re going to go after some things like the turn-taking, the silences, moments of human connection based on some existing definitions. But we’re also going to maintain the openness to discovery... we have to redefine what we’re looking at and make sure we can reliably find [and name these moments].”

Finding Patterns

Donna Rizzo, Ph.D., professor in UVM’s Department of Civil and Environmental Engineering, is an expert on machine learning. She’s applied it to better understand a wealth of environmental challenges, including humanity’s impact on groundwater, the development of cyanobacteria blooms, and how soils swell and shrink. Now, she is leading efforts with Gramling’s team to apply



Donna Rizzo, Ph.D.

it to the StoryListening Study’s televideo conversations.

She also knows grief. Several years ago, she and a colleague from her department attended a talk Gramling hosted at UVM. It hit home.

“It was at a time in my life when I was the primary caretaker for three people over the age of 90, one had dementia,” she says. “Three of the people I love most in the world. And one was my mom.”

She witnessed their struggles to be heard and understood in a healthcare system that didn’t always prioritize human connection. When a doctor truly listened to them, she could see a weight lifted.

“It relieved stress,” she says. “And it preserved an amount of dignity that people should have at that age in their life.”

At the same time, Gramling was seeking specialists in complex systems to help to scale up analysis of palliative care conversations.

“I think it was just at the right time in my life,” she says. “We both ended up tracking each other down, but for very different reasons.”

Rizzo says the computational methods she’s used to tackle large-scale problems as an engineer lend themselves to understanding human connection. In both cases, patterns emerge.

“There are tools out there that are really good at identifying fear in a conversation, or sadness or happiness, or certain emotions that you can link,” she says. “But in order to train these algorithms to do a good job so that they’re not biased, you do need human coding the first time around. That’s where Bob’s data set, I think, is rather unique. I don’t think there’s another data set out there, at least associated with serious illness, that has had humans go through such a large collection of conversations and identify these connective moments.”

As the study unfolds, she’ll be fine tuning the algorithms to assess the exchanges the team records, looking for correlations among what participants describe as meaningful and the features of those conversations.

She’s also completed UVM’s end-of-life doula certificate program and is speaking with study participants. The conversations she’s had have reinforced the healing power of storytelling. And going through the training, about six months after the death of her mother, and less than one year after the death of her aunt, brought her peace in a way she didn’t expect.

“I didn’t realize I was grieving as much as I was,” she says. “Just knowing that you’re not alone, that other people are experiencing this same kind of trauma, was comforting.”

The Value of Storytelling

End-of-life doulas learn to pick up on the subtlest of cues to help support people through intensity, says Francesca Arnoldy, director of UVM’s certificate program.

“As a doula, I consider myself a chameleon caregiver on assessing the need and then meeting the moment,” she says.

The eight-week program has exploded in popularity in the last several years, buoyed even further by the pandemic. She says people who have been furloughed or lost their jobs have signed up, as have individuals who have reassessed what they want as they faced quarantine and death on an entirely new scale.

“There’s just been this awakening to this idea of mortality

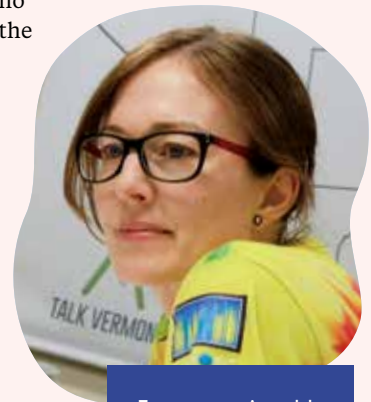
that people can no longer ignore,” she says.

End-of-life doulas learn to help people navigate the myriad challenges the end of life brings, whether it’s the minutiae of end-of-life planning, having difficult conversations with loved ones, or dealing with grief and loss. When Arnoldy heard Gramling was launching the StoryListening Study, she knew it was an opportunity for collaboration.

“I said ‘Bob, this speaks to me. If you are able to get this off the ground at some point, I would love to talk more because I really feel like story listening is something that doulas provide. We do this very naturally.’”

Now, three end-of-life doula graduates and Arnoldy herself serve as the StoryListening interventionists, hosting video conversations with people who have lost a loved one during the pandemic.

“What I’ve seen in my sessions is that some people have a real need to celebrate the life that was lost,” says Arnoldy. “And they want to share stories about this person. Whereas other storytellers want to express deep sadness and yearnings or some of the physical manifestations of grief...And other people, it’s maybe trauma, and it’s that they had a complex relationship or a painful relationship with this person.”



Francesca Arnoldy

No matter the story, there’s value in telling it.

“Being able to tell your story to a really engaged listener who doesn’t have a vested interest in your story other than that you get a chance to tell it can be quite freeing,” Gramling says. “The expertise of being a doula is to bear witness to people’s unfolding story.”

There are implications here for physicians, nurses and healthcare professionals, says Rizzo.

“We have an insufficient understanding of what features naturally occur in conversations,” she says. “And the fact is that these things coalesce into beautiful observable patterns. If we could match those patterns to at least what the patient thinks was a good conversation, maybe we could transform the way doctors and clinicians interact with patients in the future.”

In the long-term, Gramling wants to define and delineate the value of these conversations. If the medical system can shift its approach to death and dying—and if clinicians within it can understand and foster connection—maybe more patients and their families could experience peace and comfort in the most difficult of times.

“In the context of training people to listen, which is fundamentally what we’re going after, what does it mean to listen well? How do we promote that? How do we welcome people to shape their story as it’s unfolding? A lot of the settings we study are potentially high in suffering and also high in joy. They’re high in a lot of raw human experience. And those are also times that we humans often search for meaning.” VM