

Researchers focus on helping dying patients take care of unfinished business

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Hospice workers have watched patients emerge from comas and cling to life long enough to tell someone they love or forgive them.

This phenomenon of taking care of unfinished business has been observed, but researchers from the Frances Payne Bolton School of Nursing and the College of Arts and Sciences at Case Western Reserve University will begin groundbreaking studies to understand what drives the dying to live long enough to resolve these issues.

With the research data, they will design interventions to help patients in [hospice](#) care and families before and after the person passes.

Before now, end of life research primarily focused on making the patient comfortable by easing suffering or discomfort from the illness.

But, the approach of Barbara Daly and Mary Jo Prince-Paul from the School of Nursing and Julie Exline from Arts and Sciences is to relieve [psychological distress](#) by marshaling the patient's inner strengths and [social connections](#).

These qualities include the resilient feelings of hope, optimism and connectedness that they mustered to make it through difficult and even life-threatening situations before their terminal illnesses. Marshaling these inner resources has been shown to improve the psychological outlook of healthy people, and the researchers want to find out the benefits for those severely ill.

In the past, researchers have shied away from approaching dying patients with questions, but among the goals of these projects is to give hospice patients options to participate in research. They also will organize a biomedical research group interested in palliative care that focuses on the patients' and family members' inner strength.

Daly, the Gertrude Perkins Oliva Professor of Oncology Nursing at Case Western Reserve and clinical ethics director at University Hospitals Case Medical Center, will establish the BEST Center (Building End-of-Life Science through Positive Human Strengths and Traits) to encourage research and recruit faculty in this area. The National Institute of Nursing Research funds the research.

Over the next year, three faculty members will receive support to concentrate 75 percent of their time on research. Each faculty member will receive \$30,000 to launch a new project. As part of the hiring requirements, researchers must have a project ready to begin at their start date.

Approximately 20 faculty members across the Case Western Reserve campus work in the area of end-of-life issues. As one function of the BEST Center, the Palliative Care Education and Research Leadership (PEARL) group will meet regularly with the opportunity to collaborate and share ideas and findings.

"Many people want the end-of-life experience to be meaningful," says Prince-Paul, assistant professor of nursing and hospice nurse at Hospice of the Western Reserve who has worked in hospice and palliative care for nearly 20 years.

With funding from the American Cancer Society, 163 patients ages 18 and older with an advanced cancer diagnosis will participate and test a new communication tool developed by Prince-Paul.

Patients will be interviewed three times over the course of a year or at the time they enter hospice care about what they feel is important. They will see how life goals and key communication expressions, such as love, gratitude, and forgiveness might change.

Prince-Paul explains, when people come face to face with death, hospice care workers have noticed that people want to "clean up" unfinished business.

"At the end of life, people have limited ability and energy to communicate. We need to strategize and capitalize on the time they have to facilitate those things that matter most in their life," says Prince-Paul.

Families sometimes have unresolved issues to settle, too. Exline, a psychologist and associate professor of psychology, and Prince-Paul will lead the study of 200 family members who have someone near the end of life or have died.

Among those issues can be forgiveness. Exline, who has studied forgiving oneself, others and God over the past decade, will survey family members before and after the death of the loved one to see how hospice workers can help them as they undergo the emotional stress of caring for this seriously ill family member and then the challenges of bereavement.

With Fetzer Foundation support, Exline will lead the researchers in testing new survey tools to help determine how hospice workers can help family members.

The researchers will collaborate with healthcare workers from the Hospice of the Western Reserve, who will distribute questionnaires for those with a family member in hospice home care. Another group of family members will be interviewed during the bereavement period.

A primary caretaker in the family will answer questions that define some of the issues and emotions experienced at this time. The researchers will start by asking an open-ended question such as "If you had an opportunity to say something to your family member, what would it be?" Other detailed questions will follow.

The researchers will conduct another study during bereavement to assess if there are any unresolved issues with the deceased family member and if there is a continued bond with that family member.

Exline is interested in how people experience struggle and how forgiveness is part of that process.

According to Prince-Paul, the research projects focus on taking this new direction by building on human strengths -even at the time when people may have little resources left.

The researchers plan to take their findings and translate them into practice.

Source: Case Western Reserve University ([news](#) : [web](#))

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