

SPECIAL AWARD WINNER

POPULATION-BASED PALLIATIVE CARE
RESEARCH NETWORK (POPCRN)

Denver, Colorado





In a care specialty hungry for measurable outcomes, PoPCRN is making a tremendous difference. Because most end-of-life care takes place outside academic institutions, research into best practices has been challenging, and many well-intentioned end-of-life programs find themselves scrambling for workable solutions. PoPCRN is changing that scenario and raising the bar, bringing an innovative, data-driven approach to end-of-life care.

Based in the Division of General Internal Medicine at the University of Colorado Health Sciences Center, PoPCRN conducts rigorous research into end-of-life issues. As its name implies, PoPCRN does its research where end-of-life care takes place. Its research network comprises a voluntary group of programs of all sizes providing care in private homes, nursing facilities, and freestanding hospices in urban and rural areas, in the Colorado region and beyond. This highly diverse network makes PoPCRN's findings relevant and applicable in a wide variety of settings. Participating organizations use standardized data-collection procedures that allow data to be analyzed scientifically and distributed in ways consistent with confidentiality requirements. Collaboration between clinicians and administrators from participating organizations and the PoPCRN research team ensures that issues under study are clinically relevant and that the studies themselves are well-designed to yield valid information.

PoPCRN studies often focus on issues that hospice and palliative care programs face daily. "Ideas are constantly bubbling up from our network," says Jean Kutner, M.D., director of the program and associate professor of medicine at University of Colorado Health Sciences Center. "The enthusiasm for our program has been astounding. These are busy people in a complicated field, who are trying to survive physically and emotionally, and yet they're making research a priority, because they want to do a better job for patients and families. Their interest and willingness to be a part of something bigger than themselves is what makes this effort work."

PoPCRN's first three major investigations exemplify its focus on the big issues of end-of-life care. The first, entitled "Symptom Burden at the End of Life: Hospice Providers' Perspectives," revealed that hospice providers felt that their patients had many unrelieved symptoms, and that there were even more unrelieved symptoms of which hospice workers were unaware. The results motivated several hospices to institute changes in the way they assess symptoms and to increase staff education around assessment of sensitive topics, such as sexuality and depression/worrying.

In another major study, called "Psychosocial and Spiritual Issues among Hospice Patients," one-on-one interviews with hospice patients substantiated the idea that preserving quality of life remains an important issue among terminally ill individuals — a finding with important implications for physicians, families, and other caregivers.

PoPCRN's third study demonstrated that confusion among hospice patients is common, frequently severe, and usually problematic, indicating that routine assessment is needed. "Those results really opened my eyes," says Michael Preodor, M.D., medical director of Horizon Hospice in Chicago. "We used to guess that about 20 percent of hospice patients were confused. The study told us that the real number may be much larger than that. We learned that we have to ask better assessment questions. Bottom line, PoPCRN is providing a scientific backbone on which to build better ways to help our patients."

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INNOVATION HIGHLIGHTS

RESEARCH CONDUCTED WHERE CARE IS GIVEN

COLLABORATION WITH ACADEMIC RESEARCHERS

FOCUS ON PRACTICAL AND POLICY ISSUES

As PoPCRN gains experience in field-based research, it's branching out into new areas, looking at pharmaceutical costs, the role of hospices in educating nurses and doctors, and other relevant subjects. PoPCRN also is a key contributor to a series of nationally-funded studies that are following the natural history of symptoms at the end of life. Recently, PoPCRN completed a study of the outcomes of patients who are discharged alive from hospice — an investigation that may have significant implications on criteria for hospice eligibility.

PoPCRN-based findings regularly translate into practical changes in end-of-life care. “We learned a lot from our participation,” says Barb Kamlet, transitions coordinator for Exempla Lutheran Hospice in Wheat Ridge, Colorado. Exempla collaborated in the pain and symptom management study in 2001. “We gained new insight into what families and patients experience. And as a result of the study, we changed the way we asked our assessment questions. PoPCRN has been phenomenally helpful to us.”

Martha Barton, president and CEO of Pikes Peak Hospice & Palliative Care in Colorado Springs, agrees. Working with PoPCRN, Barton's organization measured the incidence and impact of last-minute referrals to hospice. “When we saw the data, we changed our intake process by creating a Rapid Response Team, which addresses patients' and families' highest priorities first,” says Barton. “I've seen, firsthand, how PoPCRN studies can positively influence our interventions.”

Collaboration with the academic community has been a key to PoPCRN's growing success, says Kutner. “Academic researchers have welcomed the opportunity,” she says. “Their main comment usually is, ‘What a great idea. Why haven't we done this before?’ We're bringing an evidence-based approach to something that has, until now, been mostly experience-based.”

Interest in PoPCRN's approach and its findings is growing rapidly. To date, 137 hospice/palliative care organizations in 28 states have expressed interest in participating in PoPCRN studies, and 36 organizations have collected data for six studies. Quickly emerging as a respected “lab” for addressing important issues in the care of dying people and those around them, PoPCRN is eager to share its findings as widely as possible. To that end, it publishes its results in peer-reviewed literature, in a seasonal newsletter, and on its website (www.uchsc.edu/PoPCRN), which also has links to other palliative care sites. In the interest of offering the fast feedback that hospices want, PoPCRN also has begun using web-based research and reporting techniques to generate study questions, announce new projects, and distribute results quickly.

“Ultimately, what we hope to offer are practical assessment tools, a broader perspective on end-of-life care, and solid data on which to base decisions,” says Kutner. “The wonderful thing about this approach is that we're all learning together.” •