UB researcher explores first-responders' role in end-of-life calls

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New study provides glimpse into largely unknown area

Paramedics and emergency medical technicians (EMTs) are trained to save lives. But they sometimes enter situations where a dying patient's end-of-life wishes contradict their professional code.

What do they do when faced with someone who is imminently dying and whose pre-hospital order is "do not resuscitate"? Until recently, the dynamics of that environment were a mystery.

"One way to gain perspective on these crises was to interview the paramedics and EMTs involved in them," says Deborah Waldrop, a professor in the University at Buffalo School of Social Work.

The study resulting from those interviews, conducted with UB collaborators Brian Clemency and Heather Lindstrom and Arizona State University's Colleen Clemency Cordes, and published in the *Journal of Pain and Symptom Management*, is providing profound new insights into the complex, yet largely unknown juncture of emergency care and end-of-life care, the place where life meets death.

The findings provide one of the first scholarly examinations of how pre-hospital providers assess and manage the type of emergency calls that can determine whether a person's end-of-life wishes are upheld.

Waldrop, an expert in aging, end-of-life care and advance care planning and first author on the study, has interviewed hundreds of families through a 16-year collaboration with Hospice Buffalo, trying to better understand the psychosocial needs of patients and their families faced with a life-limiting diagnosis.

She repeatedly heard that people didn't know what to expect watching someone die. Providing end-of-life care, in fact, is among the most stressful human experiences. Emergency calls are often a way of coping with that stress, especially when a patient's symptoms change suddenly for the worse.

"We are not born into this life knowing how to die or knowing how to care for someone who is dying," Waldrop says.

And first responders are not trained in end-of-life care, yet Waldrop says they do a lot more end-of-life care than anyone gives them credit for.

"They have to," she says. "They're usually the first medical personnel on scene."

To learn the specific nature of these end-of-life emergencies, Waldrop interviewed EMTs and paramedics based in Western New York, working with Rural/Metro, an emergency services provider in 21 states.

Paramedics and EMTs expressed the need for more training in end-of-life care, but even in the absence of that training, first-responders have developed ways of managing these situations.

If a person is actively dying, that might include coaching the family through the process, clarifying what's happening.

"They fill the void for families looking for help, looking for knowledge about what's happening and what to do."

But it's a challenge and conflicts are common.

If there are no medical orders or they can't be found first-responders are professionally bound to begin life-saving interventions and transport to a hospital even if family members say otherwise.

"It's why the end-of-life conversation needs to happen at the time of a life-limiting diagnosis or when something changes on the trajectory of that illness and why those documents have to be in a prominent place," says Waldrop. "In the heat of the moment, families don't want to be shuffling through files."

All these things need to be in place well in advance of the emergency call to prevent unwanted actions and unnecessary treatments.

"It's someone's life that may end differently than they intended if we fail

to take these steps," she says. "Those memories don't easily go away."

These calls are low frequency, but high intensity. Events happen quickly. First responders assess the patient, family and environment, identifying relationships to establish who might be serving in a decision-making capacity. The emotional intensity of the environment also raises safety concerns.

"The death of a loved one can bring out the worst in people," says Waldrop. "Emergency personnel have to be mindful of the scene."

Waldrop says there is so much that can be done, and the pre-hospital providers' role in end-of-life care should be further explored to increase their ability to uphold end-of-life wishes while providing emotional support to families.

She offers the following tips for those facing end-of-life decisions:

- Following the diagnosis of a life-changing illness, initiate conversations about the person's goals of care and wishes for life-sustaining treatment.
- Ask health care providers about what to expect over the course of a chronic, life-limiting illness. Information is key to making choices and upholding a person's wishes.
- Revisit the person's wishes periodically and when the situation changes, such as after a symptom crisis or hospitalization.
- Discuss wishes for resuscitation (or not) with all caregivers who are involved.
- Assure that all family members (those who are caregiving and those who are at a distance) are aware of the ill person's wishes.
- Place copies of a Non Hospital Do Not Resuscitate Order or Medical Orders for Life Sustaining Treatment (MOLST) in a prominent location such as on the refrigerator.

Provided by University at Buffalo