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To: Listserve, American Clinicians Academy on Medical Aid in Dying

From:
Thalia DeWolf, RN, CHPN.
Director of Nursing Education
American Clinicians Academy on Medical Aid in Dying

Clinicians,

As you know, the history of medicine is a long and winding river, always course correcting and revising. As the 2023 National Clinicians Conference on Medical Aid in Dying made clear, aid-in-dying care has become a part of that evidence-based flow.

The Academy has been diligently gathering aid-in-dying information and data from clinicians in the field, analyzing it, and recommending best practices for patient care.

We’ve been especially intrigued by the continued development of non-oral routes (PEG, ostomy, rectal) of self-administration of aid-in-dying medications. Results — time to sleep; time to death; comfort and side effects — have been consistently close to those with oral self-administrations.

In October 2022 the Academy revised and expanded our procedure guidance on non-oral administration to allow for “doulas or competent family members to manage the non-oral procedure if the attending/prescribing doctor reviewed the clinical circumstances, and concluded that the case was uncomplicated.” Reports of bedside experiences since then have led to the conclusion that we need to course correct, and rescind that recommendation.

We have received reports of difficulties and complications when end-of-life doulas and/or family members were primarily responsible for a non-oral self-administration, including evaluation of the relevant parts of the GI tract and the placement of catheters. These reports were rare, but even rare complications are significant for aid-in-dying patients and their families.

Non-oral self-administrations have become increasingly common — and with that, more difficult circumstances with complex gut function and anatomy have increased. Detailed clinical evaluations of the patient, and communications between the attending/prescribing physician, other bedside clinicians and, if they’re involved, end-of-life doulas, are essential. But this does not always occur, leading to potential misunderstandings and risk of complications.

We are often asked, “Can’t anyone just put in the rectal catheter, it’s like doing an enema and anyone can do that?” The question, though, should not just be about the mechanics of putting in a catheter, but rather about the condition of the patient receiving the catheter, a much more complex question that involves clinical experience and judgment. For rectal administration, in
particular, a clinician must evaluate the rectum before the procedure. End-of-life doulas are not trained nor experienced with those evaluations.

In the extremes, some GI tracts are simply not functioning well enough to proceed with aid in dying, and assertive hospice care with aggressive symptom management is a safer choice than catheter-based aid in dying. This is a difficult decision for a clinician to make, and for the patient and family to hear.

We now recommend that rectal and ostomy aid-in-dying deaths be managed by nurses and doctors, and that they establish solid communication, do repeated and thorough assessments of the GI tract, and prepare patients for alternatives long before the aid-in-dying day is at hand. Doulas, of course, can be involved in many aspects of the patients’ end-of-life experiences — but we do not recommend that they be directly involved in deciding about non-oral routes of administration, nor in placing catheters.

PEG (feeding tube) self-administrations can often, but not always, be exceptions to the above, since families are quite used to and comfortable with PEG feedings. But even in those circumstances, the attending/prescribing physician should review gut function before proceeding.

Thanks for your understanding. The Academy will continue to follow data and case reports, and will revise these recommendations if the information indicates the need for a change.

Thalia DeWolf, RN, CHPN
Nursing Education Director
American Clinicians Academy on Medical Aid in Dying