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OUR MISSION
Hospice of the Western Reserve provides palliative and end-of-life care, caregiver support, and bereavement services throughout Northern Ohio.

In celebration of the individual worth of each life, we strive to relieve suffering, enhance comfort, promote quality of life, foster choice in end-of-life care, and support effective grieving.

Better Together
Hospice of the Western Reserve and Hospice of Medina County Merge

The merger between Hospice of the Western Reserve and HMC Hospice of Medina County has been completed.

“Healthcare reform requires greater efficiency to address rising operational costs and declining reimbursements and to maintain high quality care,” explained Bill Finn, President and CEO. “Uniting the two organizations makes sense. It accomplishes these goals.”

An expanded continuum of care is available for those who struggle with progressive illness. Each agency has added programs and services in response to community needs, and many programs complement each other. Patients, families and local communities benefit from a richer and more extensive range of services.

Some of the enhanced assets and services available through the merged organizations include:

- The region’s largest team of certified hospice and palliative care professionals
- Three hospice house care centers to provide short-term, specialized symptom control and comprehensive support in the final days of life
- Home healthcare and private-pay services
- Palliative care (symptom management) for those with earlier-stage chronic disease
- A combined force of more than 3,350 dedicated volunteers
- One of the nation’s most comprehensive grief support programs, available to the community as well as patients’ families
- A Hospice Institute providing fellowships, training and continuing education credits to Northern Ohio healthcare professionals, clinical research and an award-winning end-of-life library
- An advanced illness home care program offered in partnership with insurance providers to help those with earlier-stage chronic illness maintain independence and reduce hospitalizations
Research at End of Life: Benefit or Burden?

By Barbara Daly, Ph.D., RN

Barbara Daly, a Professor of Oncology Nursing at the Frances Payne Bolton School of Nursing, Case Western Reserve University, is also Clinical Ethics Director at University Hospitals. She has conducted several federally funded research studies focused on decisions at end of life.

The notion of asking persons dealing with a terminal illness to participate in research, particularly as the end of life grows near, causes many clinicians, and researchers themselves, to question the appropriateness of this. Concerns include an assumption that people who are terminally ill should not be “bothered” with research procedures, that those who are dying are at greater risk of physiologic and emotional harms, and that people who are terminally ill are particularly “vulnerable” and should have additional protections before enrolling them in research projects.

Protecting research subjects from harm is a critical responsibility in research. Consequently, the worry that research might be overly burdensome, or even harmful, to those facing the end of life is a serious concern and one that should be carefully evaluated. Fortunately, we do have considerable data about how patients and their family members feel about participating in research.

Researchers have asked both patients and their family members, at home and during in-patient hospice stays, to tell us how they felt about participating in research during the sensitive days and weeks before death. The great majority report that the experience was helpful, that the opportunity to contribute to important work was meaningful, and that, in some cases, being interviewed or answering questions prompted further thought and conversation with family members.

The data that some, even most, patients find research participation to be beneficial not only addresses concerns about overly burdening patients, but also suggests that we would be acting unjustly if we categorically excluded persons with serious or terminal illness from research. Two of the most important principles of research ethics are autonomy and justice. Respect for autonomy requires us to allow persons to make their own decision about whether or not to participate, and the principle of justice requires that we offer the potential benefits of research to all equally.

KEY TAKE-AWAYS

Given the well-recognized need for better understanding of both physiologic processes and the end of life and behavioral interventions that might be helpful, it is critical that we continue to support research endeavors. Active involvement of hospice and palliative care providers assures that the research will be meaningful and conducted with awareness of patient and family situations. Importantly, previous research has also revealed that patients prefer potential research projects be introduced by their health care providers, reflecting the trust and confidence they have in their team.

Addressing Pain in Patients with Dementia

By Joel Martin and Carole Klingler, RN, BSN, in consultation with P. Lal Arora, MD, FRCPC

Pain, the fifth vital sign, was first coined by the American Pain Society to increase awareness among medical professionals about assessing and treating pain. It was subsequently adapted by the Veterans Administration (VA) health system and published as a tool kit in 2000. In their version, there is not much mention about the assessment of pain in patients with cognitive deficits.

According to the International Association for the Study of Pain, “pain is a subjective phenomenon that is uniquely experienced by each person.” Since it is a subjective experience, a number of scales validated in clinical trials have been proposed to assess pain. Unfortunately, most of these are not applicable to patients with limited cognitive abilities.

Aggressiveness, verbally or physically inappropriate behavior toward caregivers and anxiety, restlessness and wandering are common behaviors that can be difficult to control in long-term care settings. Anti-psychotics often become the medication of choice, despite recommendations against their use by the FDA and a number of national societies. Patients with moderate or severe dementia are often not able to express their discomfort or pain. Instead, they may simply express their pain with a new behavior, usually with agitation.

The VA recommends the use of a numerical scale (0-10) to assess and monitor for pain. The numerical scale is not appropriate for all cognitively impaired patients, even though some patients with dementia are able to complain of pain and are able to even localize the area where it hurts. The VA further advises: “Always assess the person with the pain, not just the pain alone.”

APPROACHES TO TREATMENT

It is always advisable to attempt the non-pharmacological therapies first. Gentle massage, music therapy, and a soothing environment may provide enough benefit to make the pain more tolerable. Pharmacological therapy is a double-edged sword. It helps relieve pain, but might cause side effects, including the worsening of confusion, especially with certain agents.

Responses to medication should be monitored by assessing the patient 30 to 90 minutes later, depending on the route of administration.

Empiric therapy with frequent administration of a medication without waiting for the pain to occur (especially in patients with a prior history of pain) or administration of a medication before a certain activity (incidental pain) such as bathing, dressing, taking a walk or physical therapy, usually provide added benefit.

CONCLUSIONS

1 | Usual criteria for assessing pain are not always applicable to patients with significant cognitive impairment. All the same, patients with dementia can offer verbal complaints of pain that are valid.

2 | Seek the help of the family and friends about the patient’s response to complaints of pain in terms of behaviors and response to treatment.

3 | Always start low and go slow. Be wary of the side effects of any medication. Monitor the response to treatment in a systematic way.

4 | If the medication is successful, try the medications in a regularly administered manner around the clock.

5 | Most important is the awareness that a patient with dementia may express pain in an atypical manner, and judicious trial with pharmacological and/or non-pharmacological therapy is often warranted.

Q: How often does the ethics committee meet and what is its role?
A: The committee, founded in the mid-90s, meets quarterly to review ethical principles, clarify end-of-life care issues and offer support in a non-judgmental capacity. Committee members are available 24/7 to provide guidance whenever needed.

Q: How does the committee function?
A: Ethical principles and the guidance they provide often clarifies certain care issues and can be valuable in assisting with conflict resolution. Issues are reviewed in a format that stimulates dialogue among members of the hospice team, community and other healthcare providers. The committee is strictly advisory and does not make decisions or take the place of physicians or other medical advisers.

Q: How is the committee structured and who sits on it?
A: There are currently 22 members on the committee. Included are the chief medical officer, physicians, members of the transdisciplinary team, education team, quality team, bioethicists and other community members. Other disciplines are brought in ad hoc.

Q: What are the goals of the committee?
A: The purpose of the committee is to provide a forum that facilitates education, conflict resolution, policy review and development and consultation.

Q: What are the most frequent topics for discussion?
A: The most common topics involve patient preference, autonomy and choice. Ethical dilemmas can occur when there are no advance care directives. Discussions explore issues relating to patient and staff vulnerability. We also review what happens when religious beliefs collide. We review topics relating to what is in the best interests of the patient.

Q: Can you provide an example of an ethical dilemma that creates stress?
A: It often comes back to patient preferences. Often we need to rely on the durable power of attorney (DPOA) for patients who can’t communicate. Ideally, the DPOA has had the conversation with their loved one about what he or she would want. Unfortunately, this is not always the case. So, the team may get a call from a family member who wants aggressive treatment or tests which are not in the best interests of the patient. The hospice care team becomes stressed knowing that they may be hurting the patient with unnecessary needle sticks or providing futile care. Everyone from patient to the family to the staff is impacted.

Q: Can you provide an example of a best practice that has been informed by the work of the ethics committee?
A: The most noteworthy recently has been Voluntary Stopping of Eating and Drinking (VSED). At the end of life, many patients naturally stop eating and drinking as their body begins to shut down. But what about the 97-year-old woman with dementia who is only eating because someone is force feeding her? Or a man in his mid-50s with ALS who feels he is done with living? Two very different cases, where the patient or DPOA decides to stop eating and drinking. After several cases, scenarios, and research on best practice, the ethics committee requested that the practice committee (which informs clinical policy matters) develop a practice for VSED. They, too, vetted the research and developed a sound practice, which is now in place.