NHPCO launched the Hospice Manager Development Program (Hospice MDP) in 2004 to help prepare managers specifically for their work — and the challenges they face — in the hospice setting.

Among the program’s most popular courses is the module, Ethics for Hospice Managers, which was developed by Paul Longenecker, RN, MBA, PhD, and Marion Keenan, MA, MBA, and has been offered since 2005.

As the Hospice MDP celebrates its 10-year anniversary, Dr. Longenecker, who has taught the module since its inception, looks back on of the ethical issues raised by module participants during their group discussions and examination of case studies. It’s a very interesting review of how the changing landscape of health care and hospice has affected the ethical aspects of practice. (To learn more about the Hospice MDP, see the last page of this document.)

The Ethical Challenges of Hospice Managers

By Paul D. Longenecker, RN, MBA, PhD

Approximately 1,000 hospice managers have participated in the Hospice MDP’s Ethics Module since it was introduced in 2005.

The four-week module begins with a review of ethical principles, then moves into discussions about common ethical dilemmas that arise during the delivery of care as well as in hospice management. To help get the most out of the learning experience, the group discussions revolve around case studies that are presented for examination and resolution.

It was a fascinating process to compile the remarks and feedback of participants over the past nine years in which the module has been offered. While the module has been taught in both the classroom and online settings, this article shares feedback from the online participants, organized under the key area covered over the four week period: Ethical Concepts (i.e., principles and theories); Common Ethical Dilemmas; Business Ethics; and Hot Topics (i.e., emerging issues in health care).

Ethical Concepts

Since the module was first introduced, the “patient’s autonomy” has continued to top the list of the most challenging ethical concepts hospice managers face.

This autonomy, which focuses on the patient’s ability to outline his or her own plan of care, can pose an ethical challenge when hospice managers and their staff do not agree with the patient and family’s chosen course of action. This conflict normally surrounds the ethical concepts of beneficence (doing good) and non-maleficence (not doing harm). Although the decision and choice of action rests with the patient as long as he or she is competent, the hospice team may not believe the decision is in the patient’s best interest. Educating and
supporting the patient through the decisional process appears to be at the heart of allowing the patient’s autonomy to be expressed.

In more recent years, module participants have cited the principles of veracity (truth-telling), beneficence and non-maleficence as particular challenges because, in many cases, these principles compete with one another.

For example, in respecting patient autonomy, telling the truth may cause potential harm and may not be beneficial for the patient. Also, a decision that a patient makes may cause him or her direct harm. As expressed by module participants, the ultimate challenge for hospice managers and their teams is to understand the obstacles from an ethical perspective and be prepared to objectively address them. This process can involve education and self-exploration of each individual’s moral beliefs that may interfere with the delivery of care.

**Common Ethical Dilemmas**

The dilemmas routinely voiced by module participants seem to center around three key areas: staff boundaries, patient compliance/adherence, and futile care.

When examining staff boundaries, exploring the questions at the very heart of this issue is valuable: Is this a hospice personnel issue related to staff (or volunteers) being unable to set appropriate boundaries with patients and families? Or is this an issue of hospice managers not educating and enforcing the boundary policies that are in place? When presented as outlined, the discussion can be very enlightening as module participants analyze where their organization fits on this continuum.

Where feedback has changed is in the area of compliance. In the early years of the Ethics Module, discussion of compliance focused more on the plan of care being developed by the hospice team, with non-compliance meaning the patient was not following the plan of care that was developed for them. In recent years, the focus has shifted away from compliance to become more about adherence to the plan of care that is jointly developed by the hospice team and the patient. This subtle difference has generated increased discussion among module participants, and the introduction of the concept of adherence has helped lessen the ethical impact of any caregiver/patient differences.

Lastly, the topic of futile care continues to be an elusive ethical issue, namely because futile care continues to have different meanings based on where hospice programs are located. When course participants from different parts of the country compare notes, one of the key questions that arise is “who defines what is futile?” Is it the patient, the family, the physician, the insurance company, or society? With the introduction of insurance policy changes, especially since the Affordable Care Act took effect, the course discussions have taken on new points of interest.

**Business Ethics**

In the early years of the Ethics Module, many participants did not perceive themselves as very involved in the business side of their organizations. Interestingly, this perception appears to still hold true.

The primary method we use in the module to explore business ethics is through case analysis of business-related topics, although the focus of the business related cases has changed. Module participants are asked to analyze one of two cases: one relating to contracts or another relating to artificial nutrition and hydration (ANH). They are then asked to post their analysis of the case, respond to each other’s posts, and note whether other participants’ posts changed their opinion about the case.

Interestingly, the ANH case is routinely selected three to four times more often than the contract case, regardless of whether the module participants come from the clinical or business side of the hospice. It would appear that even though hospice care delivery has taken on a stronger business model over the last decade, hospice...
managers’ perceptions of their role in business operations — and the ethical challenges confronting their organizations in this area — have not evolved along with the changes.

**Hot Topics**

It is in this portion of the module where the perceptions of participants have really changed in recent years.

For example, in 2006, ANH was familiar to module participants, although admittedly challenging; palliative sedation, on the other hand, was completely unknown.

Today, both ANH and palliative sedation are familiar topics, with module participants having had specific experience with addressing the dilemmas that arise during policy development and utilization. Although the ethical dilemmas associated with these issues have not gone away, module participants have become far more comfortable with confronting them.

Another area of change relates to pediatric care, appearing to replace palliative sedation as ‘unknown territory’ among module participants. This of course is not surprising, given that pediatric hospice care is truly specialized care. In fact, NHPCO Facts and Figures reports that just 0.4% of all hospice patients served are age 24 or younger.

Pediatric hospice care appears to introduce a few key challenges to the application of ethical concepts. With pediatric patients, the issue of “competence” impacts autonomy since the patients are not able to express their wishes themselves. Issues of doing good (beneficence) and avoiding harm (non-maleficence) when related to children also appear to change the focus of the analysis and the willingness and desire to do more. Veracity (truth-telling) appears to create a large barrier to sharing information due to a fear of taking away hope. Although pediatric hospice care is not an area of care delivery that most module participants perceived as part of their care delivery model, group discussions of a pediatric case typically generate many different perspectives on the ethical principles involved.

**Some of the Module Takeaways**

Since the Ethics Module was introduced nine years ago, the limited use of a hospice ethics committee has been cited as a key obstacle among participants. Back in 2006, I had observed that ethics committees within hospice programs were not as common as I had anticipated. Unfortunately, this observation appears to still hold true. Although no specific statistics were collected on the topic, the number of managers that identified the presence of an ethics committee in their hospice has shown little change. In addition, it was noted that in hospices with ethics committees, many had no formal mechanisms for educating their committee members on ethical analysis or providing ethics training to their staff.

Although the absence of ethics committees is a concern to me, it’s always uplifting when I see, as part of the course evaluation, the number of module participants that identify the need for creating an ethics committee, better utilization of their ethics committee, and utilization of the course case analysis tool by their ethics committee. Many module participants have also expressed a willingness to help start an ethics committee or serve on the ethics committee of their organization.

Another common takeaway among module participants is the desire to apply an ethical perspective to the issues and challenges they face in their practice. Many have noted their “new ability” to focus more on objective
analysis of the issues rather than take a subjective approach. In addition, many have reflected on the importance of viewing issues from a broader perspective rather than focus only on the clinical impact.

**In Summary**

Only minor variations have been noted over the nine-year period in which the Ethics Module has been offered, namely increased use of palliative sedation and pediatric care, and a stronger utilization of a business model requiring a need for more awareness of ethical concepts. These variations seem to follow the changing trends of end-of-life care in the U.S. (i.e., increased patient/family involvement and continued advancements in technology and treatments), and have resulted in issues that impact ethical hospice care delivery.

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**About the Hospice MDP and Ethics Module**

Many hospice managers have either risen up within an organization and have little management training or they are brand new to the hospice field. They need training on how to perform as managers within the hospice interdisciplinary team. This is where the Hospice Manager Development Program (Hospice MDP) can help.

The Hospice MDP is a comprehensive program that is divided into three levels:

- Level 1 requires completion of a two-day face to face foundational course and two online learning modules
- Level 2 requires completion of six online modules
- Level III requires completion of additional enhancement modules as well as self-study and an independent learning project under the direction and guidance of an NHPCO leadership coach.

The two-day, *face-to-face* foundational course addresses hospice leadership and management principles. Once the foundational course is completed, participants can take additional Level I and Level II *online* modules that delve more deeply into specific application of the principles.

**CEUs and Certificate of Completion**

The Hospice MDP foundational course and companion modules have been approved to provide credit for nurses and social workers. NHPCO has pursued credit for the disciplines of spiritual caregiver and counselor, but the Hospice MDP has not been approved to provide continuing education credit for these disciplines.

When participants complete all of the modules that comprise a level, they are awarded the Hospice MDP Level designation, are recognized on NHPCO website, and receive a framed certificate of recognition.
Taking Individual Modules
If hospice staff members are not able to enroll in the Hospice MDP, they do have the option of enrolling in specific online modules, such as the Ethics Module discussed in Dr. Longenecker’s article.

Learn More:

For general information about the Hospice MDP, visit www.nhpco.org/mdp or see Frequently Asked Questions. Members can also contact the Professional Development Department: education@nhpco.org or 703-647-5178.

To get a firsthand account of a manager’s experience in the Hospice MDP program, see the interview with Deborah Goodman in the March 2014 issue of NewsLine.