FROM THE EDITOR
Mark P. Aulisio, Ph.D.
Assistant Director of the Consortium Ethics Program

As Editor of Community Ethics, I am pleased to introduce this special issue, which focuses on ethical issues in post-acute settings. Traditionally, most attention to ethical issues in health care has centered on acute care settings, to the relative neglect of ethical issues emerging either between care settings, such as the portability of advance directives, or in other care settings altogether, such as rehabilitation, long term care, and home care. While some basic issues in healthcare ethics will be similar in any care setting, different care settings pose unique challenges. Challenges to autonomy, informed consent, or confidentiality in the uncontrolled environment of the home, for example, present very differently than they do in acute care. Creative practical solutions to these challenges will have to differ as well. In this issue of Community Ethics, we take on a challenge of our own, that is, the challenge of identifying how ethical issues emerge in and among post acute care settings in the hopes of stimulating thinking about creative practical solutions.

In addition to taking up the challenge of post acute care ethics, this special issue of Community Ethics embodies another ideal, that of active participation by members of a vibrant ethics network. As a Consortium, we are fortunate to have a most valuable resource, that is each of you, our members. It is our hope that Community Ethics will become more and more a forum for your contributions, and a vehicle for the exchange of ideas. It is this hope that the current issue embodies, with excellent contributions from your fellow CEP representatives Joan Nypaver (on rehabilitation), Michelle Strobel (on long term care ethics) and Gene Hirsch (our CEP poet laureate!), as well as from Rosa Lynn Pinkus, our director; Elizabeth Stow, our staff editorial assistant; and myself.

Joan Nypaver, BSN, CRRN, and Robert M. Frampton, of Forum Health Hillside Rehabilitation Hospital, offer an instructive case study on responding to a patient who comes to therapy on a daily basis, but refuses treatment despite physician orders and family support. Joan and Robert lend insight to how a therapist in this predicament might respond based on the discussion and recommendations of Hillside's ethics committee.

Michelle Strobel, MSW, Director of Social Services at the Charles M. Morris Nursing and Rehabilitation Center of the Harry and Jeannette Weinberg Village, uses the case of Mrs. A to raise the issue of how caregiver attachment to patients can sometimes complicate decision making in long term care. The long term care setting, as Michelle points out, differs from the typical acute care setting in that patient stay is normally a matter of months and years, rather than hours, days or weeks. Michelle shows how this setting, and the attachments it encourages, raise special ethical challenges for patients and caregivers alike.

I then look at how the unique environment of the home poses ethical challenges for home care. Indeed, the home environment has physical restrictions, affords a less supervised delivery of care, and poses potential threats that are simply not present in acute care settings. These features of the home environment raise ethical issues that demand creative practical solutions.

Rosa Lynn Pinkus, CEP Director, and Jeffrey Carr, Esq. then describe a very interesting home care ethics consult they did, which raises a host of ethical issues concerning confidentiality, patient well being, elder abuse and provider responsibilities in the home care setting. This case, along with its legal and ethical analysis, illustrates well the unique ethical challenges posed by delivering care in the home.

This issue is also filled with other interesting and useful features, such as Gene Hirsch's thought provoking poem, Elizabeth Stow's summary of the 8th Annual Current Controversies in Medical Ethics Conference, which was co-sponsored by the CEP, Words from our Sponsors, and a schedule of upcoming CEP events!

Finally, I am honored to announce that this special issue of Community Ethics serves to inaugurate the CEP's 10th Anniversary Year. Our 10th Anniversary sees us at the same time enthusiastically welcome back so many of you who have helped the CEP to grow and flourish over the years, and warmly embrace the many new members (see page 13) who will help, with their ideas and energy, to ensure that the CEP continues to thrive for many years to come. Our 10th Anniversary serves as an occasion, then, both to reminisce about our past successes (and failures) and to look forward to the challenges and opportunities of the future. Most importantly, however, it is a time to appreciate the "moral community" (as Rosie describes it so well in her "Director's Column") that we have all joined together to form through our common interest in contributing to the ongoing conversation of ethics in health care.

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**Ethical Issues in Rehabilitation: When No Doesn’t Mean Maybe**

by Joan Nypaver and Robert M. Frampton

Forum Health Hillside Rehabilitation Hospital

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**Case Study:**

An 82 year old WF, with a primary diagnosis of paraparesis (lower extremity weakness) and sensory loss due to incomplete spinal cord compression, was admitted to an acute rehabilitation facility. She had minimal cognitive impairments, which did not impact her decision-making capacity. She had an infected decubitus ulcer on her buttocks for which she was a possible surgical repair candidate. Her nutritional status was compromised. From a medical perspective, she needed wound care, nutritional reinforcement, and exercise to prevent sepsis and prepare her for the proposed surgery. Her family wanted her to remain in the facility and participate in the rehab program.

Throughout a four week length of stay, she stated daily to her therapist that she did not want to participate in Physical Therapy (PT). This was reported at team meetings.

In the business of rehabilitation, one often serves as a patient motivator/facilitator through consistent physical or cognitive exercises and patient/family education, progressing toward an improved level of functional ability. When a patient comes to the therapist on a daily basis, refusing treatment despite physician’s orders and family encouragement, how should the therapist respond? This question was brought to the Ethics Committee at Hillside Rehabilitation Hospital Forum Health for discussion and recommendations.

Certainly, we discussed the patient’s autonomous right to refuse treatment. Other feedback from two hospital-wide discussion groups fell into four interdependent categories: team process, communication, alternatives, and billing/financial correctness.

Rehabilitation therapies revolve around the key team player, the patient. When the patient’s wishes differ from those of the family and the treatment team, how do we respond? Neither the patient nor family are routinely present during team meetings at our facility. The team can recommend a patient/family team conference as necessary to discuss difficult treatment plans or conflicts. The patient/family may also request to be present at team meetings. Had the family participated in a team meeting in this instance, perhaps they would have gained an understanding of the dilemma faced by the therapist, who felt as if she were forcing or antagonizing the patient daily, since the patient was refusing PT.

How often and under what circumstances were her refusals made? Asking the patient why she refuses recommended therapy may result in creating acceptable alternatives. Listening, a core component of effective communication, demands that we “seek first to understand, then to be understood.” Is the patient refusing particular services or overall treatment? Possible alternatives when particular services are refused may include: 1) co-treat with another discipline; 2) decrease the number of PT sessions with a corresponding increase in the number of Occupational Therapy sessions, which the patient might prefer; 3) observe another’s successful interaction with the patient to facilitate increased rapport; 4) try innovative methods of treatment — including suggestions from those outside your area of expertise; and finally, 5) consider transferring the care of the patient to another therapist.

If we are listening to one another in team meetings, we should be able to pick up on the frustration imposed upon the therapist who is attempting to work according to the team’s decision to continue the length of stay. What recourse does one have when the team’s decision is morally unacceptable to an involved person? One should refer to professional practice guidelines—in this case, the Guide for Professional Conduct of the American Physical Therapy Association—for guidance on how therapists might look out for the best interests of the patient. Physical Therapists are obliged to “advise their employer(s) of any employer practice that causes a physical therapist to be in conflict with the ethical principles of the Association” and must attempt to rectify the same.

The final category which needs to be addressed is that of billing/financial correctness. Billing must be in compliance with all ethical and legal guidelines. If a therapist is forcing a patient to participate, while achieving zero to minimal functional gains, can the therapist ethically bill at the usual rate? When therapists spend time listening to the patient, motivating and teaching, they provide quality professional services and should be able to bill accordingly, despite minimal functional gains. If it becomes clear that despite team efforts, attempts at successful communication and alternative therapies, the patient does not wish to receive these services, the therapist may not continue to bill for them or indeed force them upon the patient.

When the patient disagrees with the opportunity for rehab, we need to listen, acknowledge the expressed concerns, and respond respectfully. Consequences of the patient’s decision, such as nursing home placement as opposed to home discharge, should be fully discussed with patient and family. As rehab specialists, we remain ready to motivate, and gently nudge people down the road to recovery. Daily reflection assures that gentle nudging does not become paternalistic prodding. Effective communication within a patient-focused team process facilitates meeting the best interests of the patient and practicing quality rehabilitation care.
ETHICAL ISSUES IN LONG TERM CARE: A FAMILY FOR MRS. A

By Michelle Strobel, B.S.W.
Director of Social Services
Charles M. Morris Nursing and Rehabilitation Center
At the Harry and Jeanette Weinberg Village

When people think about ethics, they think about CPR, life support, and mechanical respirators. Hospital staff deal with life and death issues in a critical moment and snap decisions are made on a daily basis. Ethical issues in long term care facilities can be quite different. Caregivers in long term care facilities face the same life and death issues but are often faced with an array of emotional issues that accompany such ethical dilemmas. I decided to work in long-term care after working as a social worker in an intensive inpatient rehabilitation hospital—when I realized that doing discharge planning that affects the lives of people I hardly knew was difficult. I imagined that it would be good to have an opportunity to really get to know the clients that I helped, and long-term care seemed to be the answer. It is true that working in a nursing facility does afford you great opportunities to know your patients. It also affords caregivers the time to become emotionally attached to the residents for whom they care. Though often rewarding, this can sometimes complicate the ethical issues caregivers face. The following case, adapted from an actual case,* illustrates how caregiver’s emotional attachments can complicate end of life decision making in long term care.

Mrs. A was a 96 year old widowed female, with no children or family. Mrs. A had resided at our facility for approximately 4 years. She had dementia and was quite confused, but she was able to express simple thoughts and communicate socially with the staff who cared for her. She wheeled herself in her wheelchair, often in and out of others’ rooms. She had a very poor appetite, attributable to many decaying teeth which needed to be removed. In the absence of her ability to consent to the surgery or any family to consent on her behalf, the facility petitioned the courts to have a guardian appointed. Once obtained, the guardian was very involved and Mrs. A did well after her surgery. The guardian remained very involved, visiting often, talking with the staff for updates, and researching the social history of her newest client. After an extended period of time, as Mrs. A’s dementia rapidly progressed and other medical complications developed, her condition was judged to be terminal. At the same time, as a result of ongoing weight loss and decreased intake, the time came to consider placement of a gastric tube to maintain adequate nutrition. With careful review of her condition, consultation with the nursing staff and physician, and review of Mrs. A’s living will (which indicated that she wanted no extraordinary measures, including tube feeding), the guardian denied placement of the feeding tube. Once this was done, a care plan was developed with emphasis placed on keeping Mrs. A comfortable through the anticipated decline of her health. A hospice consultation was also made.

Mrs. A’s caregivers learned of the care plan, and as they watched her physical condition deteriorate, they began to question the decisions that had been made. Her caregivers had grown extremely attached to her and had great difficulty accepting the decision not to place a feeding tube. The staff began to question the living will executed by Mrs. A prior to admission to the nursing facility. They also began questioning the nurse manager and went so far as to question the guardian about the decisions made. Many staff members asserted that because they believed that Mrs. A had a good quality to her life and enjoyed her home and caregivers, they could not in good conscience respect the decisions made about Mrs. A’s treatment. There was so much controversy and misinformation discussed throughout the facility that the emotional needs of the staff were addressed in a very unique way. A meeting was held with the direct caregivers, social worker, RN manager, guardian, physician, and hospice staff. Mrs. A’s medical condition, Pennsylvania law regarding living wills, as well as the contents of Mrs. A’s living will, were discussed with the team. More importantly, in this case, the emotional and ethical issues of the staff were addressed, and the staff caregivers were reassured that everyone had Mrs. A’s bests interest in mind. Eventually, as a result, understanding and healing occurred, and the caregivers provided the most extraordinary end of life care that any human being could ask for. The staff kept round the clock vigil to make sure that Mrs. A was comfortable and that all her needs were met. The staff were so interested and caring that they also requested some level of involvement in the funeral arrangements. They picked out Mrs. A’s clothing, selected the music (“Gospel” was her favorite), and attended the ceremony.

Healthcare providers and caregivers face ethical issues on a daily basis. Some are more difficult than others. Some issues strike a nerve in us that makes it very difficult to think clearly, and we find ourselves reacting with our emotions. In long-term care, attention must be paid to the wants and needs of the residents, with an emphasis on compassion. At times, this compassion can overwhelm us, leaving us struggling to understand, respect, and cope with the difficult choices made by others. But that’s what we do—we care.

*This case is based on an actual case, but altered to protect confidentiality and to illustrate how caregiver emotional attachments can complicate decision making in long term care.
THE HOME SETTING:
POISING ETHICAL CHALLENGES TO CLIENTS AND CAREGIVERS
by Mark P. Aulisio, Ph.D.

Home Care differs from acute, rehab, and long term care in many respects, not the least of which, of course, is the setting in which care is delivered. Indeed, the setting of the home poses special ethical challenges for clients and caregivers alike. In this article, I will walk through two cases, each illustrating a different feature of the home setting that can pose ethical challenges.

**Mrs. Jones and Those Abominable Stairs**

Mrs. Jones, an 83 year old client with moderate congestive heart failure, chronic lung disease, arthritis, and impaired vision was asked to walk five hundred feet one to two times a day. She achieved this goal with difficulty during her time in a rehabilitation center by taking daily assisted walks. When she was discharged to her home, however, this became nearly impossible because she lived in a cramped second floor apartment with no elevator. Even with the assistance of her home caregiver she found herself unable to negotiate the stairs without severe shortness of breath and physical exhaustion. This frustrated her home caregiver who found the care plan nearly impossible to follow.

At first glance, it may appear that the physical surroundings of the home hinder only the implementation of Mrs. Jones' care plan; a medical, not ethical, issue. However, these physical restrictions actually compromise the important ethical values of autonomy and beneficence for both Mrs. Jones and her caregiver. Mrs. Jones' control over her life, her ability to live her life according to her values, is actually diminished by the fact that she lives in a second floor apartment with no elevator. Indeed, the ramifications are far reaching since she will actually grow sicker over time due to the fact that she cannot follow her care plan, further compromising her autonomy. Mrs. Jones' plight caused frustration for her caregiver as well, frustration which could easily lead to a sense of moral failing and a belief that she cannot promote her client's good, thus compromising beneficence.

Compromises to autonomy and beneficence due to the physical restrictions of the home environment need to be addressed in creative, practical ways that promote these basic values. For example, solutions for Mrs. Jones might be as simple as acquiring a treadmill for rehabilitation, or as complex as moving to more suitable housing. Usually we think of home care as giving clients greater control over their lives and, therefore, as enhancing autonomy and beneficence. The case of Mrs. Jones illustrates that this is not always true.

**Gloria and Her Abusive Husband**

Gloria, age 45, with progressive symptoms of multiple sclerosis, requires maximum assistance for bathing, feeding, dressing, smoking, toileting, transfers, exercises, and ambulation with a walker. She has unpredictable and severe exacerbations, especially weakness, intermittent memory loss, and variable ability to communicate verbally. Urinary tract infections and bladder spasms related to an indwelling catheter are frequent complications. She remains alert and communicative with smiling responses which strongly affirm her desire to remain at home. She attends a daycare program three days per week. Gloria lives with a belligerent husband in a private home in a high risk neighborhood where burglaries, assaults and homicides are common. Her husband is the designated responsible party and receives payment from the state for assisting in her care. His alcohol and drug abuse aggravate emotional responses, including physically and verbally intimidating young female caregivers, refusing male caregivers, and threatening staff on occasion with a gun. Under these circumstances staffing of caregivers is difficult and requires daily problem solving. Schedules are arranged around the husband's perceived drinking and waking habits to limit the safety risks. Reports of possible neglect and physical abuse are being reported to authorities while the agency works with staff, Gloria and her husband, and caseworkers to establish a safe home environment where her needs can be met. (adapted from Talkington, 1995, 290-291)

As the case of Gloria illustrates, home care is delivered to clients from a wide variety of social, economic, and personal backgrounds. The habits, environment and social surroundings of the client can vary widely. Unfortunately, this means that home care workers can sometimes be asked to deliver care in an unsafe setting. Problems include those as seemingly simple as the presence of vicious dogs or the improper disposal of used needles, to criminal activity such as drug dealing, to verbally or physically abusive clients or family. Because the provider is on the client's "home turf," caregivers are often less inclined to object to potentially dangerous circumstances. These problems can be aggravated by the fact that in home care, unlike in institutional settings, the caregiver has limited access to security or even other care providers. Ethical problems can be further exacerbated by personality or other conflicts between caregivers and clients or families. As in Gloria's case, families or others sometimes intentionally make
the home setting uncomfortable for caregivers because they simply “don’t like them.”

Gloria’s case raises an addition ethical issue concerning prejudices and biases that can create tensions between caregivers and clients (Combs, 1996; Haddad, 1992). Some clients even demand they not receive care from members of certain ethnic or racial groups. Clearly, this violates a provider’s moral and legal rights to non-discrimination, and should not be used as a basis of assigning, or hiring, home care workers. At the same time, however, it should be recognized that these racial biases and prejudices do exist, and can result in tensions between caregiver and client. Home care providers should be granted no less respect for their own rights than health care workers in more traditional institutional settings. In the home care setting, however, because the caregiver is on the client’s “home turf,” and because the caregiver lacks many of the formal mechanisms of support that are present in institutional settings, special attention must be paid to ensuring that care can be delivered in an environment which respects those rights.

The cases of Mrs. Jones and Gloria highlight how the home setting can differ from institutional settings in ways that actually pose ethical challenges for clients and caregivers alike. We have looked at just two features of the home care environment, physical restrictions and “home turf,” that pose ethical challenges, but there are, of course, others as well. Ultimately, meeting the ethical challenges of this setting requires both sensitivity to the different ways ethical issues present themselves in home care and creative practical problem solving.

References


**HOME CARE WEB RESOURCES**


Home Care Association of America, Inc. [http://www.hcaahomecare.com/](http://www.hcaahomecare.com/)


Confidentiality, defined as "a rule or duty requiring one entrusted with private or secret matters to refrain from using them," in the acute care setting has been described as a "decrepit concept." In a situation where an estimated 212 persons may have access to a patient chart during a one week hospital stay, this is understandable. In the rehabilitation setting, where a patient's care is characterized by a team approach, the sharing of confidential information about the patient in team meetings may mean the difference between a successful program and a thwarted one. What are the responsibilities, limits, and "red flag" issues surrounding confidentiality for home health nurses? Just as the physical surroundings in the home create unique dilemmas regarding patient safety and rehabilitation, the familiarity fostered by visiting a patient's private residence also can pose a specific dilemma for both patient and caretaker. The following case explores this issue and provides some practical guidelines, informed by both ethics and the law. These guidelines can aid home health caretakers structure confidentiality issues and consider where and how to draw the line between two professional obligations: reporting information to third parties and respecting the individual patient's confidentiality.

1. THE CASE

Sara Jones was a new employee at Home Healthcare, the hospice outreach service of the region's largest HMO. She enjoyed the intimacy of caring for patients in their homes, for she felt that as a nurse, she was able to provide comprehensive care and also serve as a patient advocate. One patient in particular challenged this dual role. Sara had been assigned to Connie Blake's case about 3 months ago. Suffering from the last stages of colon cancer, Connie was determined to be at home when the end came. She and Sara worked hard at maintaining a pain medication regimen that would allow her to be both active and free of pain. In the process, they had become friends, sharing stories, laughter, and tears. About four weeks ago, the pain regimen that they had worked hard to perfect just quit working. Connie was losing weight and was generally depressed by the lack of sleep and inability to eat, due to the constant pain. When Sara suggested that perhaps a hospital admission was needed to investigate what had changed, Connie tearfully explained that her 19-year-old daughter, who had a history of drug abuse, was taking the prescribed medication.

Sara was relieved, in one sense, for she now understood how to provide her patient with the needed pain relief, and immediately requested additional pills. Beyond that, she spoke to the physician about why she needed the additional meds and also to a social worker, who was scheduled to come to the house and counsel Connie's daughter about joining a drug addiction program. When Sara explained this to Connie, she was both shocked and hurt by the response she received. Connie was neither grateful nor relieved—instead, she was angry and upset. She explained that she had confided in Sara as a friend and accused her of breaching her confidence. Sara was genuinely confused by this accusation. Had she breached her patient's confidentiality or merely done her job? The following discussion provides and legal and ethical guidance for answering this question.

2. APPLICABLE LAW

There are three primary sources of guidance for Home Health Agency (HHA) nursing practices. First, both the Federal and Pennsylvania government have regulations pertaining to HHAs. Second, certain aspects of the Pennsylvania Patient's Bill of Rights may be applicable in a HHA setting. Third, Pennsylvania's professional and vocational standards of nursing conduct and licensing requirements can prove helpful.
The two best guidelines for HHA nurses and their ethical duties to patients are found in federal Medicare insurance requirements and the Pennsylvania Administrative Code's provisions for HHAs.

Federal codes mandate that in order to qualify as an HHA for Medicare participation, an agency must meet specified plan of care requirements. These standards require the HHA physician and personnel to perform periodic reviews of the plan of care. The plan physician is required to review the total plan of care as often as the patient's condition requires, but at least once every 62 days. Included in this review standard is the requirement that "agency professional staff promptly alert the physician of any changes that suggest a need to alter the plan of care." The code also speaks directly on the point of drug therapy. "Agency staff [must or shall] check all medicines a patient may be taking to identify possible ineffective drug therapy...and promptly report any problem to the physician."5

In accordance with the conditions for participation in Medicare, registered and licensed practical nurses "prepare clinical ...notes." Clinical notes are defined by the regulations as a "notation of a contact with a patient that is written and dated by a member of the health team, and that describes signs and symptoms, treatment and drugs administered and the patient's reaction, and any changes in physical or emotional condition." The mandatory review of the "total plan of care" by the plan physician would presumably include these clinical notes.

Furthermore, prior to furnishing services, the HHA must provide patients with written notice of their rights, which the HHA must protect and promote. One of these patient rights is the confidentiality of patient records. "The patient has the right to confidentiality of the clinical records maintained by the HHA. The HHA must advise the patient of the agency's policies and procedures regarding disclosure of clinical records."7

Pennsylvania has adopted regulations for the purpose of protecting and promoting public health through "minimum standards in the construction, maintenance, and operation of home health agencies." The state requirements of HHA staff pertaining to reporting drug therapy and the conditions of the patients are practically indistinguishable from the federal regulations. Pennsylvania regulations require a periodic review of the plan of treatment as often as the patient's condition requires, but at least once every 60 days.8

II.

Although promulgated for the governing process of hospitals, the Pennsylvania Patient's Bill of Rights may have application in the home health setting. However, it is important to note that these rights are not "intended to serve as evidence of a standard of reasonable conduct for the purpose of determining civil liability between providers and consumers of health services." Thus, at most, a violation of the Patient's Bill of Rights serves as evidence that the complained-of conduct fell below the standard.

Included in the Patient's Bill of Rights is the patient's right to "every consideration of his privacy concerning his own medical care program. Case discussion, consultation, examination, and treatment are considered confidential and should be conducted discreetly." In addition, the patient has the right to have his or her medical records held in confidence "except as otherwise provided by...third-party contractual agreements."9

III.

The Pennsylvania Standards of Nursing Conduct require a nurse to protect patients from the abusive or illegal practice of any individual.11 A liberal interpretation of this provision would appear to apply to an individual taking the patient's medications. Such a situation deprives the patient of the appropriate drug therapy, and is one in which the nurse is arguably responsible for prevention or correction. However, a narrow interpretation of this nursing standard may limit the "practice of any individual" to medical professionals. If this interpretation is employed, then the case in question would be removed from the scope of the nurse's duties, since the child of the patient is not a medical professional.

Another pertinent section of the Pennsylvania Standards of Nursing Conduct requires the nurse to document and maintain accurate records.12 Accurate records, in this case, would include clinical/progress notes reflecting the ineffectiveness of the drug therapy, with an explanation of the reason or reasons for the same. These clinical notes must in turn be reviewed by the HHA physician; hence, disclosure is unavoidable.
3. DRAWING THE LINE: A PRACTICAL APPROACH TO CONFIDENTIALITY DILEMMAS

It is evident that a nurse of a HHA must provide information—in the form of clinical notes—that is crucial to the patient’s treatment and progress. The HHA merely serves as a unit in whole, and patient information must necessarily travel between different employees of that unit. To qualify for Medicare and to meet state regulation minimums, the HHA must provide the patient written notice of their rights under the plan of care program prior to care.

If a patient is not taking his or her medication, the drug therapy as prescribed by the plan is ineffective. For the protection and health of the patient, circumstances preventing the proper administering of medicine should be conveyed to HHA staff so appropriate plan modifications can be made. The circumstances and progress of the patient should be accurately described in the clinical notes for the physician’s review.

To protect the HHA and the patient in the event sensitive information is discovered by a visiting nurse, it would be beneficial to both parties to define the scope of patient confidentiality in advance. For example, the written notice of rights can state: “information provided by a patient to a visiting nurse is confidential but will be disclosed to other HHA staff members, including the plan physician, as necessary to properly evaluate and modify the plan of care.” The patient should also be assured that the HHA must hold in confidence, from those outside the agency, the patient’s medical information except as provided by law or third-party contracts.

In this case, reporting the cause of the drug regimen’s temporary failure to the physician at the agency was a clear obligation of the nurse. How to prevent the problem from reoccurring is a separate but related issue. While she had good intentions, the nurse could have discussed a range of options with her patient and then supported the one she chose.

Confidentiality in the home health setting is informed by practical ethics, professional codes, and legal guidelines. Taken together, these three sources suggest that both an institutional and a personal ethic be explicitly defined “up front” to both patients and caretakers. As a preventive measure, this would go a long way towards insuring that cases like the one discussed here are avoided in the future.

NOTES
5. 42 CFR §484.18
6. 42 CFR §484.2; 42 CFR §484.30
7. 42 CFR§484.10
8. 28 Pa. Code §601.31, §601.1
9. 28 Pa. Code §103.21
10. 28 Pa. Code §103.22(a)(3,4)
As part of its 1998-99 class schedule, the CEP encouraged its members to attend the Seventh Annual Conference on Medical Ethics and Religion: "Professionalism and Caring in Today's Healthcare Environment," held at the Bayer Learning Center of Duquesne University on May 12, 1999. Rosa Lynn Pinkus, Ph.D., Director of the Consortium Ethics Program, was the moderator for this year's conference, which focused on the patient-health care professional relationship in the current health care environment.

One of the unifying themes of the day was that health care involves much more than just finding and eliminating illnesses of the body; it involves healing. The conference speakers demonstrated, from different religious and secular perspectives, that developing a caring relationship between patients and health care professionals, while increasingly challenging in today's health care setting, is essential for successful healing.

Dr. John W. Hoyt, MD, Director of Emergency Medicine and Critical Care Departments at St. Francis Medical Center and Clinical Professor of Anesthesiology/Critical Care at the University of Pittsburgh, outlined what he called an "old time vision of the physician patient relationship": a vision which included remembrances of desegregation and free clinics, plans to change the world, and, above all, advocating for patients. These values, he explained, had grown in him from his earliest years, when he was first impressed by his family physician and struck by the realization that a patient actually surrenders him or herself to the care of a doctor. Later, family illnesses further stressed the importance of patient advocacy, while school experiences instilled in him a sense of duty and responsibility.

Dr. Hoyt indicated that although the health care environment of the 90's differs substantially from the one in which his values took shape, he does not believe he must relinquish the role of patient advocate. The medical profession has, for him, taken on additional dimensions, so that at once he is a business man, a hospital administrator, and a physician. Even though the health care professional may maintain several different roles, explained Dr. Hoyt, the most important of these remains advocating for the patient.

Dr. Edmund D. Pellegrino, MD, M.A.C.P., John Carroll Professor of Medicine and Medical Ethics at Georgetown University in Washington, D.C., pointed to the Hippocratic model, in which the relationship between a physician and a patient is a "covenant." Health care is viewed as a human good, and the health care professional as a steward of precious gift of knowledge. Dr. Pellegrino showed that the health care profession is, in its pure form, a vocation which manifests itself in "True Elitism"—that is, the practice of demanding more of oneself than of the other. He observed, however, that not all individuals involved in health care today share this view. Various scientific, societal, political, and philosophical forces have transformed the Hippocratic Ethos in such a way that what was a vocation has become, for many, an occupation. The covenant has been replaced by a contract, and the steward becomes a proprietor, directed by market forces and the interests of investors. In the face of such challenges, the need for a sound, trusting relationship between health care professionals and patients has become more urgent than ever.

Dr. Margaret Mohrman, M.D., Ph.D., Associate Professor of Pediatrics and Medical Education at the University of Virginia, explained that listening is an integral part of the health care professional/patient relationship. Physical suffering is not simply a mechanical failure; often there is a deeper, more important suffering which lies at the base of the medical complaint. As part of her practice, therefore, Dr. Mohrman makes a point of paying close attention to what patients have to say—encouraging them by asking questions as they relate their medical histories—allowing the whole person to emerge, for a medical history is not just a disconnected list of physical ailments over the years; it is a story—often about human suffering—complete with context, plot, and meaning, which may have significant bearing on the medical case at hand. A complete diagnosis, according to Dr. Mohrman, must attend not only to the causes of a physical ailment but also to the causes of the patient's suffering.

All of these speakers, while taking different approaches, emphatically echoed the conference theme: although today's health care environment presents serious challenges to the health care professional's deeply held standards of patient advocacy, such standards need not—indeed, must not—be abandoned. Discussions such as this must continue to search for ways to address the challenges confronting health care professionals who seek to sustain a caring—and therefore more completely healing—relationship between themselves and their patients.

As always, we welcome comments, questions and suggestions from our readers. Please feel free to contact us!
DIRECTOR'S COLUMN:
IS THE CONSORTIUM ETHICS PROGRAM A MORAL COMMUNITY?
By Rosa Lynn Pinkus, Ph.D.

I recently received a request from a prestigious ethics center in the Midwest to explain how to create an ethics consortium like the CEP. The center is planning to build a program like ours and wanted some pointers on how to do it. Over the years, I’ve had many such requests, and I must admit that when I explain what it actually takes to implement and keep the program running, the interest wanes. It’s not just that it takes “generous start up funds,” which the Vira Heinz Endowment supplied for us; rather, it’s the commitment to paying attention to the day-to-day details that seems to derail people’s enthusiasm. Judith Ross Wilson, in discussing how to keep an ethics committee thriving, called these details “housekeeping issues.” In her words, if ethics committees are to thrive and contribute to their institution’s understanding of itself as a moral community they will have to pay more attention to the housekeeping issues, to the dailiness of ethics committee’s life. There is a “dailiness,” if you will, to running an ethics consortium. Scheduling classes, reserving rooms, evaluating sessions, planning retreats, and securing continuing education credits for our members are such “housekeeping chores.” We are fortunate to have both Jody Chidester and Betsy Stow attend these. Added to the skill and competence they bring to their job, their helpful ways and good cheer contribute much to the genuine generosity of spirit that characterizes the CEP.

But how can paying attention to these chores contribute to a CEP member’s understanding of itself as a moral community? An invaluable suggestion for the yearly CEP retreat was volunteered by our evaluation consultant at a planning meeting. Her observation provides an example of how a moral community springs from these ordinary tasks. She pointed out that we had never invited a patient to provide his or her perspective at any of our sessions. Somewhat taken aback at this, we asked Robert Arnold, M.D., one of our core faculty, if he could include a patient or a family in his session on “End of Life Decision-Making,” which was to be presented to a group of approximately 130 retreat attendees. Bob invited a patient who was HIV positive and discussed with her a range of issues of how to give bad news. Their conversation captured the sentiments and ethics of such an encounter. It also provided those present with a unique window to view an open, honest “doctor-patient relationship.” The encounter was poignantly captured in a poem, written by the CEP resident poet, Eugene Hirsch, a retired cardiologist. The poem, in turn, was sent to the patient and published in Community Ethics, the CEP Newsletter and included in “AIDS and the Community: A Resource Manual for Community Hospitals.”

Finally, moral community was nurtured through one of the exercises the CEP constructed for representatives to learn both ethical theory and case analysis. They were asked to write a case encountered within their facility and then provided with guidance as they analyzed it. The cases were then edited by CEP faculty to insure confidentiality and compiled in an internal publication. This casebook was available for use by participants responsible for leading an ethics case discussion at their institution. The exercise and a subsequent one have formed the basis for a new casebook in clinical ethics for community hospitals. Most of the representatives who had contributed cases for this exercise were in the Advanced Phase of the CEP when the book contract was secured. They were sent their original case and asked to “revisit it” (now that it would be published). This, in turn, provided an opportunity for members to explore the issues in the cases in greater depth, examine them under the new context of managed care and compare their original resolutions to what they would do now. Together with others in the Advanced Phase, they formed groups, and each prepared a presentation, which focused on one of the cases. These presentations were given at two advanced seminars.

Thus, when I am approached by ethicists from various regions in the country about ways to replicate the CEP, I explain the need for start-up funds, the nuts and bolts of the everyday details, such as curriculum design and the setting of fee scales. I also stress that the CEP is “more than the sum of its parts.” It is also a moral community; yet the faculty and staff of the CEP do not “create” the moral community. We provide our participants with a process for reflection. We gather an interdisciplinary group and elicit diverse opinions. We assure that an “evenness” of ethics concepts is learned across institutions. But equally important is the fact that we are privileged to be part of the community. This collegial sharing is one of the most distinctive features of the CEP.


NOTES:
In the summer of 1998, the University of Pittsburgh Provost and the Senior Vice Chancellor for Health Sciences approved an expanded mission for the Center for Medical Ethics to include research, education, and policymaking on legal issues closely related to bioethics. As a concomitant of these substantive changes, closer programmatic and structural ties have been established between the School of Law and the Center for Health Law and Bioethics, and the name has been changed to the Center for Bioethics and Health Law. These changes reflect the fact that the interests and activities of Center faculty have always been broader than the Center’s name suggests, and that it is an inescapable fact of contemporary American society that ethical issues and legal issues frequently intersect in general and in bioethics in particular.

Another important change concerns the Masters degree program. After residing in the Department of History and Philosophy of Science since its creation in 1989, the Masters Degree in Medical Ethics was moved to the Office of the Dean of the Faculty of Arts and Sciences (FAS), and I was appointed co-director of the newly named Masters in Bioethics Degree, with Kathleen DeWalt, Associate Dean of the FAS. The degree is now administered by the Center for Bioethics and Health Law and core courses are taught by Center faculty—Bob Arnold, Brad Lewis, Mark Wicclair, and Lisa Parker who also serves as Director of Graduate Programs. This change has allowed us greater flexibility in the program requirements and has permitted us to advertise the program more widely. As a consequence, we have the largest class ever, beginning in the fall of 1999, composed of three full-time students, one JD/MA student, one MD/MA student, three-part-time students, and one matriculant in the School of Law who will join the program in Fall 2000 and one matriculant in the School of Medicine who will join the program in the Fall 2002.

The Center also administers the collaborative programs with the School of Medicine and with the School of Law. The former include the joint MD/MA in Bioethics, and the Medical Humanities Concentration for medical students which starts this fall, directed by Dr. Bradley Lewis. Programs with the School of Law include the joint JD/MA in Bioethics, the joint JD/MPH (with the Graduate School of Public Health), and the Health Law Certificate Program for law students. We are also planning to add a one-year law degree, the Masters of Studies in Law (MSL), intended to provide education in law for practicing professionals and graduate students to complement their primary area of practice or study. This program will begin in Fall 2001, pending approval by the American Bar Association. This new program may prove to be of special interest to participants in the Consortium Ethics Program who are interested in learning more about health law.

This summer, we welcomed Dr. David Barnard, formerly University Professor of Humanities and Chairman of the Department of Humanities at the Pennsylvania State University College of Medicine, The Milton S. Hershey Medical Center. Prior to assuming his position at Penn State, Dr. Barnard taught at Harvard Divinity School, Northeastern University and the Institute for the Medical Humanities at the University of Texas Medical Branch. He has published and lectured extensively on ethical issues at the end of life; suffering, meaning and hope; hospice and palliative care; and medical education. He will serve as Director of Palliative Care Education and will divide his time between the Center’s programs and those of the UPMC Comprehensive Palliative Care Program.

Dr. Howard Degenholtz, who joined the Center in the summer of 1997, has recently received two grants. The first—Measurement Indicators and Improvement of the Quality of Life in Nursing Homes—is in collaboration with Dr. Rosalie Kane of the University of Minnesota, and the other—Informed Consent and Therapeutic Misconception—is in collaboration with Dr. Charles Lidz, formerly of the Center for Bioethics and Health Law, and now at the University of Massachusetts. Dr. Judith Erlen was awarded a grant by NIH/NINR to study “Adherence to Protease Inhibitors” in AIDS patients. Dr. Robert Arnold received funding from the Nathan Cummings Foundation for “Evaluating Doctor’s Emotional Reaction to their Patient’s Death,” from The Greenwall Foundation for the projects “Public Attitudes Toward the Definition of Death and Organ Procurement Policy” and “Examining the Impact of Financial Incentives on Organ Donation,” from NIH/NIA for “Improving the Quality of Life During the End-of-Life,” from AHCPR for “Public Attitudes Towards Death and Organ Procurement,” and from the Ohio Department of Health for “Developing a Model intervention to Increase Consent.” Finally, the director of the Consortium Ethics Program, Dr. Rosa Lynn Pinkus, received funding from the National Science Foundation for two projects, “Learning & Intelligent System: Modeling Learning to Reason with Cases in Engineering Ethics” and “Understanding Student Analyses of Complex Ethics Cases.”
Hospital Council of Western Pennsylvania continues to offer timely and important educational programming to its members. Recently, Charles A. Peck, MD, FACP, director of Physician Services at Arthur Anderson LLP provided the keynote address at the Annual Membership Meeting held in early August. “Physicians and hospitals need to go back to the core goals of being in the business of relationships and managing care, not costs,” said Peck.

Peck addressed the audience of approximately 200 healthcare leaders on the topic of “Practical Issues for Physicians as Partners, A New Value Framework.” “Healthcare continues to over invest in things and under invest in people,” Peck said. “We need to put an emphasis on asset allocation and redesign our organizations’ values to measure what we truly value, including people, information, and other intangible assets.”

“In the current economic model, hospitals equate intangibles such as people, training, and marketing with expenses,” Peck noted. Under the New Value Framework model, intangibles are measured as assets, instead of expenses.

“An example of successful organizations which measures assets is the information industry,” Peck said. The information industry chooses customers and employees as its priority assets, while manufacturing companies choose physical and financial assets as its priorities.

“By strictly focusing on cost cutting,” Peck said, “healthcare is behaving like manufacturing companies. Instead, the focus should be on revenue enhancement, as in the information industry.”

Healthcare organizations, Peck said, should focus on the building of partnerships with physicians and others. “Hospitals should leverage their assets with their partners. Involve people, like physicians, who you say are your partners,” he said. “Treat physicians as your true partners, and they will participate and do some good work.”

The Hospital Council of Western Pennsylvania is a non-profit, member-based organization representing hospitals, health systems and other health care organizations in the region. Hospital Council offers healthcare leaders from throughout western Pennsylvania access to renowned healthcare leaders and educational opportunities on issues of interest. To be added to Hospital Council’s program mailing list, or to find out more information about educational opportunities please contact Education Services at 724-772-8391.

Hospital Council’s website also has information about upcoming education programs. The website address is www.hewp.org.
The Consortium Ethics Program extends a heartfelt farewell to Jean Rumsey, Ph.D., who retired from Clarion University this spring and returned home to Wisconsin in June. Jean plans to begin her retirement by doing some writing and working with preschoolers, leading a library story hour. Jean’s contributions to the Consortium through class and retreat activities, and the educational and consultative services she has provided for CEP hospital ethics committees over the years, have been invaluable.

Thanks for everything, Jean! We wish you all the best; keep in touch!

Welcome Aboard

The CEP’s educational network continues to grow! We are pleased to welcome our newest institutional members, including:

- Citizens General Hospital
- Northwest Medical Center
- UPMC Home Care
- UPMC Presbyterian
- UPMC Rehabilitation Hospital
- UPMC Senior Living Services
- Visiting Nurse Association of Indiana County
- Western Psychiatric Institute and Clinic

and individual member

Susan Scherpereel, Ph.D., Pennsylvania State University

Many thanks to these and all our returning members...we couldn’t do it without you!

The 8th Annual Current Controversies in Medical Ethics Conference
By Elizabeth J. Stow, MA

This spring, the Consortium Ethics Program sponsored the 8th Annual Current Controversies in Medical Ethics Conference and 16th Annual Messer Lecture, along with the Ladies Hospital Aid Society of Western Pennsylvania, the Ira R. Messer Fund, the University of Pittsburgh School of Nursing, Children’s Hospital of Pittsburgh, and the Center for Bioethics and Health Law. A great success thanks to high-quality presentations, the conference (held on April 12, 1999) drew over two hundred attendees—from five different states and a wide variety of professional and disciplinary backgrounds.

This year’s conference focus was the crisis in organ transplantation. Thomas E. Starzl, MD, a pioneer in organ transplant, set the stage for discussion with his talk, “Historical and Social Context of Organ Donation and Transplantation: Forty Years of Controversy and Crisis.” Dr. Starzl indicated that before 1963, organ transplantation was denounced by many scientists and physicians as a “pipe dream,” a field with dangerous implications and little chance of success. Indeed, up until this time, there were only a few examples of long-term (more than six months) survival after kidney transplantation. However, with the introduction of immunosuppressants, which curbed immune reactions involved in the rejection of organs, more and more patients not only survived longer, but were also able to resume relatively normal lives. As kidney transplant recipients began to develop tolerance, transplantation began to take new directions, and the stage was set for liver, heart, and lung transplants.

As organ transplantation’s success rate grew, however, so did the controversy surrounding it, and those involved were faced with various medical, philosophical, and societal concerns. Dr. Starzl pointed out that organ transplantation had important implications for medical practice. Physicians, who until this time had been primarily concerned with extracting the last bit of function from a failing organ, now had the option to consider having that organ replaced. The introduction of a new type of therapy changed the definition of organ-related specialties, and its implementation raised questions about immunological tolerance. Furthermore, while researchers viewed an endless series of possibilities ahead, philosophers looked back and wondered, “What might have been?” Could a kidney transplant have saved Mozart—the musical genius who died, at the age of 35, of renal failure?

Dr. Starzl observed that some of the controversy raised by organ transplantation centered around societal concerns. Governor Lamm of Colorado equated organ transplantation with interrupting the falling of leaves in autumn. In other words, this new therapy was one which was often perceived as an

(continued, page 14)
Transplantation carries the risk of transferal of neurological disorders as well as of viral infections, such as hepatitis and HIV.

Having set up the background of the organ transplantation controversy, Dr. Starzl specified the three main points that have, since a 1965 London conference, formed the central structure of transplantation ethics:

1. Questions of human experimentation;
2. Questions about donors;
3. Questions regarding the equitable distribution of resources.

The first of these points, human experimentation, was an issue of some concern in 1965, primarily because many experimentation horrors from World War II were still fresh in the minds of the conference attendees. The Helsinki Declaration (1964), explained Dr. Starzl, defined three tiers of human experimentation.

Before concluding his presentation, Dr. Starzl explored briefly questions about donors and allocations. He indicated, among other things, that there might be informed consent issues in the case of live donors, since there is often pressure (real and perceived) on family members to be donors for their children, parents, siblings, or other relatives—at times without knowing the risk involved in the procedures.

The question of allocation was covered in more detail in the second address, given by James Childress. Ph.D., Kyle Professor of Religious Studies and Professor of Medical Education at the University of Virginia, this year’s Messer Lecturer. His talk, “Organ Allocation: Who Lives? Who Dies? Who Decides?,” dealt with current controversies surrounding organ allocation policy, such as that going on between the United Network for Organ Sharing (UNOS), which advocates a regional organ allocation policy, and the Department of Health and Human Services (HHS), which supports a national allocation policy.

Several current debates in organ donation and transplant focus on the question of ownership: “Who owns donated organs?” and “Who should decide how they are used?” Childress indicated that according to the Report of the Task Force on Organ Transplantation (April 1986), donated organs are scarce public resources, belonging to the community. However, he further commented that this judgement is still problematic, since the meanings of “community” are highly diverse, particularly in reference to the “transplant community” (i.e., surgeons, procurement teams, donors, and recipients). Ownership could be assigned to a national, regional, state, or local community. In any case, the policies and criteria in organ allocation should be public-oriented and fair. Organ procurement depends upon voluntary public gifts, but the public is often wary of donation—a distrust which can be traced to two specific issues: first, many potential donors may be fearful that their deaths will be hastened for the acquisition of their organs; and second, the public perceives an unfairness in the distribution of donated organs.

Childress, who supports a national community as the morally relevant community of ownership, recognizes the paramount importance of developing fair allocation standards. He addressed the issue of setting such standards first by drawing the distinction between morally relevant and morally irrelevant material criteria. Though recognizing that many criteria can immediately be sorted out and discarded as irrelevant, Childress acknowledged that even the three criteria he suggests as just for organ allocation (patient need, probability of success, and time on the waiting list) are difficult to specify and balance. How should “need” and “benefit” be defined? Which should take precedence in a conflict? How should “futility” be defined? When does “wait time” begin?

Such difficult questions indicate the need for specificity in planning in organ allocation: for example, point systems may be used to select patients from waiting lists; the wait list criteria should be a “tie-breaker” for persons with similar need and probability of success; firm status categories might help define waiting time; policies need to be organspecific. Childress further commented that organ-allocations systems should be continually monitored, evaluated, and revised, if appropriate.

Discussion with the audience raised a number of interesting questions. Among them was the question, from Alan Meisel, J.D. (Director, Center for Bioethics and Health Law), “Could the international community be morally preferable to the national community?” Childress offered the suggestion that there are ethical and pragmatic reasons to keep the policy more or less on the national level, but there may be justification, in some instances, to have limited international sharing.

The remainder of the conference consisted of lectures and panel discussions, which covered such issues as quality of life, living organ donors, the “Dead Donor Rule,” bias in organ bequests, and cultural and religious perspectives on donation and transplantation.

The Consortium Ethics Program is pleased to have co-sponsored this conference, which played an important role in the ongoing dialogue between and among health care professionals and the broader community about one of the leading current controversies in medical ethics.
COMING SOON...

Consortium Ethics Program
10th Annual Retreat

Date: September 24-26, 1999
Location: Lakeview Resort & Conference Center
Theme: Medical Ethics and the Law

MARK YOUR CALENDAR...

Fall Class Schedules

CEP BASIC CLASS SERIES:
Foundations of Law and Ethics in Health Care

Date: Monday, October 18, 1999
Time: 9:00 AM - 12:00 PM
Topic: The Role of Law in Bioethical Decision-Making
Speaker: Andrew Thurman, J.D., MPH
Allegheny Health Education & Research Foundation

Date: Tuesday, November 23, 1999
Time: 1:00 PM - 4:00 PM
Topic: Informed Consent: Why Bother? (Ethical and Legal Perspectives)
Speakers: Rhonda Hartman, J.D.
Duquesne University
Mark Wieclaw, Ph.D.
University of Pittsburgh

Date: Thursday, December 16, 1999
Time: 9:00 AM - 12:00 PM
Topic: Provider-Patient Confidentiality and Privilege: An Imperative of Quality Health Care
Speaker: David Herrera-Korman, J.D.
University of Pittsburgh

CEP ADVANCED CLASS SERIES:
Law and Ethics in Clinical Practice: Function, Application & Implementation

Date: Monday, October 18, 1999
Time: 1:00 PM - 4:00 PM
Topic: Law, Morals, and Health Care Ethics: Never the Twain Shall Meet?
Speaker: Mark Aulisio, Ph.D.
University of Pittsburgh, Consortium Ethics Program

Date: Tuesday, November 23, 1999
Time: 9:00 AM - 12:00 PM
Topic: Provider-Patient Confidentiality: Sexually Transmitted Diseases and Domestic Violence--Mandatory Disclosure or Mandatory Silence?
Speaker: David Herrera-Korman, J.D.
University of Pittsburgh

Date: Thursday, December 16, 1999
Time: 1:00 PM - 4:00 PM
Topic: When Are You Really Dead?
Speaker: Rosa Lynn Pinkus, Ph.D.
University of Pittsburgh, Consortium Ethics Program
As always, we extend special words of thanks to Vira I. Heinz Endowment for contributing the seed money to establish the Consortium Ethics Program. We are also deeply indebted to the Hospital Council of Western Pennsylvania and the University of Pittsburgh Center for Bioethics and Health Law for their continued co-sponsorship.

If you have suggestions or questions regarding the Consortium Ethics Program, wish to submit information for an upcoming edition of Community Ethics, or wish to receive this newsletter, contact Mark Aulisio, Ph.D., Consortium Ethics Program, 3708 Fifth Avenue, Suite 300, Pittsburgh, PA 15213, phone (412) 647-5734, FAX (412) 647-5877, e-mail <cep+@pitt.edu>. 