CONSORTIUM ETHICS PROGRAM WELCOMES NEW MEMBERS

The open enrollment period for the Consortium Ethics Program is drawing to a close and we wish to thank and acknowledge our new members who will join us for a three-year period beginning September 1995. As of this writing, fifteen hospitals have confirmed their intent to participate. They are: Braddock Medical Center, Brownsville General Hospital, Butler Veterans Administration Medical Center, Conemaugh Memorial Hospital, East Ohio Regional Hospital, Good Samaritan Medical Center, Hillside Rehabilitation Hospital, Kane Community Hospital, McKeesport Hospital, Punxsutawney Area Hospital, St. Francis (New Castle), The South Side Hospital, Southwest General Hospital, and Titusville Hospital. These will join the current twenty-eight member institutions to form the most extensive cooperative continuing education and resource network in medical ethics in the nation!

In addition, two senior care "umbrella" organizations are considering membership. Further plans to reach out to long-term care facilities are being made (see following story).

A limited number of additional applications for membership will still be considered on a case by case basis. For further information, contact the CEP at (412) 624-3481.

"ETHICS IN LONG-TERM CARE" WORKSHOP A SUCCESS

Seventy-five physicians, nurses, social workers, and administrators attended the day-long workshop "Ethics in Long-Term Care" on April 7, 1995. Faculty from the Consortium Ethics Program collaborated with academic and health care professionals from Pittsburgh and around the nation to provide an introduction to ethical issues in long-term care. The topics covered included legal and ethical principles of end-of-life decision making, problems in patient transfer, and guardianship issues. The keynote speaker was Patrick Dunn, M.D., Assistant Professor of Medicine at the Oregon Health Sciences University and Chairman of the Health Ethics Network of Oregon. He discussed the development and implementation of a state-wide prehospital DNR system in Oregon. Dr. Dunn's experience in this area is of great interest as a number of CEP member institutions are currently working with neighboring hospitals, long-term care facilities, and EMS teams to improve their ability to respect patient wishes during transfer.

As befits a consortium, the CEP worked with a wide variety of co-sponsors including the Ethics Task Force of the Hospital Council of Western Pennsylvania (HCWP), the University of Pittsburgh Center for Medical Ethics, the Health Policy Institute of the University of Pittsburgh, the HCWP Committee on Aging, the Southwestern Pennsylvania Partnership for Aging, Hospital Shared Services, and the University of Pittsburgh Center for Continuing Education in the Health Sciences. This event is another step forward in meeting the ethics needs of long-term care providers in Western Pennsylvania.

In the next three-year module (CEP-3), the Consortium hopes to include several long-term care organizations and facilities as members. Furthermore, the CEP faculty will continue to work with interested co-sponsors to design specific programming and intensive workshops to meet the needs of long-term care providers throughout the region. *Community Ethics* will keep you posted on these programs as plans are released.
The Consortium Ethics Program is conducting a project designed to address ethical issues related to the AIDS pandemic. This project has two components. The CEP is (1) fostering an informal, direct-contact network of health care providers in the Western Pennsylvania region who have extensive AIDS practices and (2) creating teaching materials on ethical issues in treating AIDS patients. The teaching materials will be developed based on insights gained through the network of AIDS caregivers, and will be used by CEP faculty and members in teaching sessions throughout the Western Pennsylvania region.

About a year and a half ago the CEP received a small grant from the Jewish Healthcare Foundation to develop materials related to ethical issues and AIDS. These materials were intended to assist hospitals in Western Pennsylvania who have difficulty in finding professionals committed to providing quality care to AIDS patients. As a starting point, the CEP held its first AIDS dinner/workshop - "AIDS and the Local Physician" in May 1994. This informal gathering brought together area physicians with extensive AIDS practices to share perspectives on the problems they face. This focus group was essential to the CEP's efforts in two ways. First, by bringing together urban and rural providers, the group showed how a regional network could provide critical information and support to providers who are "roughing it" in relative isolation from their local community. Second, the group provided information on the kind of clinical ethical issues that a provider of services to HIV/AIDS patients faces in the local health care community.

The agenda of a second dinner/workshop (on May 15, 1995) was similar to the first but incorporated a greater variety of health care providers and focused directly on problematic cases the group members encountered in clinical practice. Seventeen physicians, nurses, nurse practitioners, and social workers gathered for this forum and presented their cases. Although it is difficult to come up with the "right" solution in dealing with these problems, powerful insight was gained and strategies evolved.

Based upon these successful gatherings, the CEP is developing "Ethics and AIDS" resource materials for health care providers. These materials include an AIDS teaching manual and video which will foster a better understanding and awareness of the prominent ethical issues related to the HIV/AIDS pandemic. The issues covered in the manual will include the public's reaction to the disease; the role of the primary care physician; risk reduction factors; confidentiality; the "duty" to treat; HIV and the Elderly; Families and AIDS; and HIV and Adolescents. Preliminary video footage, produced with the collaborative efforts of the Pennsylvania AIDS Education and Training Center (PA AIDS ETC) and the Pennsylvania HIV/Mental Health Project, includes interviews with the physicians who participated in the initial workshops. The video is meant to provide insight into the personal and professional experience of treating HIV/AIDS patients.

The CEP will continue its ethics resource-sharing efforts in regard to this project. When the final production of the AIDS teaching manual and video is completed, the CEP plans to conduct a training session for health care workers on "Ethics and AIDS." With the HIV/AIDS pandemic already in its second decade, we hope that we can use our resource materials to increase general understanding of prominent issues surrounding this disease.

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**ADVANCE DIRECTIVE EDUCATION MATERIALS STILL AVAILABLE**

The member hospitals of the Consortium Ethics Program regularly devote resources to community education and service; this often involves helping their constituents to understand and plan for end-of-life decisions. To help save time and increase effectiveness in these efforts, we have designed a packet of materials on advance directives geared toward community presentations.

The collection of educational materials, "Talking About Death: Community Programming on Advance Directives," includes notes on key points to keep in mind when preparing to speak, cases and analogies suitable for presentation, and three articles that succinctly review the Pennsylvania Advance Directive for Health Care Act and the national legal consensus on forgoing life-sustaining treatment. This packet is a kind of Cliff's Notes on advance directives. Because it is meant to be to the point and user-friendly, "Talking About Death" does not try to include all relevant materials but is designed and organized for someone who knows how to talk about death with a lay population but who could use a brief review of the more technical aspects of advance directives.

Although the packet was created specifically for CEP members, a limited number of copies are available by phoning the CEP office at (412) 624-3481. There is a brief evaluation sheet that we would ask you to complete and return for your free packet. Your comments will help us to revise and improve this valuable educational tool.
The barrier between assisted suicide and forgoing life-sustaining treatment cracked like the Liberty Bell on the second Tuesday of November when the Oregon electorate approved a referendum legalizing physician-assisted suicide. Like the Liberty Bell, the barrier was cast with this flaw, and forgoing life-sustaining treatment would be fatal. The Oregon "Death with Dignity Act" will have no problem that there was no guarantee that such a doctor would necessarily await the request of the dying patient. How many people (possibly including King George V) would rather have suffered to the end rather than going swiftly into the night will never be known, but we can surmise that more than a few must have been dispatched by doctors on their own initiative, in part because of doctors' fears of opening up the topic for discussion and in part because the tradition of medical paternalism applied to all medical practices, illicit as well as licit.

Legalizing assisted suicide and placing it in the hands of physicians under legal supervision will bring an end to these problems. But will it cause other, perhaps more serious, ones? Are we, as some would have it, headed down the slippery slope toward Nazidom?

The Oregon "Death with Dignity Act" will have no such result. In fact, it is so carefully crafted, so narrowly-drawn, and so laden with procedural safeguards that it may well demand more energy and fortitude to comply with it than some terminally ill people who nominally qualify are likely to have. A person must be an Oregon resident, over age 18, "capable" (i.e., in possession of decision making capacity), and suffering from a terminal disease which will lead to death within six months. The person must make a written and two oral requests for medication to end his or her life, the written one "substantially in the form" provided in the act, signed, dated, witnessed by two persons in the presence of the patient who attest that the patient is "capable, acting voluntarily, and not being coerced to sign the request," and there are stringent qualifications as to who may act as a witness. The patient's decision must be an "informed" one, and the attending physician is therefore obligated to provide the patient with information about the diagnosis, prognosis, potential risks and probable consequences of taking the medication to be prescribed, and the alternatives, "including but not limited to, comfort care, hospice care and pain control." There must be a confirmation of the diagnosis, the patient's decision making capacity, and the patient's voluntariness by another physician. There are requirements for counseling if the patient is thought to be suffering from a mental disorder, for documentation, for a waiting period, for notification of the patient's next-of-kin, and reporting to state authorities.

But the real hooker is that having complied with all of this, the person requesting to die is only entitled to a
The rebirth of Nazidom. Almost 20 years after the suicide seems peculiar to me. Perhaps this is simply because, as some - possibly many - situations in which patients are not able to administer the medication to themselves by the time they meet all the statutory requirements, or there are likely to be aesthetically unpleasant instances in which patients are able to take some but not all of the medication and wind up merely taking a long deep snooze or making themselves nauseous. I would venture to guess that many patients who are able to comply with the act are also capable of hoarding enough pills to end their lives without a doctor's help and for them the act will provide no advantage.

The Oregon "Death with Dignity Act" does not herald the rebirth of Nazidom. Almost 20 years after the Quinlan case, doctors still anguish over passive euthanasia; even with the sanitized name of “forgoing life-sustaining treatment” or “termination of life support,” some anguish so much that they manage to avoid doing it. (See Solomon et al., “Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments,” American Journal of Public Health, 1993,83:14-25.) It’s not likely that they’re going to embrace assisted suicide with open arms, let alone abuse it.

But more important, we are not the Nazis. We can even progress further down the slippery slope and still not become the Nazis. These practices must be viewed in context, and the American context is a democratic one. The Nazi euthanasia program did not make the Nazis totalitarian; it was their totalitarian political system that made the euthanasia program acceptable. Democratic political systems provide ample opportunities for establishing toeholds on the slippery slope and contain requirements that make me confident that we can compassionately practice assisted suicide and prevent its abuse.

The intensity of the national dialogue on physician-assisted suicide seems peculiar to me. Perhaps this is simply because, as a Western Pennsylvanian, I live in a state that is relatively slow to address end-of-life issues. When former Governor Casey signed our living will law into effect in April 1992, more than 40 states had already enacted such legislation. In planning educational programs, I am far more likely to be asked to speak on forgoing treatment than to talk about assisted suicide. Thus, what is a “current” topic varies somewhat from state to state. Still, we should see what we can learn from our neighbors on the west coast, even if assisted suicide is not likely to be on the legislative agenda in Pennsylvania for a long time.

Perhaps the most important issue with which we must wrestle is the relationship of assisted suicide to our current consensus on forgoing treatment. The current ethical and legal consensus allows one to refuse medical treatment that only serves to prolong dying or whose benefit is dubious. This practice has become known as ‘forgoing treatment’ or ‘allowing to die.’ Has allowing patients to refuse life-sustaining treatment placed us on a slippery slope that inevitably culminates in active forms of euthanasia? This question is at the heart of the controversy.

Before we can answer this question, we should note that many in our nation do not realize there is a distinction in principle between forgoing treatment and killing. Important subtleties that are commonplace for lawyers and ethicists are often blurry in the public mind. When the question of physician-assisted suicide arises in political campaigns, at cocktail parties or, on an electronic bulletin board, many people say they support assisted suicide. However, the examples from personal experience they cite suggest they are actually arguing for the right to forgo treatment. From this phenomenon we might conclude that there are many patients who wish to refuse treatment at the end of their lives but whose wishes are not being carried out. These wishes require no new legislation to be honored; they should be followed under the current ethical and legal consensus.

It is possible that the failure to honor patients’ treatment refusals is driving the national dialogue on assisted suicide. Our failure to recognize the current laws and withdraw treatment when the patient or surrogate wishes may drive patients and families to demand complete control over the way, the means, and the hour of death. The imagery of medical paternalism is apt. Paternalism implies a stern parental relationship, supposedly for the good of the patient; but, like a father who is so unyielding that he incites his children to rebellion, the medical establishment may be discovering that withholding patients’ power over end-of-life decisions leads to a demand for total control.

Successful attempts to keep physician-assisted suicide from marching forward as the law of the land must begin by listening to patients, honoring their existing rights, and helping to transform the present “culture of dying.” By helping patients to retain dignity during the process of dying, by actively treating their pain, and by honoring their treatment refusals, the demand for that ultimate medicalization of death, the active taking of a human life, may be marginalized.

[This article is reprinted with the permission of the American Society of Law, Medicine & Ethics, from their newsletter, ASLME Briefings, 12, Winter (1995): 1-4.]

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QUESTION:
Are nursing ethics committees useful and helpful in acute care hospitals? If the hospital has a typical hospital ethics committee organized at the medical staff, administrative, or board level (hereafter "HEC"), why have a second ethics committee, a "nursing ethics committee"? If we say that the nursing ethics committee's function is to educate the nursing staff, why can't this be done by the HEC? Might hospitals? If the hospital has a typical hospital ethics committee addressing forums and by developing scholarly resources on national issues. Now, the question concerned nursing ethics committees and is one that we hear from CEP members. The responses below are reprinted by permission of the authors. (See also the "Truly Useful Literature" feature of this edition for more on the topic.)

I disagree with those who would like to have hospital nursing ethics committees established. I think there is no need to separate the bio-ethics into separate professions. Ethical problems in medicine belong to no one group. Nurses as well as physicians and other hospital staff should be represented on one hospital ethics committee. The ethics committee should be involved in issues affecting the patients, families, nursing staff and physicians and indeed as Stanley Joel Reiser described in the Hastings Center Report of Nov-Dec 1994 ("The Ethical Life of Health Care Organizations"), the ethics committee should probably be involved in their own institutional ethics.

Maurice Bernstein, M.D.
Assistant Clinical Professor of Medicine
University of Southern California
School of Medicine
DoktorMo@aol.com
ad057@lafn.org

Perhaps the reason that nursing ethics committees have sprung up in part due to the fact that nurses have not felt their concerns were adequately addressed by the traditional ethics committees. Nurses should be well represented on the ethics committee and have much to offer. I can attest to the fact that in our institution—a large tertiary care hospital in the inner city—one of our educational efforts includes a monthly "ethics for lunch" meeting and guess what? Nurses seem much more interested than doctors, especially young docs, and have great concern about ethical issues "on the firing line" where they work. The answer, I think, is to be sure they are an integral part of the ethics committee.

George Bower, M.D.
GeorgeB337@AOL.COM

As a former chair of a nursing ethics committee, I would like for you all to consider the positive benefits that I've not seen discussed on this list. Yes, the Hospital Ethics Committee (HEC) could provide education (but it didn't in our case). And there were nursing members from our group on the HEC. However, it became apparent to us (rather quickly) that nurses who were with our pediatric patients and their families had needs that were not being met anywhere in the institution. Part of the educational process was helping them sort ethical issues from other types of issues, which was not a role the HEC played in our institution.

MANY of the problems brought to our nursing committee were doctor-nurse conflict (divided loyalty) issues that were also not appropriate for our HEC. Our main role became one of supporting nurses as they dealt with their own feelings and reactions to the issues with which they were dealing. Over time, it became clear that our role dealt with the ethics of caring while the HEC focused on ethics related to treatment, etc. decisions. There was no research or hard data, but feedback from many of those nurses indicated our involvement really helped reduce stress, burnout, etc.

If the HEC could also fill the needs of those nurses, then I suppose a single 'non-denominational' committee would be acceptable. I have yet to see that kind of committee in action... But the political heat from the kinds of arguments I've been reading here made it really tough to support nurses who were in great need. I'm off doing other things now.

Linda Woolery, Ph.D., R.N.
Assistant Professor
School of Nursing and Medical Informatics Group
University of Missouri—Columbia
nurswool@mizzou1.missouri.edu

The questions and comments I have seen on this list regarding nursing ethics committees [...] seem to me rather more negative than my experiences with such committees [...] I want to bring the issue back in part to talk about what such groups do rather than what they might be. In most hospitals, nurses are very interested in ethical issues yet, simply because of the large numbers of nurses in hospitals and the small number of nurses on committees, there is virtually zero chance for most of them ever to participate on a committee. The nursing ethics groups
I know have been created largely for nurses to have a more realistic opportunity to participate in something that is important to them. In some instances, the nursing ethics group is open to any nurse who wants to attend. If we think that ethics is for specialists and experts, then there will be something about this that will seem wrong. But if, instead, we think of ethics as the responsibility of adults as they move through their lives, then it will make good sense. Saying that the "real" ethics committee can have as its task to educate the interested nurses feeds into that "expert" model, implies that the nurses are to be passive recipients of the official ethics word. Ethics is about serious reflection: everybody needs to do it and most people do it. The ethics group provides an opportunity to do it out loud in a more focused way. This is at least one reason why nursing ethics forums, emergency medical tech ethics forums, dental hygienist ethics forums, and any other group ethics forums make good sense, at least in my view.

Director's Note: Having directed the CEP for five years and having been an ethics consultant to a wide variety of healthcare institutions, i.e., university-affiliated acute-care hospitals, community-based hospitals and rehabilitation centers, it seems that the particular political-cultural "character" of the organization defines the function of an ethics committee. Decisions regarding whether or not a separate nursing ethics committee is "useful" will in part depend upon this organizational profile. The institutions in the CEP have developed a variety of mechanisms tailored to meet their individual needs. The comments from healthcare providers on the electronic bulletin board seem to reflect this also.

Judith Wilson Rose
Center for Healthcare Ethics
ST. Joseph Health System, Orange, CA
park@SUNSHINE.NET

TRULY USEFUL LITERATURE
by Alan Joyce


These three articles cover a broad spectrum of issues in nursing education and practice. They provide a good picture of problems faced by nurses in the acute care setting; they also offer suggestions for changes in nursing education programs and in the hospital which may enable nurses to better confront these problems. Erlen and Frost present a process for and evaluation of a study of nurses' perception of their own role in resolving ethical dilemmas. The study examined a common perception that, while nurses are frequently involved in cases in which ethical dilemmas arise, they are often unsure of their abilities and responsibilities regarding the resolution of these dilemmas. The investigators interviewed 25 nurses in an acute care setting and found that all of them, regardless of age, education, or work experience, perceived themselves as powerless in these situations. The factors cited as contributing to these feelings were physician dominance of cases, lack of physician-nurse communication, the perception of nurses as "equipment managers," rather than caregivers, and a lack of knowledge of alternative approaches to caring for patients.

Erlen and Frost note that the physician-nurse conflicts may result because physicians and nurses often perceive ethical dilemmas differently.

Carlson-Catalano's article proposes a number of changes to nursing education programs, most of which could help to prevent these feelings of powerlessness and to empower nurses in dealing with ethical dilemmas. Carlson-Catalano claims that most nursing education programs instill ideals of subservience and obedience in future nurses and keep them in an atmosphere of confinement. She suggests an alternative educational approach that contributes to nursing students' sense of professionalism, ability to think critically and independently, and ability to effect change. This approach is based on four elements:

1) Analytic Nursing: In teaching students to apply the problem-solving process to dilemmas in the hospital, nursing education should make use of actual experiences of the educator or students. Students should learn to collect all relevant data, make an objective statement of the problem, and to develop, implement, and evaluate a solution.

2) Change Activity: Students should internalize the importance of change; this can be accomplished by assigning group projects that encourage students to identify resources and assume leadership in change activities (e.g., health fairs, support groups, etc.).

[Continued on page 7]
Upcoming Events

WESTERN PENNSYLVANIA

CEP Retreat—Hidden Valley Resort
September 29 - October 1, 1995

CEP Series One Classes*
(For all hospital representatives who are beginning CEP training for the first time in 1995.)
1995: Nov. 14 1:00 p.m. - 5:00 p.m. (tentative date)
Dec. 18 8:30 a.m. - 12:00 p.m. (tentative date)
1996: Mar. 5 1:00 p.m. - 5:00 p.m.
Apr. 2 8:30 a.m. - 12:00 p.m.
May 8 Duquesne University Conference (all day)
Jun. 6 1:00 p.m. - 5:00 p.m.

CEP Series Two Classes*
(For CEP reps who began CEP training prior to 1995.)
1995: Dec. 18 1:00 p.m. - 5:00 p.m. (tentative date)
1996: Mar. 5 8:30 a.m. - 12:00 p.m.
Apr. 2 1:00 p.m. - 5:00 p.m.
May 8 Duquesne University Conference (all day)
Jun. 6 8:30 a.m. - 12:00 p.m.

* All CEP classes, except May 8, are held at the Education Center of the Hospital Council of Western Pennsylvania, Warrrendale, PA.

NATIONAL

American Association of Bioethics
University City Sheraton, Philadelphia, PA.
For information, contact Kim Segal, executive director, AAB; University of Utah, FHP Center for Health Care Studies, 2127 Annex Building, Salt Lake City, UT 84112.
Phone: (801) 581-4673; FAX: (801)585-5489.
E-mail: ksegal@cppa.utah.edu

Society for Bioethics Consultation
Stouffer Hotel, Cleveland, OH.
For information, contact: Françoise Baylis, Ph.D., Department of Philosophy, University of Tennessee, 801 McClung Tower, Knoxville, TN 37996-0480. Phone: (615) 974-3255.

"Ethics, Medicine and Health Care: An Appraisal of the Thought of H. Tristram Engelhardt"
September 29-30, 1995
Youngstown State University, Youngstown, Ohio.
The conference is convened in recognition of the Second Edition of Engelhardt’s The Foundations of Bioethics.
For information, contact: James E. Reagan, Ph.D., Center for Ethics, St. Elizabeth Hospital Medical Center 1044 Belmont Avenue, Youngstown, OH 44501-1790.
Phone: 216-460-2265; Fax: 216-480-2957.

American Society of Law, Medicine and Ethics
Theme: “Managed Care, Integrated Delivery Systems, and Consolidation — Law, Medicine and Ethics.”
For information, contact: Rebecca Loud, ASLME, 765 Commonwealth Avenue, Boston, MA 02215.
Phone: 617-282-4990; FAX: 617-437-7596.

Society for Health and Human Values
Theme: “Values of Health Care: Diverse Perspectives.”
For information, contact the SHHV National Office, 6728 Old McLean Drive, McLean, VA 22101; Phone: (703) 555-9222; FAX: (703) 555-8729, E-mail: SHHV@AOL.COM

CONSORTIUM ETHICS PROGRAM
Rose Lynn D. Feinbus, Ph.D., Director
Mark Kozleski, Ph.D., Associate Director & Editor of Community Ethics
Arne McGee, R.N., B.S. Evaluation Consultant
Judy Chalfant, Administrative Assistant
Allan Joyce, Editorial Assistant
Connie Rehak, Intern

As always, we extend special words of thanks to the Vera L. Henshaw Foundation for its continued support of the Consortium Ethics Program. We are also deeply indebted to the Ethics Task Force of the Hospital Council of Western Pennsylvania for its continued encouragement, guidance, and assistance that it lends to the CEP.

If you have suggestions or comments regarding the Consortium Ethics Program, or if you would like information on an upcoming edition of Community Ethics, please write to Rose Lynn D. Feinbus, Ph.D., Director, Consortium Ethics Program, 3400 Forbes Avenue, Suite 110, Pittsburgh, PA 15213, Phone: 412 394-3466, Fax: 412 394-1291, or e-mail <cmeth@med.pitt.edu>.

[Truly Useful Literature continued from p. 6]

3) Collegiality: Students should “develop the skills necessary to value the support of colleagues and the extensive experience of other nurses”; this can be facilitated through consistent “valuing and rewarding of students’ efforts” and by encouraging students to seek assistance from fellow students who possess a special competency.

4) Sponsorship: Forming mentor relationships between students and experienced nurses can provide students with access to problem-solving resources and allow them to develop related skills.

Edwards and Haddad’s proposed response to nurses’ difficulties with ethical dilemmas is the formation of nursing ethics committees. Multidisciplinary committees, they claim, do not address “the specific and unique ethical concerns of nurses.” The general purpose of nursing bioethics committees, they claim, is to assist nurses in developing their knowledge of ethics. More specific roles can be (1) helping nurses to assume more responsibility and make better judgments in ethical dilemmas; (2) examining and influencing policy development; (3) serving as a resource to clinicians and managers; (4) developing “support within the system for nurses’ active participation in ethical decision-making”; and (5) functioning as the group from which nurses will be selected to serve on a multidisciplinary hospital ethics committee, if it exists. The authors also suggest the use of surveys to guide committee educational efforts. They describe a survey distributed to their nurses’ ethics committee which identified the respondents’ baseline level of knowledge and specific areas of need and interest for educational sessions.