

Summary of the proceedings of
The End of Our Lives: Guiding the Research Agenda

convened by the
NIH End-of-Life Interest Group
--a multi-disciplinary group
focusing attention on, and coordinating efforts,
to advance the national end-of-life research agenda—

hosted by
National Institute of Nursing Research

and cosponsored by
National Center on Complementary and Alternative Medicine
National Cancer Institute
National Institute on Aging

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Masur Auditorium, Clinical Center
National Institutes of Health, Bethesda, Maryland

Patricia A. Grady, PhD, RN, FAAN
Director, National Institute of Nursing Research
Bethesda, MD

Dr. Patricia Grady began the seminar by outlining the history of the agenda for end-of-life research. She credited the End-of-Life Interest Group—with support from NCI, NIA, and NCCAM—for initiating the dialogue about the future agenda of end-of-life research. She went on to note that the number of funded end-of-life research programs is increasing because of the concerted efforts of NIH.

Dr. Grady explained that the format for The End of Our Lives: Guiding the Research Agenda program would include four end-of-life experts. Each expert would be reflecting on video excerpts from the highly publicized documentary series, “On Our Own Terms: Moyers on Dying”, produced by Bill and Judith Moyers and broadcast on public television. Following the four presentations questions and comments would be welcomed from the audience.

Ann Knebel, DNSc, RN, FAAN
Program Director, National Institute of Nursing Research
Bethesda, MD

Dr. Ann Knebel, the program director at NINR for the end-of-life research portfolio, facilitated event beginning with an introduction of the four panelists. The panelists were asked to address one of four aspects of end-of-life care:

- Dr. Thomas Smith would be addressing technological interventions in end-of-life care. Dr. Smith is professor and chair of the division of hematology and oncology at the Medical College of Virginia.
- Dr. Ann Berger was introduced as the presenter for palliative care. Dr. Berger is the Chief of the Pain and Palliative Care Service at the Clinical Center at the National Institutes of Health in Bethesda.
- Dr. Christine Grady of the Department of Clinical Bioethics at the Clinical Center would be addressing ethical concerns.
- Dr. Richard Payne, Chief of the Pain and Palliative Care Service at Memorial Sloan Kettering Cancer Center in New York, would be discussing ethnic and cultural factors in end-of-life research.

[View portion of video “On Our Own Terms: Moyers on Dying”, produced by Bill and Judith Moyers]

Thomas Smith, MD
Medical College of Virginia
Richmond, VA

After a brief video clip from the Moyer’s program, Dr. Thomas Smith shared his thoughts on technological interventions in end-of-life care. He noted that there are high costs involved in using new technologies to diagnose and treat serious illnesses. Demands for treatment with new technologies have increased, regardless that such technologies typically increase costs about 27 percent.

Dr. Smith pointed out the disparity between what Americans pay for these technologies and the consequent survival rates. In some European countries, the cost of certain cancer protocols may be significantly less than in the U.S., but the survival rates are higher. In Scotland for instance, specialist surgeons compared to non-specialist surgeons have anywhere from five to ten percent better survival rates.

Dr. Smith went on to note the higher risk ratio of receiving certain treatments at a low volume hospital—60 percent higher than at a high volume hospital. He went on to point out that having esophageal surgery at a low volume hospital, there is a 17 percent mortality rate. Treated at a high volume hospital, it is three percent.

Dr. Thomas admitted that these figures are not directly related to palliative care, but noted that the data about the size of a health care facility is significant with regards to how palliative care is accommodated into practice. He noted that if care is standardized—such as coordinated care, regional palliative care networks, ethics in the ICU, “in-your-face ethics”, and the culture of pain management—costs can be reduced by about 10 to 15 percent and the quality maintained. Dr. Smith cited an English study in which a nurse coordinator directed care. Dying patients had one phone number to call for direct care. People still died. People still threw up. Symptoms were no different; even the death rate was no different. The total cost however was reduced by 41 percent,

attributable to decreased hospital days. Other studies, he noted, showed similar results of reduced costs and higher quality of treatment.

Dr. Smith also highlighted a program by Dr. Betty Farrell at the City of Hope National Medical Center, where the intervention was to change the “culture” of palliative care through pain resource training. City of Hope had a reduction of pain admissions by one-and-a-half percent, a savings of over \$2.5 million of avoided admissions.

Dr. Smith also noted a study at Deaconess that applied an educational ethics program for house staff, nurses and attending physicians. Researchers found that by providing care more appropriate to the patient's needs, the average decrease in length of stay was from 28 down to 16 with savings to the hospital estimated at \$1.18 million.

Another study that Dr. Thomas mentioned was Dr. Mel Dowdy's study in Richmond where anybody on the vent for 96 hours had an automatic consultation, and showed proportionately findings.

Dr. Smith concluded by asserting that adequate palliative care, while ethically responsible, could also be economically sensible.

[Video clip shown.]

Ann Berger, MD
Chief of the Pain and Palliative Care Service
Clinical Center, National Institutes of Health
Bethesda, MD

Dr. Ann Berger began her response to the excerpt of the Bill Moyer's video by challenging the audience to reconsider their notion of palliative care. She asked the audience to conceive of palliative care as providing health care across the spectrum. This stands in contrast to the tension of focusing on cures while symptoms are interfering with the patient's quality of life.

Dr. Berger noted that health professionals need to change their thinking about palliative care. Palliative care is not just end-of-life and hospice care. She quoted Joanne Lynn's statement that "...palliative care is not about death. It is about living with a disease that is going to kill you and about living well on the way to death." Dr. Berger went on to note that the inevitability of the end of each human life, regardless of the means, is reason enough to provide proactive and compassionate health care as a collaborative and interdisciplinary priority. Palliative care focuses on the physical, psychological, social and spiritual needs of the patient, family and caregiver. It is optimized when people come to the medical system with a symptom. Palliative care should be initiated at the time of diagnosis and comprehensively utilized throughout the disease trajectory.

Dr. Berger noted that the health care system has not traditionally dealt with symptoms. "If someone comes to us with shortness of breath," she noted, "some chest pain and some weight loss, a multimillion dollar work up is put together, and we find the patient has lung cancer. Then we do a multi-million-dollar treatment plan of radiation, chemo,

surgery, the whole nine yards. Or how many times even symptoms like anorexia are totally ignored until it is really far too late, until the horse is way out of the barn. Then we sit there and go, well, maybe we should start TPN.”

To change the culture of the health care community, stressed Dr. Berger, providers must begin to see that palliative care is not just end-of-life care. Pain and symptom management should be part of the treatment plan from the beginning. Interestingly, Dr. Berger noted that the video clip includes a quote that symptom management should be undertaken prior to palliative care. Even the video associated palliative care with end-of-life care. Palliative care is a philosophy of care, not a treatment modality. Palliative care is the management of physical, emotional, social and spiritual suffering, and is not just restricted to pain management.

As Chief of Pain and Symptom Management Services at the NIH Clinical Center, Dr. Berger noticed that the palliative care team was initially getting consults for solely pain management. Pain, she pointed out, is often the “tip of the iceberg.” Other symptoms as well as social concerns and spiritual concerns usually accompany symptoms of pain.

Professional healthcare providers, according to Dr. Berger, should have some responsibility for helping to bridge science and humanism; to provide competent and compassionate care, early intervention of symptom management, education and support to patients and their families; and to equip them with coping skills. Dr. Berger recommends that this be a normal treatment approach from the health care community and not just at the end of life. A system that bases its practice model on palliative care will promote collaborative relationships, centered communication, relief of suffering, and improvement of quality of life. Such a system promotes the validation and dissemination of information through research-based investigation and documentation, and the integration of palliative care into the mainstream of medical therapy.

Issues that need further attention, according to Dr. Berger, include advance directives, psychosocial concerns of patients, spiritual care, as well as financial concerns. Palliative care deals with many symptoms, including lack of energy, worrying, sadness, pain, nervousness, and so on. These symptoms need attention from the outset of a patient's illness.

A barrier to incorporating palliative care into a health care system is the fear of addiction of opioids. This anxiety is evident in most every institution. This is true even at the NIH. “It is something we hear every single day.” This misconception has hampered the integration of palliative care into most health care systems, and more research is needed to show how this approach can be better integrated into mainstream health care systems.

Financial and regulatory obstacles are also barriers to incorporating palliative care into normative treatment practice.

In closing, Dr. Berger reiterated that no inconsistency exists between the ability to achieve great diagnostic and therapeutic victories, and the ability to provide comfort when those victories are beyond reach. “As a nurse, a physician and, most recently, a patient, most patients want both the ability to be cured and to be taken care of in the utmost; basically, to get good palliative care. They want this from the time that they get

sick, not just concentrating on end-of-life care.”

[Video clip shown.]

Dr. Christine Grady
Department of Clinical Bioethics
Clinical Center, NIH
Bethesda, MD

Dr. Christine Grady began her comments by noting that the individuals in the video excerpt were facing extraordinarily difficult decisions. Such decisions are influenced by how much information a person has and how free they feel to make a decision, as well as by deep-seated values and interests, spiritual beliefs, and the particulars of each person’s life story. Decisions are also influenced—in fact sometimes severely restricted—by the social and economic circumstances and options that form the context of life.

Dr. Grady noted that as she was preparing for this panel, she considered the particular contribution that ethics can make to the forum about end-of-life and about how decisions are made at the end of life. She summed up her approach to this question with a definition of ethics followed by a series of questions about ethics for life and for end-of-life.

- “Ethics, as you probably all know, is a branch of philosophy that deals with questions about what is a good life. How do we live a good life? What are the right actions and behaviors that contribute to a good life?”
- “You may ask, in the same kind of way, what is a good death? What are the actions and behaviors that contribute to a good death? How do we make the dying experience a part of a good life?”

A part of discerning what a good death is, she continued, is the issue of how decisions are made. How does one define the contours of the obligations that clinicians and family members have to people who are dying? Most would agree that an important part of a good death is preserving the integrity and the dignity of individuals, and a feature of preserving a patient’s integrity and dignity is helping the patient prepare for what is ahead, following her expressed wishes, assisting to finding ways to express those wishes, and helping to achieve optimal function with minimal suffering, until the moment of death.

Dr. Grady pointed out that one couldn’t talk about a patient’s needs at the end of life without also addressing the particular role of the clinician. The challenges of the clinician’s role include understanding professional obligations; understanding how decisions are made; making responsible decisions that respect the dignity and integrity of individuals while maintaining professional integrity; and developing and maintaining the systems—including institutions, policies, and laws—that facilitate end-of-life care.

Dr. Grady went on to say that bioethical research is a critical method of helping to understand and address all of the various issues involving end-of-life. Research data—

as information that is gathered in a reliable and valid way, and is carefully analyzed—is invaluable in informing end-of-life discussions, deliberations, and decisions. This research is critical at every level. It is critical to the individual who is dying, to the individual in relationship to the people he or she loves, to those who provide care, and to policy makers and society at large.

The Institute of Medicine's report on end-of-life care defined a “good” death as one that is free from avoidable distress and suffering, for patients, for families and for care givers, in general accord with patients' and families' wishes, and reasonably consistent with clinical, cultural and ethical standards. In light of this definition, Dr. Grady outlined some of the questions that need to be asked:

- How well do we understand how to measure, predict and reduce distress and suffering of patients, of families, and of caregivers?
- How well do we solicit and understand the wishes of patients and families?
- How well do we help people express their wishes?
- How well do we help them make realistic informed choices about care?
- How well do we prepare people for death and the end of their lives?
- How well do we communicate these concerns and decisions to them?
- When we know the patients' and families' wishes, how well do we follow them?
- How well do those wishes guide the care decisions that we make?
- How do we justify decisions that are not guided by those expressions of wishes?

Dr. Grady continued by identifying a list of particular ethical dilemmas, including: physician-assisted suicide or assisted death; achieving adequate pain control while worrying about the side effects of potential medications; withdrawing food and fluids as a treatment modality; advance care planning and the value and limitations of advance directives; and end-of-life care options constrained by insurance coverage of financial limitations.

These issues, Dr. Grady pointed out, are not peculiar to the drama presented by Bill Moyers. These are issues that have occupied the attention of clinicians and bioethicists and others for a long time. How can research help with these kinds of issues? Certainly, in the first clip, Jim Richter wanted to know what could be done for him when life was no longer worth living. His doctor said he could help him remain comfortable but would not help him kill himself.

There has been a lot of public interest, Dr. Grady continued, in the possibility that assisted death or assisted suicide might relieve or circumvent suffering and, in that way, provide a good death. The data indicates that only a very small number of people—about three to four percent of all who die—choose euthanasia or assisted suicide. Dr. Grady then shared that data from her professional colleagues, Zeke Emmanuel and his colleagues, Bob Perlman and others, have demonstrated that, contrary to popular belief, pain is not the major motivating factor for requests with assistance in death or assisted suicide. Rather, the motivation is the psychological distress about the care-giving burden on people that they love. More research is needed to determine the extent to which psychological interventions could work to reduce depression, to reduce psychological distress, as well as to address caregiver needs, systems and support. This would therefore reduce interest in assisted death.

Dr. Grady noted that research is needed to help predict which people are at high risk for psychological distress. There is data to suggest that efforts at relieving pain and other symptoms, although absolutely critical to our care of people at end-of-life, are insufficient. These efforts don't always suffice to relieve the burden of suffering. Patients are concerned about loss of dignity, not being dependent, not being a burden, and loss of control; possibly more concerned than they are about their physical and psychological symptoms.

Dr. Grady noted her interest in Dr. Thomas Smith's slide where he had dignity with a question mark after it with respect to research. She concurred with that sentiment saying that research is needed to help define and test interventions that are likely to help people feel like they can maintain dignity and maintain control. More research is also desperately needed regarding caregiving needs. What are the needs of caregivers? How do they influence their own health, their ability to give care and, in turn, reduce the psychological distress of the recipient of their care?

Dr. Grady invited the audience to recall the video clip of Pam and Bill Bartholome and their discussion of the durable power of attorney for health care. Bill Moyers asked her if it was hard or unfair that she would have to make decisions for her husband. Her face seemed to indicate that she was in fact scared of having to make those decisions.

Over the last 10 or 15 years, the requirements of the Patient Self-Determination Act and JAHCO [Joint Commission on Accreditation of Healthcare Organizations] have made issues about advance directives a regular part of the hospital experience for most people. This is for a good reason: the right of individuals to consent to or refuse treatment has finally received recognition, and there is a mechanism for making decisions and plans about the future.

Advance directives are a great idea. Most people in the United States support them. However, while more than four-fifths of United States citizens think advance directives are a good idea, only about one fifth have an advance directive. This is also true of people who are seriously ill. If you look at data from the support study and also from studies done by Manicoff, Gamble, Grecko and others, approximately 20 to 25 percent of seriously ill patients have advance directives.

Dr. Grady pointed out that certain interventions that have been tested to try to increase this number have not succeeded. Strong cultural and ethnic differences exist with respect to interest in advance directives, and perhaps more will be heard about that in a moment. Data exists, as Ann Berger says, to suggest that preferences can change over time. Advance directive preferences could also change over time. Even among people who have advance directives, less than half of them actually discuss their advance directives with their physicians. For an advance directive to be followed, a physician must know what it says. In addition to data that suggests there are very few discussions with physicians, there are other data to suggest that even physicians who do know about advance directives sometimes choose not to follow them because of their own beliefs in the person's chance of recovery or because of lack of clarity in the instructions that are put forth in an advance directive.

Dr. Grady then pointed out that data from Ashe, Schneiderman, Christokas, and others suggests that age, training and specialty, as well as personal beliefs of physicians,

dictate, to some extent, how willing they are to follow the wishes of patients expressed in advance directives.

More research is needed, Dr. Grady asserted, to address how to help people think about the future and how to make decisions about the future, whether that is in the form of an advance directive or not. The discussions, the planning, the preparing, the communication about decisions that will need to be made, all need to be done better. Research is needed on how to enhance communication between health care professionals and patients, between health care professionals and proxies or families.

There was a recent article in JAMA by Larson and Tobin. [*Larson LG, Tobin DR. End-of-life conversations: evolving practice and theory. Journal of the American Medical Association, September 27, 2000, 284(12): 1573-1578.*] They suggested we need randomized controlled trials to examine new models and approaches for enhancing end-of-life conversations, looking at the frequency and quality of such discussions, the perceived control issues, the cost benefit analysis. We need research on strategies to empower decision making by proxies and to support the decisions that they make.

Dr. Grady then shared that she has had friends and colleagues who have been in the position of having to act as a proxy or a durable power of attorney for a loved one, and have second-guessed their decisions later, for feeling lack of support in the decisions that they were making. Information is needed about outcomes in order to support decision-making by individuals and proxies. For example, what are the merits of fluids in certain situations? Does discontinuing foods and fluids enhance suffering or reduce suffering in different cases? How does discontinuing certain things like food and fluids contribute to the suffering of families? How do families understand suffering in their loved ones with certain decisions about treatment?

She went on to say that data about the predictable side effects of interventions is needed, as are more discussions about goals, about the need for adequate pain relief, even recognizing, but needing to understand, the unavoidable consequences.

“We need data to be able to identify and predict the trade offs that are made when certain decisions are made. We need better strategies to promote open discussion, discernment of patient family wishes and concerns, and respect for decisions that are made. We need symptom management research for symptoms like loss of control, fear of being a burden on one's family, loss of dignity. We also need symptom management research on grief, how to treat grief, how to help people let go and hold on at the same time.”

Last but not least, research is needed in the health services arena. Health services research and systems research is needed to inform public policy and priority setting with regard to health care services and financing. Dr. Grady recalled that in the video, Bill Bartholome says \$5,000 coverage for hospice is a joke because it doesn't cover even a month's pain medication for him. He is a physician, who is tied in to wonderful support systems and has a lot of information. He is also an ethicist. He understands these issues in ways that so many people don't. Imagine the sort of situation confronting someone who has no health insurance, someone who might be homeless, someone who is isolated, or someone with a much less predictable kind of illness.

More data is needed on trajectories toward death. Coverage for hospice care, for example, is based on criteria about estimated time left before death; yet, data doesn't exist to reliably predict trajectory to death in many different diseases.

Data is also needed, Dr. Grady concluded, to understand the merits and costs of different interventions and systems already in use. These interventions then need to be further developed to reduce symptoms, promote dignity, and reduce suffering across the board.

[Video clip shown.]

Richard Payne, MD
Chief of Pain and Palliative Care Service
Department of Neurology
Memorial Sloan Kettering Cancer Center
New York City, NY

Dr. Payne began his presentation by discussing some themes raised by the other speakers and the video clip. He also spoke of his intention to address palliative and end-of-life care from the perspective of under-represented minority groups and other vulnerable populations. He emphasized that many people want the same thing when it comes to end-of-life care:

- No one wants to die alone.
- People want to be free of physical symptoms to the extent that that is realistic and possible.
- People want care in accordance with their personal, particularly spiritual, preferences.
- People want care that honors their life.
- Everyone says they don't want to be a burden to their family.

Dr. Payne pointed out that, while there is consensus about the basic goals, there are barriers to increasing access and utilization of palliative and end-of-life services in minority groups. Dr. Payne's perspective, he noted, comes from his extensive work in the African-American community. He recalled speaking to a skeptical African American elderly man who was dying of prostate cancer. During the discharge process, the patient asked Dr. Payne whether he talks to all of his patients about "this DNR stuff" and about going into hospice care.

In another anecdotal example of barriers in the minority community, Dr. Payne recalled talking to a group of African American pastors about how they could raise awareness by talking about end-of-life care planning in their churches. One of the spokespersons said, "Wait a minute, a generation ago my father could not set foot in a hospital. Now how am I to really believe that this hospital has my best interests in mind now? ...How many other African American physicians are in this hospital?" Dr. Payne admitted that there were, in fact, only a very few African American physicians.

Dr. Payne referred to Dr. Thomas Smith's remark from earlier in the seminar that hospice services in particular have been perceived—and in fact shown to be—predominantly

utilized by the white population. Dr. Payne then referred to a recent article by Gregory Townsend, a hospice administrator in Birmingham, Alabama, asserting that in 1999, less than 10 percent of the 700,000 patients receiving hospice care in the United States were African American. This is occurring, Dr. Payne noted, in spite the fact minority groups are over-represented in the death rates from cancer and HIV and AIDS. Given this information, one could have expected that minority groups might be over-represented in palliative and end-of-life programs.

Dr. Payne then noted Christakis' data published in 1996 (*Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. The New England Journal of Medicine, July 18, 1996: 335(3)*) which looked at 1990 Medicare data. Ninety-three percent of patients utilizing the Medicare hospice were white. Dr. Payne pointed out that current statistics show this has improved but not by much.

Dr. Payne then exhibited a map of Manhattan that indicated the seven zip code areas surrounding North General Hospital in Harlem. The community population is in excess of 200,000. Nevertheless, the largest hospice provider in the area reported less than fifty cases referred into their hospice program in this area.

Dr. Payne offered further evidence of the disparity of utilization of hospice by citing Joanne Lynn's analysis of Medicare data from 1992 to 1996. The study supported by RAND and Americans for Better Care of the Dying indicated that about fourteen percent of the population using the Medicare hospice benefit were people of color. The interesting thing is that the costs in the last year of life were actually greater for African Americans than some other population groups. In this data set, the average cost to Medicare in the last years of life were \$25,000 for whites and really other minorities -- Latinos and other minorities -- but \$32,000 in the last year of life for African Americans. Dr. Payne noted that it is unclear why this cost disparity exists. Nevertheless, the study shows that there is higher percentage of non-hospice inpatient deaths for minorities, particularly African Americans, noted in that study.

Another barrier to access and utilization to end-of-life care for minorities, Dr. Payne noted, has to do with the differences in patient perceptions, in physician perceptions, and in African American physician perceptions about end-of-life care.

Dr. Payne began by pointing out that there needs to be more research on perspectives on end-of-life care. He then cited a health disparities study by McKinley in which black and white patient perspectives on advance care planning and end-of-life care are compared. McKinley reported that black patients were much more likely to feel that advance directives would increase the sense of hopelessness and lead to decreased levels of care, although when asked directly about trust in the system, black and white patients were equally like to say that they trusted the system.

Dr. Payne also noted that differences in physician perspectives have also been published. In a widely cited study of physicians from AMA and NMA data bases, black physicians were much more likely, in some scenarios up to six times more likely, to endorse aggressive life-sustaining treatment for their patients and themselves when given scenarios about hopelessly ill patients and then use of aggressive life-sustaining treatment.

Dr. Payne then asked a series of questions:

- “Does the issue of underutilization in minority and medically underserved communities come down to a lack of access?”
- “Is it related to a lack of knowledge of the benefits from the communities in general, about the values of hospice and palliative care?”
- “Is there a failure of currently structured palliative care and hospice programs to meet the needs of medically-underserved populations in particular?”
- “The answer is yes to all of the above.”

Dr. Payne asserted that more and better research is needed to understand what specific factors in these areas are the most important and can be targeted by interventions. He noted that there are many historical and societal factors that have led many in the African American community to sense a breach of trust by the health care systems. He recalled question posed by the pastors in Houston, “How am I to believe that this hospital has my best interest in mind?”

Dr. Payne pointed to the general loss of credibility of institutions among the African American community. The legacy of slavery, abuses, of medical experimentation—the Tuskegee public health study of syphilis is an often-cited example—continued unequal access to care, and many studies documenting disparities in treatment and outcomes of treatment. Even when the statistics are normed for socioeconomic status, Dr. Payne pointed out, unequal treatment still appears to be related to racial and ethnic factors. With the higher incidence of violent deaths and higher death rates from chronic illnesses, one might argue as many in communities like Harlem have, that denial of death, even with a terminal illness, might be viewed as a healthy response.

As palliative and end-of-life hospital services are structured to meet community needs, Dr. Payne asserted, these important perspectives must be taken into account. Given this, how does the healthcare community move forward with a research agenda?

Dr. Payne then referred modestly to having suggested some questions that could be addressed in more detail during the discussion. In moving forward he further suggested looking at programs in regions of the country that seem to be doing a great job in providing services and quality end-of-life services to minority groups. To address the significant under-utilization, basic epidemiological studies are needed to define regional and national utilization of hospice and palliative care service in different minority groups and between socioeconomic classes within a minority group. Specific factors that would predict utilization or non-utilization of hospice services need to be identified. Better research is needed to study the needs and preferences of minorities in end-of-life care, from the perspective of patients, physicians, and other important health care providers.

Health service research, Dr. Payne continued, also has to address health policy and financial barriers. The National Institutes of Health is involved with funding important structures in the biomedical establishment, comprehensive cancer centers, sickle cell centers. These facilities may provide a research context for evaluating and providing comprehensive, non-fragmented end-of-life care for patients receiving care in these centers. Dr. Payne noted that there might be a role for demonstration projects in these centers to develop models of care delivery and to evaluate the effectiveness of this care.

Dr. Payne went on to mention two broad models of care in comprehensive cancer

centers. One model is at Sloan-Kettering Memorial, which involves collaboration with North General Hospital, a community hospital in Harlem. Memorial has utilized expertise and training to establish a multi-disciplinary, comprehensive palliative care service in Harlem. Joint professional appointments have been set up and a community provider network has been established called the Harlem Palliative Care Network. This was all possible by this umbrella collaboration between an academic health center and a community hospital strategically placed in a medically underserved community.

The other is a program going on at M.D. Anderson in collaboration with a hospital in San Juan, Puerto Rico. There is also a center specifically for minority studies within M.D. Anderson Cancer Center.

As these systems of network providers are set up, Dr. Payne continued, better research is needed in terms of both formative and summative evaluations of these networks. Questions need to be asked about what the important processes of putting these networks together are. And how the most important outcomes accounted for? Academic health centers here can have a major role to play.

Dr. Payne then added a final thought about the research. Better studies are needed, he stressed, in order to understand the cost of end-of-life care in different populations.

- Are these increased costs, for example in African Americans, related to established patterns of care early in the disease state that are carried through to the end-of-life care?
- Or is the need for increased rates of hospitalization for terminal illness something that is specific to the needs of an urban African American population?

Dr. Payne also stressed that improving access and quality of end-of-life care in medically underserved communities should be addressed in the context of improving access and quality to the entire spectrum of health care. “In fact,” Dr. Payne suggested, “it would be unethical to do otherwise, and certainly not politically sustainable, and that academic health centers could really have an opportunity here to re-emphasize their leadership roles in improving care for underserved populations.”

Panel Discussion with Questions and Remarks from the Audience

Dr. Ann Knebel, Facilitator

Following an invitation for comments from the audience, Dr. Knebel solicited follow-up comments from the panelists regarding the other panelists' presentations.

Dr. Richard Payne remarked that there is confusion about the language used to talk about palliative oriented treatment. He noted that we should be talking more about ways to allow for a natural death as opposed to “not resuscitating” or “not providing feeding tubes”.

Dr. Christine Grady responded by agreeing that the wrong language is often used for describing things that are much more complicated. Discussions about advance directives, do-not-resuscitate decisions, or limiting treatment make sense only within an explicit discussion of what the goals are for a particular individual and how we get

- there. “What is it we want to be able to do for that individual within what is realistic? And, given that this is hopefully a goal that everyone agrees to, what are the right strategies to get there?” She continued by saying that a decision not to resuscitate someone should never be a decision that is made in isolation from a lot of other discussion about what other things are or are not being done for that individual. A DNR order, she added, can change everything that we do. Without the bigger discussion of the goals, the context, and why we are making that decision to begin with, it isn't representative of what should be done for the patient.
- Dr. Thomas Smith added that the Thomas Hospice Palliative Care Unit in Richmond was set up specifically to serve medically underserved populations. Family members are often relieved to have the discussions about the goals of the care for a loved one. Providers are often the ones pushing decisions to do medically inappropriate things, rather than the family.
- Dr. Ann Berger agreed with Dr. Smith. She reiterated how these discussions need to start earlier on. She gave an example of a case involving an elderly woman with thyroid cancer who had been followed by the palliative care team for several months. Total parenteral nourishment was considered, yet the team had had conversations with the primary physician and the family and decided against aggressive treatments.
- An audience member expressed concern about medical future planning. She expressed concerns that publishers and corporations have the option to affect awareness about planning for one's medical future, but there is surprisingly little interest. She thanked the panelists and the facilitator for their efforts to promote planning decisions and suggested planning guides for planning medical futures, as a way of providing productive cost savings and maintaining individual integrity. She noted that she often hears of people's distress at the indignities of the institution and gate keeping systems. She urged that a research agenda include attention to institutional behavior. She also cited an example of poor institutional behavior in mentioning an HMO in California that “takes elderly people and infantilizes them, no matter how functional they are. Each one is ‘Sweetie’, none is recognized for his or her individual dignity and personality.”
- Dr. Christine Grady responded by noting that how we address people, what we call them, is one piece of how we show respect for their dignity.
- Dr. Thomas Smith added that it is possible to design a medical care system that provides the type of care that you would want if you were sick, everything from reasonably good parking to someone who greets you at the front office with “Hello, how are you?” to a reasonable waiting area where there is something to do and maybe even some food and water to drink while you are waiting for what can be a long time, to doctors and nurses who know what they are doing. He cited as an example of someone who is addressing this issue, Dr. Peter Eisenberg, an oncologist in northern California, who has designed and operates a model practice for physicians who use a written plan to outline exactly what is supposed to happen to everybody from the get go. Having witnessed the procedures in action, Dr. Smith noted that it saves time and increases patient satisfaction and patient knowledge. The practice also has memorial services for people who have passed away. Eisenberg's practice has gone to California Blue Cross Blue Shield and that, because his service is of higher quality,

they will pay him more per patient than they pay other services. He also mentioned that the American Society of Clinical Oncology is showcasing the model practices at Medical College of Virginia in May 2001.

Dr. Knebel noted that building on model programs is an area for research.

An audience member shared a suggestion and an observation. He is president of a hospice association, a coalition of sixteen hospice programs that cared for about 10 percent of the 700,000 patients nationwide in 1999. Having recently concluded a study of the experiences of 750 patients admitted to 11 programs across the country, 30 percent of those patients were admitted into hospice in pain. Within 72 hours, 82 percent of those patients reported that their pain had been brought to a comfortable level. The bad news is that 30 percent of the patients admitted to hospice had been admitted with pain. That was within a relatively brief period of time brought to a comfortable level. He then applauded current efforts at helping reduce the number of patients in pain who are admitted to hospice. He then shared his observation that the definition of palliative care may be boldly pushed to the point of diagnosis. It may also be more boldly pushed to the point of risk. He noted that there are some hospice programs, like San Diego hospice, where an early intervention program works with parents whose child will be born dying. The question of who is the patient is a really interesting question there. Of course, this does not fall under the definition of Medicare hospice benefit and is one of the really significant ways in which the work group is contributing to the redefinition of palliative care. He then shared an anecdote from a planning meeting with the Hastings Center, a prominent bioethics center in Garrison, New York. While wrestling with language issue, death was defined as the permanent obliteration of self, then offered the rhetorical question: Is there anything worse than permanent obliteration of self? Someone said under his breath, "Yes...torture, or possibly the continuation of bad circumstances." The audience member then concluded his comments by suggesting that it might be interesting to look at the experiences of individuals who have aggressively combated bad circumstances throughout their life, in trying to determine why they deny death so strongly.

Another participant at the workshop then shared a personal caregiving experience with her ailing parents, then posed a couple of questions: What does one do in a case where decisions need to be made and siblings are called in, but there are totally different opinions about what should be done? According to Maryland law, whether or not one uses a feeding tube does not have anything to do with the medical directive unless it is specifically mentioned. How might this policy be addressed? Lastly, do you think that the cultural emphasis on youth and lack of family values is one area that makes it difficult for palliative care to really take hold?

Dr. Christine Grady suggested that, when there is disagreement among siblings, one obviously has a painful and difficult situation. She noted that it is exactly for that reason that people need to be encouraged to think about who they would like to make decisions for them when they can no longer make them. She offered that if the parents designated a decision maker, differences of opinion among the siblings wouldn't necessarily be less difficult. In the end, the decision is in the hands of the one designated and that person's understanding of what the parents would have

chosen, had they been able to choose. Dr. Grady noted that the participant had also described decisions being made in contradiction to the advance directives. There may have been a lack of clarity about who had the legal authority to make decisions. It is important to be as clear as possible up front and to address differences of opinion as soon as possible.

- Dr. Ann Knebel pointed out that the video clip illustrated that the “naked” durable power of attorney would hopefully make it clearer in terms of the lines of decision. She then asked the panel if there are alternatives to the durable power of attorney.
- Dr. Christine Grady noted that there are other types of advance directives that are helpful in guiding decisions about their treatment when they can't be consulted. Most people believe that a designated person as a durable power of attorney is best, though the ability to predict what the decisions might be is limited. One can't foresee what is going to happen or what kinds of decisions are going to be made. Expressing values and general ideas about how one wants one's care to be directed is helpful. It is also helpful to do that with your designated durable power of attorney for health care so that they can make decisions based on what they know is wanted—not on what they prefer or what they think is good for you.

Another member of the audience shared that there seems to be an intermingling of clinical care at end of life with the desire to develop a research agenda at end of life, and expressed that there are differences that aren't being addressed. Specifically, she stated that there are ethical issues involved in doing research at the end of life that need to be brought more to the forefront. She identified intrusiveness in the life of the dying patient and the family as a major ethical issue in trying to understand how to provide quality care and what interventions work. Another major issue that the participant noted is in identifying comparison groups. As an example, she pointed out that in researching whether or not the withdrawal of feeding leads to a more peaceful end, how does a research select people to be in those groups? How does a researcher acquire consent? And in the case of those who refuse to participate, what factors inform their decision? She noted that the medical center that she is associated with has been attempting to find ways to look more closely at people who refuse to participate in end-of-life research. She then expressed interest in the panel's response about the ethical issues in end-of-life research, and what thoughts they might have on how one might go forward in developing an agenda that really heightens our awareness of what those ethical issues are.

- Dr. Thomas Smith noted that he is an oncologist, conducting research throughout the process of treatment and at the end of life. He added that the American Society of Clinical Oncology is introducing at the May meeting a mandatory curriculum for symptom management. He endorsed the curriculum's emphasis on symptom management from the very beginning to the very end of care. Regarding research, Dr. Thomas stressed that there needs to be a greater awareness of the burden of research on patients. Researchers should be using the shortest amount of instruments possible. An instrument should be tested prior to use to reduce the burden on the patient.
- Dr. Payne addressed the questioner's point about the validity of control groups. Determining what the appropriate control or comparison group is for certain studies is

a difficult issue. He also highlighted the issue of informed consent which he agreed poses ethical issues in two ways. In the last weeks or days of life, he suggested, when there may be serious compromise in cognitive ability, how do we understand informed consent, and what is our position toward surrogate decision makers, in terms of consenting to research?

Dr. Smith responded with an example of how a randomized control trial of nebulized fentanyl was halted by the Institutional Review Board because of the vulnerability of the population. Had a randomized clinical trial been conducted at the beginning, we would be six months ahead of where we are now. He continued suggesting that consent forms should be simplified. They should be one page, he suggested, simple language, dummed it down to where it is readable by third to fifth grade reading level, get that through the legal department, then take it from there, and then allow proxy consent for people who can't judge by themselves, particularly for very low risk interventions.

Dr. Payne expressed his confidence that Dr. Smith provides an easy out for patients in the control group, if they no longer want to participate, and probably provide rescue dosing of some kind of intervention for both groups. Dr. Smith confirmed that procedure. Then Dr. Payne went on to say that that is usually the method by which he and his team usually try to ameliorate some of the ethical concerns about getting a placebo in these very sick populations.

Dr. Smith cited various symptoms that can create ethical dilemmas as they are treated, such as depression, fatigue, terminal delirium or pre-terminal delirium. There are no instruments that actually help the lack of dignity, but I think one researcher is working on one that may work. Randomized clinical trials can be designed but they require National Cancer Institute funding and even then, it is three years from when you submit the trial to when the trial gets started. Dr. Smith concluded by recommending the establishment of a mechanism to fund to pay for a data manager.

Dr. Knebel summed up that response by noting that the essence of the debate is whether or not randomized clinical trials are the only ways to answer questions.

A member of the audience who identified himself as a recreation therapist addressed his question to the issue of denial in groups of patients, regardless of race or other factors. He began by claiming his need to address an issue of denial in his personal life. He went further to admit that it is a coping technique that works short term. Then again, he posited, how long is short term when you are dealing with patients in palliative care? Do you have to wait a long time before patients and family members come around to dealing with denial? Having worked in clinical settings with alcoholics, he noted that if the treatment clinicians were to honor the alcoholic's denial issue, there would be little progress toward healing. How can a clinician be sensitive to a style of coping that some people have used through their life, or to families who have coped with adversity through denial, and still deal with denial as assertively and kindly as I possibly can and address the issue?

Dr. Payne commended the participant's key observation that denial can be, particularly in the short run, a healthy coping response. He went on to note that for programs and structures that have been successful in embracing poor people—medically

underserved groups in whom this could be a particular issue, the key thing is acknowledging—simple affirmation and acknowledgement—that “life ain't fair.” The reason that palliative care is important, Dr. Payne continued, is because usually it is the most appropriate medical care for this particular clinical situation. There was a study that found that an insured black male with stage one lung cancer might not be referred for curative surgery. If that same patient returns months later and is now dying of the lung cancer, a simple affirmation that the system is not fair is required. The reasonable thing to do now is ask what can we do for the patient now that makes the most sense and is most beneficial to him in this particular circumstance. One only approaches these issues when they become an issue in a specific patient or family.

An audience member who identified herself as a nurse practitioner in the community offered the comment that palliative care is recognizing more of a trajectory than just a certain point in a disease state. She also commented on the traditional way that healthcare has regarded end-of-life care and hospice, and the resources, requirements, and definitions related to that. For instance, heart failure is the most common diagnosis for patients over 65 and it is a terminal illness that is characterized by peaks and valleys. Someone could die tomorrow or someone could die three years from now. It is just beginning to be looked at in terms of getting some patients into hospice, a process that is always difficult. She commended the process of hospice eligibility as an important issue for further discussion.

Dr. Ann Berger commended the participant for her suggestion and agreed that other diseases in addition to cancer be seriously considered in end-of-life research. Research on severely diseased cardiovascular patients would probably reveal that the difficulties patients and families have at the end is one can never be certain that something is irreversible. In oncology there is often more certainty than in other illnesses. Patients may express in an advance directive that they don't want anything done if things are irreversible, but it is very difficult to say when a situation is irreversible. Decisions are different in some illnesses and researchers need to study these issues.

Another participant asked a two-part question about physician-assisted suicide. Data presented from The Netherlands suggested that people made the decision to end their lives, not because they were in pain or they were uncomfortable, but because they were depressed or they weren't in a state to make the decision. Has the same kind of data come out of the Oregon assisted suicide experiment? Secondly, is it possible to design physician-assisted suicide legislation that discourages people from making the choice based on family pressures or depression, and still allows people who are honestly in pain and uncomfortable to choose to end their lives?

Dr. Christine Grady responded by noting that data from studies in addition to the findings from The Netherlands shows that pain is not the major motivating factor. There have been several studies in the United States. Some of the preliminary data on decisions made in Oregon confirm that as well. Those who choose or who want assistance with suicide are more likely to do so based on these other factors. Actually, relieving the burden on their families is one of the major reasons that people make the choice to die. Designing legislation that would somehow eliminate that possibility is a very interesting question. I don't know how you would ever eliminate that particular aspect

of most people's existence or reduce a real worry that people have. The issue involves many decisions that people have to make in their clinical care, The impact on family members is as much of a consideration as how they are feeling, in many cases.

Another participant commended the panel and the audience for bringing up a great many of the potential research issues that should be addressed, and noted that there are many more. She named quality improvement as a research method for improving systems of end-of-life care delivery, the financing issues around hospice for non-cancer diagnosis, and the regulations under Medicare. There is going to be a report that comes out of this presentation. Is that report, she inquired, going to then go back to the National Institutes of Health and help influence and direct funding for end-of-life care research?

Dr. Knebel responded, "In a word, yes." Dr. Knebel elaborated by saying that the special interest group that has been formed is dialoguing about what the initiatives will be. She noted that the group wanted to listen first, before proposing initiatives, and any initiative that NIH or the institutes therein decide to pursue must be approved through channels. The report of this conference as well as some other initiatives that we have planned will be the guiding forces behind the proposed initiatives that we. She stated that she couldn't be more specific than that at this point.

A cosponsor of the event, Dr. Sid Stahl of the Behavioral and Social Research Program that deals with end-of-life research at the National Institute on Aging, posed two questions for the panel. Most of the comments heard so far, he noted, have essentially regarded palliative care. Are there burning research issues that deal with systemic problems besides the parking issue that someone mentioned earlier, systemic issues in research that the National Institutes of Health need to look at? The second issue concerns the elderly. Most of the people who are dying in the United States are, in fact, older individuals. He noted that he had not heard anything about research issues that concern the elderly at the end of life. Most of it has been the drama of dying with congestive heart failure or dying with cancer of some sort. He invited the panelists to take on one or two burning research issues in each of those areas.

Dr. Christine Grady asked for Dr. Stahl to clarify what he meant by systemic?

Dr. Stahl identified the Health Care Financing Administration (HCFA) as an example—the six-month admission requirement for hospice. One of the panelists also addressed organizing how people are greeted when they enter the system within which people die.

Dr. Ann Berger noted that by regarding palliative care early on in the trajectory of an illness, geriatric care or care of the elderly patient is palliative care, particularly for those in long-term care facilities. She commented that prior to coming to NIH, she was involved in a project with the Office of the Ombudsman at the University of Medicine and Dentistry of New Jersey. Her project was to set up pain and palliative care teams in 11 different institutions. One of the biggest barriers was financial. The success depended on whether there was administrative support. The financial barriers were huge in terms of things like bringing in hospice at the very end. It was

clearly more economical for them to put people on acute care rehab units than have them with hospice. There were long-term care facility administrators who would say, when we went back for bedside rounds that they were not making money out of this. Clearly, this needs to be looked at. The question needs to be asked about what can be done to change that. Financing long-term geriatric palliative care for longer than a six month period is going to take a commitment from researchers and institutions and policy makers.

Dr. Thomas Smith noted that as of now, there is no funding mechanism for looking at the quality of care that is provided. He noted that if he were to set up a bench mark for his faculty members to look at days in hospice, from the time the referral is made to death, as well as complication rates for chemotherapy, use of visual analog scores in pain; and then make a list of about ten things that, as a medical oncologist, are really important to provide good care as well as good end-of-life care and symptom management care, there would be no one willing to pay for that. In his own institution (Medical College of Virginia), he notes that he could possibly browbeat a little bit of a programmer analyst's time. Without being compared on any of those benchmarks to any other health care plan anywhere or any other provider, there is little incentive. He continued by noting that he might show that the complication rate is too high, that the rate of febrile neutropenia after Ara-C chemotherapy for breast cancer is five percent, and that would be encouraging. The public might think it is one percent, so you can't publish that five percent is really good. If you look at the National Cancer Institute (NCI), if you look at the American Cancer Society (ACS), if you look at all the big funding institutions, none of them have any mechanism to look to fund retrospective or prospective assessment of important quality of care. It wouldn't be that expensive for any of those institutions to do that, but they have to be willing to do it at a single institutions or a couple of institutions, just to set up some benchmarks, follow them and see what actually happens. Dr. Thomas shared that he has some serious concerns about the quality of cancer care in the United States. Yet, no one is willing to go in and look at the last 2,000 cases of adjuvant chemotherapy for breast or colorectal cancer, because no one wants to know what the answer is. He then challenged NCI and ACS to put a couple million dollars into it and fund some pilot projects.

Another participant who identified herself as the editor of a nursing journal, asked the panel to address pediatric palliative care and any of the differences that exist between pediatric services and adult services. She also included a personal plea for children to be included in a research agenda for palliative care.

Dr. Knebel responded by saying that not much is known about children at the end of life, though the Institute of Medicine is interested in funding a study to look at pediatric end-of-life issues.

A participant from a university academic medical center coordinates a palliative care program. She asserted that the systemic issues must be dealt with first. There is currently too much incentive within the healthcare system for aggressive care. Administrators are actually saying that palliative care isn't needed as long as insurance covers the costs of treatments. This attitude has to change and changes in that particular system will have to be forced. The system is designed to support the antithesis of palliative care. The program, she noted, is conducting a palliative care

study with HIV patients. They are looking at what people really want. The study utilizes qualitative research based on the American Health Decisions model of focus groups with the homeless and with minority groups. She went on to commend qualitative content analysis for the end-of-life research agenda.

Dr. Mary Ann Richardson with the National Center for Complementary and Alternative Medicine—another cosponsoring organization of the day's event—offered an announcement and then a question for the group. NCCAM is working with the National Institute of Nursing Research, the National Cancer Institute, and others on an initiative or Request for Applications (or RFA) coming out the first of the year for complementary and alternative therapies at the end of life for cancer and HIV. She then asked the panelists if they have any comments to make about the use of these sorts of approaches at the end of life as this RFA is finalized.

Dr. Ann Berger responded by noting that the NIH palliative care service has been here for only three months, but it is already integrated palliative care clinic. The clinic consists of a physician, a recreation therapist, a rehabilitation therapist, and a physician who comes and does acupuncture and acupressure. Massage is also employed for patients in the clinic who have such needs. These techniques are not only employed at the end of life. She shared that she has had acupuncture for herniated disks. It absolutely works. She then indicated that she is a “true believer” and endorsed looking at some of the complementary therapies.

Dr. Payne shared that the Sloan-Kettering Medical Center employs music and art therapy in its palliative care program. I am aware that in the pain literature, both acute pain and cancer pain, there are very well designed studies that have demonstrated effects on pain control for music therapy, in particular. There are, he noted, some robust findings that one can find with some of the drug studies in the literature. Continuing, he noted that alternative interventions could be studied on targeted symptoms. He also noted that they are clearly helpful in helping patients cope and communicate in ways that patients find difficult with more traditional health care providers.

Another audience member offered a comment regarding Dr. Payne's presentation on talking to ministers. She stressed that she knows the power that the black church holds and that the Church can be an effective vehicle for introducing change. She went on to note that people should have information about palliative care before they come into the hospital, so they will know what to expect and what questions to ask. Has the Church been involved in shaping public awareness of end-of-life issues?

Dr. Payne noted that much work has been done with both churches and mosques in Harlem, in terms of programs that would provide broad education to people who are not yet facing life-threatening illness themselves, but whom may have family members involved. The second issue is about providing better clinical pastoral education for pastors and imams (Islamic worship leaders) of faith-based organizations. Often, clergy don't have a clear idea of what is realistic, what isn't realistic and what the state of the science could or should be. We have several programs looking at focus groups to understand knowledge and attitude issues and educational programs in this area. In an urban center like Harlem, where a significant percentage of the population is actually not a Christian African-American population, understanding these non-Christian perspectives on end-of-life care is quite important.

The audience member interjected that only 20 to 30 percent of black ministers are educated. Presenting a program on palliative care in the divinity schools might equip black pastors and ministers to spread the gospel of palliative care. Dr. Payne concurred and noted that there is a major initiative at the Duke Divinity School looking at end-of-life care. It is a collaborative effort between the divinity school, the medical school, and the nursing school. The faith communities are very important in this effort and need to be partners. They have a lot to offer, but also need a lot of training and education.

A member of the audience then asked if there is there a mechanism to support Medicare for palliative care services in the senior homes?

Dr. Ann Berger responded that no, there is no mechanism through Medicare where you can receive coverage for good palliative care at home. This is one of the systemic problems referred to earlier. It's difficult to provide good palliative care in long-term care facilities either, but you definitely can't do it at home. The whole financial structure for palliative care needs to be looked at. NIH is like being in Nirvana for a palliative care provider, Dr. Berger added. At Cooper Hospital in New Haven, CT, it is difficult to get funding for palliative care. For example, patients on Medicare have no access to the good narcotic medications. She called the situation absurd. More invasive ways of administering medicines, like IV medicines are often covered, but the oral medications won't be. It is a systemic problem, she concluded, and it's crazy. It shouldn't be like that.

Dr. Knebel thanked the panelists, the audience, and Dr. Claudette Varricchio, Dr. Sid Stahl, and Dr. Mary Ann Richardson who co-sponsored the program.

The meeting adjourned at 3:15 p.m.