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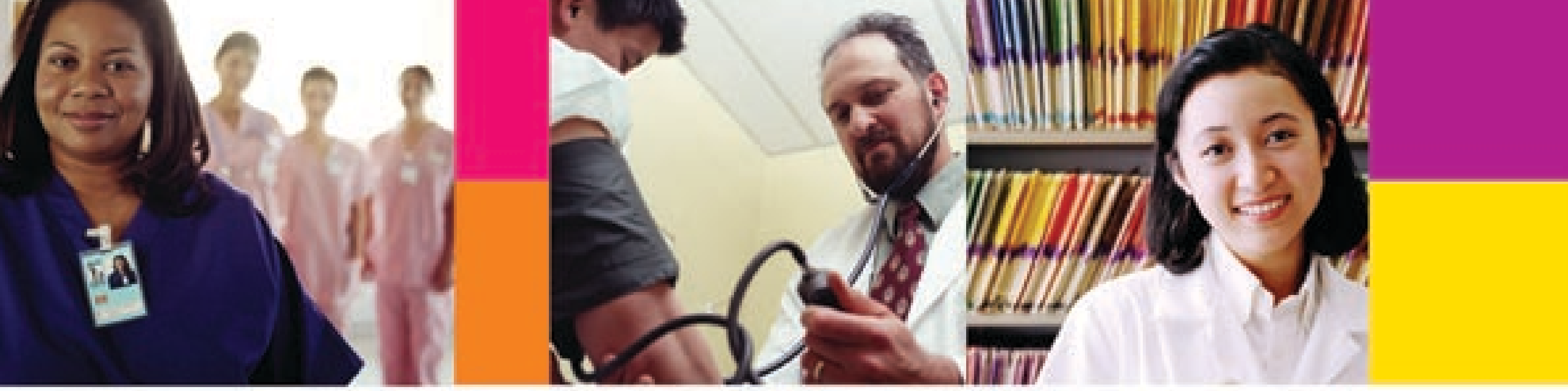

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> *"When chances for cure and survival diminish, most dying patients and their families prefer an approach to medical treatment that emphasizes comfort and quality of life."*

ARTICLE

African American Elders' Perceptions of the Influenza Vaccine in Durham, North Carolina

Sohini Sengupta, PhD, MPH, Giselle Corbie-Smith, MD, Angela Thrasher, MPH, and Ronald P. Strauss, DMD, PhD

Abstract

Objective: *To qualitatively explore community perceptions among elderly African Americans about what makes it easy or difficult to get vaccinated for influenza.*

Sample: *A total of 28 elderly (age 65 years or older) African Americans living in Durham County, North Carolina, participated in this study.*

Data Collection Methods: *In-person, open-ended interviews were conducted to perform a content analysis on factors influencing influenza vaccination use, or lack thereof, in an elderly African American population. Interviews were conducted in participants' homes and at senior centers in Durham County, North Carolina. Interviews were transcribed and analyzed to identify themes.*

Principal Findings: *Ten facilitators to encourage obtaining vaccinations were identified, including reminders from a doctor to get the influenza vaccination and the perception that the vaccination prevents influenza. Eight barriers were identified, including community perceptions to not get vaccinated and the fear of getting the "flu" from the vaccination itself.*

Conclusion/Relevance: *The study identified community perceptions of what makes it easy or difficult for elderly African Americans to get vaccinated for influenza. The findings will be useful to design and implement programs targeted to improving vaccination rates in health clinics or private physician's offices since the elderly are more likely to receive influenza vaccinations in primary care settings.*

Key Words: *Aging, Access to Care, Immunization/Vaccines, African Americans/Blacks, Qualitative Research*

Introduction

Every year influenza epidemics cause more than 20,000 deaths and 110,000 hospitalizations in the United States.[1-4] Specific target groups, such as elderly persons (≥ 65 years), young children, and persons with underlying diseases (who are often elderly) are at highest risk of influenza-related complications and hospitalizations.[5] Mortality associated with influenza, however, disproportionately affects the elderly. In a recent study, influenza mortality correlated with age, with persons ≥ 85 years old being 32 times more likely than persons 65-69 years old to die of influenza-related complications.[6] Given that the average life expectancy at birth for men and women in the United States now exceeds 74 and 80 years, respectively,[7] annual influenza vaccination is, and must, remain among the most important public health priorities to control the healthcare burden associated with influenza morbidity and mortality.

The United States Preventive Service Task Force and the CDC's Advisory Committee on Immunization Practices recommend that elderly Americans get vaccinated against influenza as a preventive measure annually.[8-9] The 1996 Medicare Current Beneficiary Survey and the 2002 Behavioral Risk Factor Surveillance Survey—nationally representative surveys to assess influenza vaccination usage and reasons for not getting vaccinated among elderly Americans—demonstrated, however, that influenza vaccination rates differed among elderly racial/ethnic groups; approximately 68%-69% in whites, and 47%-50% in African Americans.[10,11] Furthermore, not getting vaccinated was associated with not perceiving influenza to be a health risk, regardless of race.[12] In *Healthy People 2010*, one of the objectives is to increase the proportion of all elderly Americans vaccinated annually against influenza to 90%.[13] "Eliminating," not just reducing health disparities, is one of the nation's goals for the next decade.

It will be a particular challenge to increase influenza vaccinations in elderly African Americans from 47% to 90%. The Medicare Current Beneficiary Survey provided little evidence as to why elderly African Americans are disproportionately not

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getting vaccinated for influenza other than they may not know about the benefits of getting vaccinated.[14] Before we can wage a campaign to increase the proportion of elderly African Americans vaccinated against influenza, we must first understand the structural and interpersonal factors influencing their behaviors (i.e., getting or not getting vaccinated). The purpose of this qualitative study is to explore community perceptions of what makes it easy, as well as what makes it difficult, for elderly African Americans to get vaccinated for influenza.

METHODS

The target population was non-institutionalized, community dwelling elderly (≥ 65 years) African Americans living in Durham County, North Carolina. We recruited our convenience sample from senior centers, referrals from study participants already interviewed, as well as from a list of elderly African Americans through the University of North Carolina at Chapel Hill/North Carolina Central University Center for Minority Aging. Of the 41 potential participants approached or contacted over the telephone by our interviewer, 13 (31.7%) refused to participate. Reasons for refusal included that individuals were not interested, did not have the time, or they were not in good health. Our final sample was 28 participants, which was sufficient in achieving data saturation with respect to the expected and emergent issues associated with our research objectives.

Data Collection

The interviewer scheduled a one-hour interview with each of the 28 participants. Interviews were conducted either at the participant's home or at one of the senior centers where recruitment occurred. Written informed consent was obtained, followed by the interview. All interviews were audiotaped, and participants received financial compensation for their participation. The interviews were completed between May and October 2002. The Institutional Review Board of the University of North Carolina School of Medicine approved this study's protocol and consent form on October 19, 2001.

Qualitative Interview Guide

An interview guide was developed for this study to explore three main open-ended questions:

- What are the benefits (or risks) of getting vaccinated for the flu?
- What kinds of things do you think would help older African American adults get the flu shot?
- What makes it difficult for older African Americans to get the flu shot?

The interview concluded with a set of sociodemographic questions, including race/ethnicity of their main physician, age, education level, main source of income, health insurance status, whether or not they lived alone, whether or not they ever had the flu, whether or not they received a flu shot consistently on an annual basis, and whether or not their physicians offered them the flu shot during office visits.

Data Management and Data Analysis

Audiotapes of the interviews were transcribed into a word-processing program. The interviewer checked the accuracy of the transcripts by listening to, and reading along with each tape. Any identifying information in the transcripts was supplanted with generic references (e.g., Person A, Senior Center B) to protect confidentiality. The transcribed interviews were then imported into Ethnograph© v5.07, a qualitative software program for the purposes of content analysis.

For the Likert-type, and sociodemographic questions, data were entered into SPSS© 11.0.1. Frequencies were calculated for categorical variables, and medians were calculated for continuous variables. Content analysis involved the development of a thematic coding structure representing a hierarchy of codes.[15] Level 1 codes reflected each of the open-ended questions asked. Sub-codes reflected themes identified from answers to these questions. For example, *What are the benefits of getting vaccinated for the flu?*, was a theme earmarked by a level 1 code, and a sub-code for this theme was, *Protect myself from getting the flu.* We addressed validity systematically by first developing a codebook through an iterative process that delineated each

Table 1.
Sociodemographics

Variables	(N=28)
Gender	
Male	6 (21.4%)
Female	22 (78.6%)
Marital Status	
Married	12 (42.9%)
Widowed	11 (39.3%)
Other	5 (17.8%)
Income Source	
Social Security	18 (64.3%)
Retirement/Pension	10 (35.7%)
Education	
≤ High school	9 (32.1%)
Trade school	8 (28.6%)
College education	6 (21.4%)
Graduate degree	5 (17.9%)
Health Insurance	
Medicare + Private	19 (67.9%)
Private only	5 (17.9%)
Medicare only	1 (3.6%)
Other	3 (10.7%)
Lives alone	9 (32.1%)
Had the flu in the past	20 (71.4%)
Personal doctor offered vaccine in the past	24 (85.7%)
Personal doctor offered vaccine in Winter 2002	21 (75.0%)

Note: "Not sure" responses were excluded from totals that do not equal N = 28.

code (level 1 and sub-codes), their definitions, when is it appropriate to use each code, and when is it not appropriate to use each code after the research team had read a first passing of all of the interviews. The codebook provided the coders a framework of mutual understanding about each of the themes. The second step involved having coding teams independently read and code each interview for intercoder reliability. Percent agreement was compared for each code across interviews for the purposes of assessing intercoder reliability. Any code having less than 80% agreement was discussed, and discrepancies were resolved to improve agreement.

RESULTS

Description of the Sample

The 28 participants were all African American, 65 years of age or older, and living in Durham County, North Carolina (see Table 1). The mean age was 74.9 years, with the oldest participant being 86 years old. Overall, the majority of the participants was female, living on Social Security, and had both Medicare and private health insurance. Twenty (71.4%) of the participants had the flu in the past, and 13 (61.5%) of these participants received the annual flu shot consistently (data not shown in table). For 24 (85.7%) of the participants, a personal physician offered the vaccine to them in the past, and for 21 (75.0%), the personal physician offered the vaccine to them in winter 2002.

Facilitators and Barriers Affecting Influenza Vaccine Usage

To better understand why African Americans are getting or not getting vaccinated for influenza, we asked three open-ended questions to elicit what makes it easy and what makes it difficult for elderly African Americans to get the influenza vaccine. The three questions we asked were intended to improve understanding of community perceptions of the facilitators and barriers to influenza vaccine use. Tables 2 and 3 present the themes for facilitators and barriers, respectively, and quotation examples for each theme.

Facilitators Associated with Influenza Vaccination

All participants were asked about what makes it easy for members of their community to get vaccinated for influenza. Responses were categorized as either structural facilitators or personal factors (e.g., knowledge, attitudes, or health status) facilitating influenza vaccine usage (see Table 2). For structural factors, the predominant facilitator reported was receiving a reminder from their doctor to get a flu shot (N = 19). Reminders could range from an informal postcard in the mail, to a conversation with their personal doctor about the benefits for older African Americans to get vaccinated for influenza. Another important source of external information that facilitated vaccine usage was word-of-mouth from the community that getting the influenza vaccine is an important health behavior (N = 14). The "community" generally referred to other African Americans with whom they had discussed the influenza vaccine, such as friends, relatives, or church and religious leaders who were perceived as a source of positive information that older African American adults could trust. Lastly, it helped that the influenza vaccine was primarily covered by participants' health insurance (N = 7).

Several personal facilitator themes were identified. Seventeen (60.7%) participants strongly felt that being knowledgeable about influenza, its symptoms, and the possibility that it could be fatal, was a strong motivator to get vaccinated. Participants also described their own health conditions (e.g., heart disease or hypertension) as susceptible to the flu (N = 6), or the fact that they were getting older (N = 11), resulted in the need for getting a flu shot. Lastly, participants identified three main benefits about the influenza vaccination. The predominant perceived benefit given was that the influenza vaccination was effective in preventing individuals or communities from getting sick with the flu, or getting sick from cold-related illnesses (N = 24). The second most common benefit was the perception that the vaccine would diminish the severity of flu symptoms if the individual became infected with the flu (N = 12).

Barriers Associated with Influenza Vaccination

All participants were asked what makes it difficult for members of their community to get vaccinated for influenza. As in the analysis of facilitators, responses were categorized as either structural or personal factors (e.g., knowledge, attitudes, or health status) that posed as barriers to influenza vaccine usage (see Table 3). The predominant structural barrier was word-of-mouth from the community to not get a flu shot (N = 20). Within this context, "community" included community leaders, or relatives and friends, but this theme also reflected conversations individuals may have had, or might have heard at the barber shop, eateries, or other public places that were construed as dissuading elderly African Americans from getting a flu shot. Although not frequently mentioned, the theme, lack of access (N = 6), incorporated a number of different issues that prevented elderly African Americans from getting vaccinated, including not enough venues where individuals could go to get a flu shot. Lack of access also related to the issue of influenza vaccine shortages, which were salient even for participants who had regular primary care and could have received the vaccine through their physician's office.

Thirteen (48.1%) participants felt that not knowing about the severity of the flu was a personal barrier for most elderly African Americans. Participants also were influenced by what they perceived to be the risks of the influenza vaccination itself, focusing particularly on the contents of the vaccine. A predominant belief was that the flu shot itself could cause the flu (N = 21).

DISCUSSION

Our study demonstrated that participants' knowledge and attitudes about the severity and likelihood of getting influenza did not explain fully why elderly African Americans are getting or not getting vaccinated. Instead, exploring knowledge and attitudes in concert with structural facilitators and barriers provide a better picture of the challenges health professionals confront to improve influenza vaccination rates in this underserved racial group. We set out to understand the factors affecting influenza vaccination use in one elderly African American sample and to provide recommendations on how to remedy some of the key factors identified.

The study findings focused on the facilitators and barriers affecting influenza vaccine usage among elderly African Americans in Durham County, North Carolina. Interestingly, some themes were identified as both facilitators and barriers to getting vaccinated for influenza. One of these themes was word-of-mouth from the community highlighting both the pros and cons of getting vaccinated. Although more participants expressed this theme within the context of what discourages individuals from getting vaccinated, it raises an important issue about how negative experiences with the influenza vaccine are emphasized, spread, and can linger within a community. Similarly, a predominant perceived risk was that the vaccine itself causes the flu. Most likely, what participants experienced

Table 2.
Facilitators to Getting the Influenza Vaccine

Theme	Text Example	(N=28) N (%)
STRUCTURAL		
Reminder from the doctor to get a flu shot	"...and pamphlets that they [doctor's office] send you in the mail to get the flu shot. And, they [doctor's office] do write you ...And tell you the flu shot will be given such and such a time." (Female, 73 years old)	19(67.9)
Word-of-mouth from the community to get a flu shot	"And that's where a lot of people gather, so around the flu time send notices or information to the churches and the schools informing people about this flu shot and sometimes people in the church will listen if it's coming from somebody else in the church." (Female, 73 years old)	14(50.0)
Written or visual media promoting flu shot use	"I think when you get information when you go to get your flu shot, they also give you pamphlets to hand out and things like that, I think that all is a good awareness." (Female, 67 years old)	11(39.3)
Vaccine is free or low cost	"Also cost, better health insurance for, insurance making it [flu vaccine] available that way." (Female, 65 years old)	7(25.0)
PERSONAL		
Being knowledgeable about the severity of the flu	"I have had the flu, and I know how sick you can get from it." (Female, 77 years old)	17(60.7)
Having a chronic condition that puts them at higher risk for getting the flu	"See I didn't have any serious medical problem. But since I had heart disease, he [doctor] encouraged it [getting flu shot]." (Female, 75 years old)	6(21.4)
Having (Had) a job that puts them at a higher risk for getting the flu	"Because it was part of the hospital's routine, the nurses there had to take, they had to take different vaccinations and all that kind of stuff." (Female, 66 years old)	8(28.6)
Getting older	"And the reason why I took the flu shot this year is because for the last—since I've made sixty five—I see that my resistance to colds and flus are getting worse." (Female, 68 years old)	15(53.6)
Benefits of the flu shot		
* Prevention	"I think it prevents you from being miserable during the winter." (Female, 68 years old)	24(85.7)
* Decreases symptom severity of the flu	"I guess stave, stave off colds, other diseases that might be connected with the flu." (Female, 78 years old)	12(42.9)
* Greater ability to do day-to-day activities	"Because my doctor is still telling me that if I have a breathing condition, that if I got the flu, it would be milder than if I did not take the flu shot." (Female, 73 years old) I think it [flu shot] keeps my immune system stronger, so therefore I feel better, and I'm able to do the things that I enjoy doing and not have to spend time laying around, sneezing, coughing...so it really helps me so I can be more active." (Female, 67 years old)	8(28.6)

Note: Values represent the number (and %) of participants who reported each theme listed.

and were describing was an immunological response or side effects to the vaccine that they interpreted as the flu. Nevertheless, their negative experiences with taking the influenza vaccine will affect their future usage. In attempting to change behaviors among elderly African Americans, and in this case improve annual vaccination usage, we recommend the need to address historical, collective experiences (e.g., being exposed to a "bad batch" in early vaccination efforts), as well as urban myths (e.g., the vaccine causes the flu), in any targeted program developed.

Several other recommendations can be noted with respect to increasing knowledge and awareness of influenza and its vaccine in African American communities. A majority of the participants identified reminders from healthcare providers to get vaccinated

Table 3.
Barriers to Getting the Influenza Vaccine

Theme	Text Example	(N=28) N (%)
STRUCTURAL		
Word-of-mouth from the community to get a flu shot	"Those are the ones that are scared of, of getting the flu [from the flu shot]. They heard from somebody who heard from somebody else that it can give you the flu. It's hard to convince folks once they start thinking that." (Male, 72 years old)	20(71.4)
Irregular or lack of preventive healthcare	"When you're talking about medical visitation, regular visitations, a lot of people my age don't go to a doctor until they're sick. And the doctor, when they find out what's the matter with them, you know where they go first, the Emergency room." (Male, 76 years old)	7(25.0)
Lack of access	*Regarding vaccine shortage:* "When I went to the health department, they said it was somewhat late that they couldn't get the vaccine or something. I went there three times, you know. But anyway she said, 'I'll call you,' but when I did go back there was, something didn't come in... and I was interested in getting my flu shot." (Female, 77 years old) *Regarding location access:* "I think it's access to health, to places where you know the flu shot is given. There may be not as many clinics or places that you know that they can go to, or the distance that they may have to travel." (Female, 77 years old)	6(21.4)
PERSONAL		
Not knowledgeable about the severity of the flu	"Some of them are not knowledgeable enough to know what it can do for you. They don't realize the risks or the advantages." (Female, 76 years old)	13(48.1)
Fear	"I think some people are afraid. They're afraid that they're going to get sick or something from it." (Female, 79 years old)	13(46.4)
Risks of the flu shot		
* Side effects	"I think when they give you the shot, they're giving you part of that, parts of flu? And, if you're not strong enough or you can't fight it off, that's the way I feel about it. Your body's not strong enough, then I guess you just have the flu, it will give you the flu." (Female, 80 years old)	21(75.0)
* Getting the flu from from the flu shot	"My arm swolled up and I had chills and fever. Just like I was having, just like flu. And, I was just sick. And so, that stopped me from taking them [flu shots]." (Female, 80 years old)	18(64.3)
* Past problems with flu shot batches	"...sometimes the flu shot can, depending upon the batch of the flu shots that's being given sometimes they can have adverse effects and that is something I do think about." (Female, 65 years old)	5(17.9)

Note: Values represent the number (and %) of participants who reported each theme listed.

as a facilitator. The reminders can lead to elderly patients asking for the vaccine or just asking questions about the vaccine should they have concerns. Through simple reminder systems, providers can play an important role in reducing racial/ethnic disparities in vaccine use,[16] not to mention encouraging more patient education about influenza and its prevention. A second recommendation is to educate African American communities about the fact that an annual influenza vaccine is covered under Medicare, to which all over the age of 65 are entitled, and cost should not be a barrier to getting vaccinated. Lastly, since influenza immunization is seasonal, it would be useful to develop local media campaigns notifying the public in a timely and coordinated fashion when and where the vaccine will be available. This will most likely target individuals who have a desire to get vaccinated, but have had access difficulties due to vaccine shortages, late arrival of the vaccine, or not knowing locations where to get the vaccine, particularly in cases where individuals do not have a regular healthcare provider and rely on chain pharmacies or health departments for their vaccine source.

Our study has two primary limitations. First, our convenience sample was not heterogeneous with respect to socioeconomic status and gender, i.e., low-income and male participants were not equally represented. Second, our findings have limited generalizeability only to elderly African Americans with similar population characteristics to our sample living in Durham, NC. Further research would need to be conducted on a national sample of older African Americans to determine whether the same facilitators or barriers may apply in other regions of the United States. Despite its limitations, the findings demonstrate what works, and what factors pose as obstacles for elderly African Americans to get the influenza vaccination.

The public health benefits of improving influenza vaccination rates among the elderly include primary prevention, preventing secondary complications, and reducing hospitalizations and deaths associated with influenza.[9] These actual benefits, unfortunately, are not translating into increased vaccination use among the elderly, particularly elderly African Americans. In order to improve vaccination use, any public health intervention should have a multi-system approach that emphasizes what facilitates and overcomes the barriers to vaccine use at the individual, provider, community, and healthcare system levels. In so doing, eliminating health disparities, at least for influenza morbidity and mortality among elderly African Americans, could be a possibility. **NCMJ**

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POLICY FORUM

POLICY FORUM
New Directions in End-of-Life and Palliative Care

COMMENTARIES

> *"...a good death [is] 'one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.' "*

INTRODUCTION

Policy Forum:
End-of-Life and Palliative Care

The Policy Forum section of this issue of the *North Carolina Medical Journal* gives attention to one of the most complex sets of problems in American healthcare—end-of-life and palliative care. Few topics addressed in this Journal have such profound and relevant implications for healthcare quality and to the lives of all Americans, regardless of social class, gender, religion, race, or ethnicity. The inevitability of death forces all of us to think about the choices we would make at the end of life. But, as these articles make clear, all too often the family and friends of those who are dying are faced with limited choices because few of us make adequate plans for these inevitable circumstances.

In this issue of the Journal, an outstanding group of healthcare professionals, lay activists, and policy analysts with broad-reaching involvement in end-of-life and palliative care have offered a comprehensive overview of the major problems and issues in this field. Geriatrician and medical ethicist, Laura Hanson, MD, MPH, offers a panoramic overview of these issues. Other authors provide detailed analyses of the care and services provided by hospice and hospital-based palliative care organizations and some of the dilemmas of clinical decision making, including a review of current approaches to pain control and the circumstances under which feeding tubes (percutaneous gastrostomy tubes or PEGS) should be used for nutritional supplementation. In addition, we have an explaination of the legal and ethical issues associated with do-not-resuscitate orders (DNR) and the designation of healthcare power of attorney. We have also included reprints of formal statements from the North Carolina Medical Board and the North Carolina Medical Society on these issues, which can serve as useful guidelines and assurances to practicing physicians who care for dying patients.

As one reads these articles, it is clear that despite the complex issues in this field, there are some remarkable successes and indications of a growing professional concern about how we care for dying patients and their families. Given the rapid growth of North Carolina's elderly population, we are likely to see an increase in the demand for more and better trained healthcare professionals who can provide end-of-life and palliative care. Though there are healthcare professionals who have denied the need for a specialized approach to the care of the dying patient, the many facets of end-of-life care described in these articles surely underscore the contrary point of view. There is great need for professionals in a number of disciplines who are dedicated to providing the care and services needed to assure the opportunity for a "good death" when that time comes.

As always, we await your letters and other comments on these issues as we continue to bring you reviews of some of the more important and far reaching health and healthcare policy issues affecting the lives of North Carolinians.

Gordon H. DeFriese, PhD
Editor-in-Chief and Publisher

Kristie K. Weisner, MA
Managing Editor

ISSUE BRIEF

Palliative Care:

Innovation in Care at the End of Life

Laura C. Hanson, MD, MPH

What is Wrong with Healthcare at the End of Life?

Americans benefit from rapid innovation in medical therapies to prolong life and ameliorate disease, but innovation in care of dying patients has not kept pace. When efforts to cure or to manage diseases reach their inevitable limits, patients, families, physicians, and nurses question continued use of treatments designed to prolong life. Many physicians and nurses recall using life-sustaining treatments for terminally ill patients—treatments that they considered to be inappropriate at the time.[1] In extreme cases, beginning with the court battle over life support treatment for Karen Ann Quinlan, these poignant personal decisions have become public narratives of suffering. When chances for cure and survival diminish, most dying patients and their families prefer an approach to medical treatment that emphasizes comfort and quality of life. Discerning and then communicating this transition is one of the central dilemmas of end-of-life care.

Good care at the end of life is not accomplished by simply stopping traditional modes of treatment. The alleviation of suffering is one of the primary goals of medicine, yet emerging research in the care of dying patients demonstrates high rates of untreated pain and other physical symptoms. New forms of treatment and care are needed to control symptoms associated with dying. Decisions to withhold or withdraw life-sustaining treatments do not address the needs for effective treatment for pain and other symptoms. The crisis of impending mortality triggers additional emotional and spiritual suffering.[2] Forty percent of conscious patients have moderate-to-severe pain and more than half have moderate-to-severe dyspnea during the last two-to-three days of life.[3] Patients dying in hospitals and nursing homes have high rates of unmet needs for physical symptoms, emotional suffering, personal care services, and communication about treatment options.[4,5] Patients do not suffer alone; during the dying process and after a death, family caregivers experience significant emotional, physical, and financial stress.[6,7,8] Patients, families, and healthcare providers acknowledge profound deficiencies in current end-of-life care, and the need for improved palliative care services that are well matched to the needs of dying patients.

Palliative care is an emerging field in United States healthcare. Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a serious or incurable illness.[9] Because it is a comprehensive approach to care, providers of palliative care offer expert pain and symptom management, supportive care for emotional and spiritual distress, and bereavement support for surviving family. Palliative care includes and expands on the expert care of dying patients found in hospice services.

> *"Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a serious or incurable illness."*

How Do Americans Die?

More than two million deaths occur in the United States each year. Depending on the underlying cause of death, a dying patient's "death trajectory," or their functional decline prior to death, may follow a brief or prolonged course. The trajectory of illness before death may have a recognizable terminal phase, or a more uncertain and unpredictable course prior to death. The underlying cause of death and resulting death trajectory strongly influence the quality of the dying experience, the certainty that a patient is dying, and the physician's ability to discuss options for medical treatment.[10,11,12]

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Progressive chronic diseases—heart disease, cancer, stroke, chronic lung disease, and neurodegenerative disease such as Alzheimer's and other dementias—cause the majority of adult deaths. Among these causes, cancer patients have a more precipitous functional decline near death, which may facilitate recognition of a terminal phase of illness. Patients with chronic heart or lung disease have a more uncertain trajectory of worsening and remitting symptoms over months to years prior to death. Elderly nursing home residents with neurologic diseases and varied other chronic illnesses may have a very slow functional decline for many years, with no recognizable terminal phase. These individuals often die of an acute illness such as pneumonia or hip fracture. In the context of advanced dementia, these treatable acute illnesses have a 50% mortality risk at six months.[13,14]

Because Americans expect to live into old age, deaths early in life are especially painful. Premature deaths among children and teens are more often caused by relatively sudden events such as accidental injury, homicide, suicide, or complications of HIV infection or congenital abnormalities.[16] Racial and ethnic minority groups have higher rates of death at younger ages from these traumatic or sudden causes. The national Institute of Medicine's report, *Approaching Death: Improving Care at the End of Life*, emphasizes the need for overall improvements in end-of-life care and lends attention to the diverse needs of these subgroups of dying patients.[15,16]

Where Do People Die?

The site of death may be one of the most important structural determinants of the experience of dying.[5,17] Patients and their families say they prefer terminal care at home,[18] but four of five deaths in the United States take place in hospitals and nursing homes. After-death interviews with bereaved families show an association between site of death and satisfaction with terminal care. Surviving family are consistently more satisfied with hospice and are least satisfied with conventional nursing home and hospital care.[5,17,19] Hospice services, which can be provided in private homes or long-term care facilities, now support one-in-five dying Americans. In 1989 the Medicare hospice benefit was extended to nursing home residents. Hospice has since been added to usual nursing home care for 5.6% of deaths in long-term care facilities.[20] The site of death and use of hospice care varies by state. Oregon, after its highly publicized debate on assisted suicide legislation, has achieved the highest rate of hospice enrollment in the nation (31% of all deaths), and is able to provide terminal care at home for 42% of its citizens who die. North Carolinians' healthcare experiences at the end of life are very similar to the majority of decedents in the nation (See Table 1).

Table 1.
Site of Death in North Carolina, 2001

	NC	US
Site of death		
Hospital	54%	49%
Nursing home	22%	24%
Home	25%	23%
With Hospice	21%	19%

As the population ages, and as economic pressures cause reduced hospital lengths of stay, nursing homes are becoming a more common site of death. Data from the National Mortality Followback Survey, a representative sample of United States deaths in 1986 and 1993, show that the proportion of deaths that occur in hospitals decreased from 65% to 56%, while the proportion of deaths in nursing homes increased from 17% to 19%. By helping frail elders receive treatment and supportive care outside of hospitals, community-based, integrated elder-care programs such as the Programs of All-Inclusive Care for the Elderly (PACE)[22] can result in increased use of nursing homes (34%) and private homes (45%) as sites of death.[23] The availability of services within one's local health system, including readily available hospital beds, nursing home beds, and hospice services are likely to influence where people die, perhaps more than their own preferences about site of terminal care.[24,25]

How Do Patients and Families Define a Good Death?

Most medical treatments are judged to be effective if they are proven to prolong life or to reduce the risk of adverse health events or functional impairments. Good end-of-life care can only be defined by its ability to promote a "good death," or good dying experience for patients. As the potential for medical treatment to improve function and survival diminishes, patient- and family-centered outcomes become paramount. An expert consensus panel convened by the national Institute of Medicine has defined a good death as "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."[15]

Several well-designed studies explore domains defined as important to seriously ill and dying patients and their professional and family caregivers (See Table 2).[26,27,28,29,30,31] Dying patients and those who provide their care consistently value: (a) relief from pain and other physical symptoms, (b) attention to emotional, psychological, and spiritual needs, (c) compassionate communication, (d) involvement in critical healthcare decisions, (e) affirmation of personhood and dignity, (f) support for family caregivers, and (g) coordination and continuity of care.[32,33]

Innovations in End-of-Life Care

Public demand for appropriate care at the end of life emerged in the controversy surrounding dramatic "right-to-die" court cases. It has been fuelled by the debate over assisted suicide, and by descriptive studies of pain and suffering experienced by dying patients and their families. These problems are well defined, and new approaches to the delivery of medical care to seriously ill and dying patients are beginning to improve care.

Strategies to improve end-of-life care can be conceived as targeted or comprehensive interventions. Targeted interventions

Table 2.
Patient and Caregiver Perceptions of Quality in End-of-Life Care

Study Population	How do patients, family, and healthcare providers define a "good death"?
N = 126 chronically ill patients (Singer, 1999)	Receiving adequate pain and symptom management Avoiding inappropriate prolongation of dying Achieving a sense of control Relieving burden on loved ones Strengthening relationships
N = 137 chronically ill patients, family members, and healthcare providers (Curtis, 2001)	Physician access and continuity Team coordination Communication with patients Patient education Inclusion of family Medical competence Pain and symptom management Emotional support Personalization Attention to patient values Respect and humility Support of patient decision making
N = 75 healthcare providers, patients, and family caregivers (Steinhauser, 2000)	Pain and symptom management Clear decision making Preparation for death Completion of spiritual or meaningful final tasks Contribution to others Affirmation of the whole person

are designed to influence one aspect of the dying experience. Examples could include programs to improve physician communication skills, to implement pain management protocols, or to provide grief counselling for parents of dying children. Comprehensive clinical services such as hospice or palliative care units are designed to improve the overall quality of care for dying patients and their families. These comprehensive services typically include healthcare providers who can address a wide range of communication and symptom management needs for dying patients and their families.

Making Advance Directives Work

Given evidence that patients and families were dissatisfied with current end-of-life care, concerned clinicians and bioethicists reasoned that increasing patient control over major clinical decisions would result in more appropriate forms of treatment. Advance directive documents emerged, in which a patient gave prior direction about who could make decisions on his or her behalf (Healthcare Power of Attorney) and how life-sustaining treatments were to be used in the event of terminal or incurable illness (Living Will). Research on advance directives has shown that education and provision of advance directive forms can increase documentation of patient preferences. Patients generally welcome these conversations, and many are willing to record their wishes in some form.

Unfortunately, advance directives may be necessary but not sufficient to change the experience of care at the end of life. Living wills and other advance directive documents have not had a significant impact on the medical care received by dying patients.[34] In 1995, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment randomized seriously ill patients with limited life expectancy to a nurse-facilitated, written communication of prognosis and treatment preferences. The aim of the intervention was to inform and facilitate decision-making by patients and physicians. This intervention, like similar smaller studies, had no impact on pain treatment, life-sustaining treatment use, or cost of care.[35] Advance directives have the potential to promote communication among patient, family, and provider, but are not sufficient to change care at the end of life.

In retrospect, it is not surprising that advance directives alone are not sufficiently powerful to change care at the end of life. These documents may not be immediately available when patients become acutely ill and are unable to speak for themselves. Living wills are subject to interpretation and may be difficult to apply to specific clinical circumstances. Is a patient with advanced Alzheimer's and a hip fracture "terminally ill"? Is the treatment of pneumonia in a patient with end-stage cancer "life-sustaining treatment"? Another limitation is that traditional advance directives focus on withholding or withdrawing treatments, rather than a positive choice for an overall plan of care.

Advance directive documents are most useful when they serve as an invitation to conversations about patients' real concerns and values, goals of treatment, and a plan of care serving those goals. Some newer advance directives promote more comprehensive advance care planning. One example, The Medical Directive, requires a median time of 14 minutes to discuss, and allows the physician and patient to cover a broad range of health scenarios and treatment options.[36] In the mid-1990s Oregon adopted a portable physician order form which promotes discussion of preferences for resuscitation, overall level of medical treatment, and use of antibiotics, feeding tubes, and intravenous fluids. The form, Physician Orders for Life-Sustaining Treatment (POLST), is a physician order that is portable between healthcare sites.[37] The POLST has been widely accepted in Oregon, and evaluations suggest that it lowers the use of life-sustaining treatments and hospital admission among nursing home residents. A randomized controlled trial of a similar comprehensive advance directive in six Ontario nursing homes had a marked effect on hospital use and cost of treatment at the end of life.[38]

Improving Communication

Meaningful and compassionate communication is the core skill in end-of-life care. Absent this skill, physicians will be unable to help patients decide on appropriate treatments, assess physical symptoms, or address emotional and spiritual suffering. Patients facing the crisis of their own mortality require time to express fears and to seek reassurance of continuing physician attention to their spiritual and emotional needs, in addition to medical aspects of their care.

Family perspectives on the quality of the dying experience are independently important. While the patient lives, physicians must be skilled in communication with family members who make decisions for incapacitated patients, and serve as physical and emotional caregivers. Although they may not accurately represent patient treatment preferences or symptoms, family members are the ethical surrogate for incapable patients, and they will evaluate the quality of care after the patient's death.[39,40] In one study of recently bereaved family members in North Carolina, their most common recommendation for improved care at the end of life was to improve physician communication skills.[17] Their recommendations emphasized the need for communication beyond medical treatment choices, including a desire to talk more about prognosis, and about the humanity and dignity of the patient.

Communication of prognosis is essential if patients and families are to participate in informed decision-making. Prognostic models are accurate for populations, but challenging to communicate to individual patients. In the SUPPORT study population, a patient with a 50% chance of living two weeks also had a 20% chance of living six months.[41] Physicians and patients alike respond to prognostic information with optimism born of hope for survival. Physicians systematically overestimate their patients' life expectancies, and communicate even more optimistic data than they believe.[42] Patients who have cancer and an average life expectancy of six months will nearly all expect to live longer than six months.[43]

Compassionate communication about prognosis seeks to balance optimism with a gentle respect for patients' right to know the truth about their illness. Probabilities are confusing, but physicians can often tell patients whether life expectancy is measured in days to weeks, weeks to months, or months to a year or two. Patients and physicians can travel a careful middle ground together, where they "hope for the best, and prepare for the worst."[44] Prognosis is not simply a question of communicating life expectancy. Patients and family members also need information about what is likely to happen during the dying experience. Their ability to understand and anticipate the natural history of disease, its symptoms, and possible treatments will allow time for practical and spiritual preparation for more serious illness or death. It may also relieve unspoken fears.

Physician training includes little experiential learning about these essential communication skills. However, physicians who have worked to become expert in this aspect of medical practice are demonstrably more capable of comprehensive, patient-centered communication. This communication can be accomplished even within the time constraints of an office visit.[45] Experts in end-of-life communication have published useful examples of the words and approaches they use to promote continued practice of this vital skill.[44,46,47,48,49,50] Innovative continuing education programs that expand didactic education to include experiential learning techniques have a positive effect on physicians' communication skills.[51,52]

Communication about end-of-life treatment decisions may also be improved using ethics consultations for intensive care unit (ICU) patients. In a multi-site randomized controlled trial, ethics consultants led family meetings when value-laden treatment decisions were imminent. These consultations result in high levels of satisfaction, reduced use of life-sustaining treatment and ICU days, and yet had no adverse effect on the length of patient survival.[53,54]

Individualizing Care for Diverse Populations

End-of-life care varies for patients of minority, ethnic, and cultural backgrounds. Terminally ill African-American or Hispanic patients are less likely to receive effective pain treatment or to enroll in hospice than their white counterparts, and are more likely to die in hospitals.[55, 56] Physicians seeking to provide excellent care for dying patients must consider whether these differences in treatment are driven by patient values, or by failed access to or understanding of treatment options. Knowing that African-American patients generally enroll less often in hospice should not lead physicians to assume an individual patient's preference, but it may allow for more sensitivity in discussions of treatment decisions.

Patient characteristics such as education, race, and cultural or religious background may also influence values about patient and family involvement in medical treatment decisions. For example, traditional Navajos may perceive that speaking of potential bad outcomes may cause them to occur; a value quite distinct from a Western European emphasis on truth telling.[57] Patients from some cultural traditions, including African American, Hispanic, and some Asian countries, may place a greater emphasis on the importance of family involvement in medical treatment decisions even when the patient is capable of making his or her own choices.[58] Use of written advance directives and orders to limit life-sustaining treatment vary by patient insurance status, educational attainment, and racial background.[59,60] Dying patients and their caregivers desire spiritual care, and this aspect may engender particular concern among patients from minority, ethnic, or religious backgrounds.[61] Spiritual care, when available for dying patients and their families, needs to be consistent with individual faith traditions and cultural expression of spiritual practices.[62] Understanding these patterns of historical differences may allow for more nuanced communication with patients who do not share the physician's cultural heritage.[63]

Comprehensive Strategies: Hospice

Palliative care is comprehensive, interdisciplinary care designed to promote quality of life for patients and families living with a terminal or incurable illness. Hospice agencies, modelled on the inpatient treatment approach pioneered by Dame Cicely Saunders in Britain, have delivered palliative care in private homes in the United States since the creation of the Medicare hospice benefit in the 1980s. In 1989 Medicare expanded this benefit to nursing home residents, and hospice is now offered under most state Medicaid programs and many forms of private health insurance.

Patients are eligible for hospice if a physician certifies that they have a life expectancy of six months or less "if the disease follows its expected course." Patients are also expected to agree to forgo "curative treatment for their terminal illness." Patients with uncertain disease trajectories may find it difficult to meet the six-month criterion, although non-cancer diagnoses are increasingly represented within the hospice population. For many diseases, curative and palliative treatments overlap and access to specific treatments may vary by provider. For example, patients with cancer may or may not be able to continue transfusions for anemia and patients with chronic obstructive pulmonary disease (COPD) may or may not be able to continue intravenous antibiotics for pneumonia.

For patients who can qualify, hospice improves satisfaction with end-of-life care. After death, family caregivers rate hospice services more positively than any other aspect of terminal care.[5,17] In early studies, hospice inpatient units showed improved satisfaction despite modest impact on symptom scores.[64,65] In nursing homes, family caregivers believe that adding hospice care improves the quality of care for physical symptoms and emotional needs.[66] Comparison of nursing home decedents who do or do not receive hospice care shows increased use of pain medication and decreased use of tube feeding and hospitalization for those enrolled in hospice.[67] Hospice delivered in private homes can reduce the total cost of care for younger patients and those who die from cancer, but not for other dying patients.[68]

Many patients who might benefit from palliative care do not currently access hospice, or do so within only days of death. The length of stay in hospice has slowly decreased over the past decade. Patients may deny they are nearing death, or have an uncertain trajectory of illness that does not fit the six-month criterion. They may be unwilling to forego treatments, such as palliative radiation, that are prohibitively costly to include in the hospice per diem payment. Many individuals may face terrible pain and suffering, but have a cultural or personal imperative to "fight until the end." Hospices and other healthcare organizations are creating newer forms of palliative care services to match the needs of these patients.

Comprehensive Strategies: Palliative Care Programs

New model palliative care programs have increased significantly during the past decade, in response to needs for palliative care outside the traditional hospice enrollment population. Palliative care programs may be affiliated with an acute care hospital, a hospice agency, or with innovative elder care services that provide a continuum of health services.[69]

The number of physicians seeking palliative care certification is rising rapidly. The American Board of Hospice and Palliative Medicine incorporated in 1995, and began administration of its board exam in 1996. By August 2003, there were 43 active or emerging United States fellowships in Palliative Medicine, and over 1,200 physicians have met qualifications for certification in this field.[70]

Seventeen percent of United States hospitals currently house a palliative care service. Unlike hospice, palliative care programs do not yet offer a standardized array of clinical services. Hospital-based palliative care may include a variety of healthcare providers who offer inpatient consultation, outpatient consultation, dedicated inpatient beds, or bereavement programs for families. For example, the Pain and Symptom Care Program at UNC Hospitals, initiated in 2001, now provides inpatient care on 23 different hospital units. Using a consultation model, this interdisciplinary service reaches a diverse patient population; half are under age 65, one-third are African American, and one-third have terminal illnesses other than advanced cancer. Patients' average ratings of pain and other symptoms improve, and 80% of patients and families receive counselling about end-of-life issues.

Table 3.
Internet Resources for Palliative Care

Organization	Website
American Academy of Hospice and Palliative Medicine	www.aahpm.org
American Board of Hospice and Palliative Medicine	www.abhpm.org
Carolinas Center for Hospice and End-of-Life Care	www.carolinasendoflife.org
Center for the Advancement of Palliative Care	www.capc.org
Duke Institute on Care at the End of Life	www.iceol.duke.edu
End-of-Life Palliative Education Resource Center	www.eperc.mcw.edu
Last Acts Partnership	www.lastacts.org
Midwest Bioethics Center	www.midbio.org
National Hospice and Palliative Care Organization	www.nhpco.org
National Resource Center on Diversity in End-of-Life Care	www.nrcd.com

Because palliative care programs are changing rapidly and are not yet standardized, studies of its impact on care quality and cost are just beginning. One systematic review of 16 relatively well-established services found that these hospital-based inpatient services improved family satisfaction, reduced symptoms of distress, and decreased the intensity or cost of inpatient services for the patients they serve.[71] Like many labor-intensive healthcare services that do not emphasize procedures, palliative care is valued for its ability to reduce costs while improving quality of care.

Conclusion

For several decades, the medical literature has been filled with evidence of shortcomings in end-of-life care. Patients who have acquired the disease that will cause their death receive the same approach to medical care in early and advanced stages of incurable disease. Physicians fail to discuss prognosis, and patients retain hope for cure rather than hope for comfort and quality of life during their remaining days. In recent years palliative care practice and research have stimulated new programs and new clinical approaches to the care of dying patients and their families. Hospice, long the only repository of expertise in palliative care, is now joined by physicians, nurses, and other healthcare providers who have made a career commitment to excellence in healthcare for patients in the final phase of life. **NCMJ**

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Hospice:
A Vital Service Facing Increasing Demands

Judith Lund Person, MPH

Introduction

For three decades hospice providers in the United States have been changing the care for dying Americans and their families by providing options and choices that enable patients to be in control of their care at the end of life. Yet, hospice faces a number of challenges. The healthcare landscape is changing along with the demographic profile of the nation. In order to meet present and future challenges relating to end-of-life care, it is imperative that hospices build on the successes of the past and carefully listen to the needs of the changing populations served.

The Care Americans Want

The hospice movement in the United States can be traced back to the work of Dame Cicely Saunders at St Christopher's Hospice in the United Kingdom. Hospice care in America grew out of the need for more compassionate care for dying persons. In the American paradigm, hospice is not a place, but an interdisciplinary offering of palliative and support services that allows the terminally ill to be cared for primarily at home. 'Home' is defined by the patient, this may be: the patient's own home, the home of a loved one, an assisted living facility, a long-term care facility, or a hospice residence. The care that the hospice provides reflects the specific care that is in demand. Nearly 90% of adults reported that they would prefer to be cared for in their own or a family member's home if they were terminally ill and had six months or less to live.[1]

Many studies[1-4,23] have documented that when considering issues of death and dying, the American public's chief priorities and concerns include:

- home-based care;
- patient control and choice about the services available to them;
- emotional and spiritual support for patients and families;
- pain control customized to the patients wishes; and
- freedom from financial worry.

In 1982, Congress voted to support the Medicare Hospice Benefit (MHB). In providing a government funding mechanism, Congress established an all-inclusive benefit for hospice that has enabled millions of Americans to receive quality end-of-life care. More than 96% of hospices in the United States are Medicare-certified and just over 80.9% of patients claimed Medicare as their payment source in 2002.[5] Most private insurance plans, health maintenance organizations, managed care providers, and Medicaid in the majority of states also cover hospice services.

The Nation's Demographics Are Changing

Availability of hospice and palliative care is a critical issue as many more Americans begin dealing with end-of-life care decisions, for themselves and older family members. The aging post-World War II generation is bringing on a significant demographic shift that is unprecedented. The elderly population in the United States is expected to double between 2000 and 2030. By 2030, there will be approximately 70 million Americans over the age of 65. The proportion of the elderly falling into the 85 years of age and older category is increasing. This group is expected to increase from 4.2 million in 2000 to 8.9 million in 2030. Never have the chances of reaching 100 years of age been better. It is estimated that more than 72,000 people in the United States are over 100 and by 2050 that number is expected to be 834,000.[7]

As our population ages and life expectancy increases, more sophisticated and costly medical interventions will be required to provide for the nation's healthcare needs. More people will live with long-term illness that requires significant care. The number of deaths will also increase. In 2001, 2.4 million people died in the United States from all causes. The National Center for Health Statistics estimates that the number of deaths per year will grow at such a rate that in 57 years, the number will be almost 5.7 million people annually.[7] These statistics demonstrate a need to prepare for a patient base that is already changing. In order to adequately provide care, access to hospice and palliative care must expand and capacity must increase. An

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understanding of how hospice has successfully served the dying in the past will provide a foundation for future care.

Three Decades of Growth

By virtually any measure, the system of hospice care provided in the United States has been successful. One of the most dramatic measures of success has been the growth in beneficiaries. In 1975, there were 1,000 hospice admissions in the United States. By 2002, that number had grown to 885,000 annually. Over 95% of hospice patient visits are for routine home level of care reflecting Americans' preference to be in a home environment at the end of life.[6]

Today's hospice must address a broader range of terminal disease states and a wider range of palliative care services.[10] Hospice providers in the mid-1970s primarily served cancer patients, and the demographic profile of the patient population was almost entirely white and middle-class.[9] By 2002, cancer patients accounted for 50.5% of admissions. Hospices are also serving patients with end-stage heart, kidney and liver disease, along with dementia, lung disease, and other conditions (see Table 1).[8] America's hospices have taken a leadership role in the care of patients with HIV/AIDS as well.

Treatments such as chemotherapy and radiation, traditionally associated with curative care, are being increasingly used in hospice for pain and symptom management. In fact, advances in medical practice and technology for palliative, end-of-life care have prompted a significant increase in the intensity and frequency of services delivered to the hospice patient.[11] Outreach and increased access for diverse populations is also necessary. In 2002, 9.2% of hospice patients were African-American, 4.3% were Hispanic or Latino, 8% were Asian or Hawaiian/Pacific Islander, and 3.7% were classified as multiracial or 'another race.'[8]

Table 1.
Hospice Deaths in the United States, 2002

Diagnosis at admission	2002
Cancer	50.5%
End-stage heart disease	10.7%
Dementia	8.3%
Lung disease	6.7%
End-stage kidney disease	3.0%
End-stage liver disease	1.6%

More Americans Could Benefit from Hospice

Statistics suggest that more terminally ill Americans could gain access to the benefits of hospice. The United States General Accounting Office reported in 2000 that, while more beneficiaries are choosing hospice, many are doing so closer to the time of death. Half of Medicare hospice users are enrolled for 19 or fewer days, and service periods of one week or less are common. This study and other reports attribute this phenomenon to a variety of factors, including physician practices, patient preferences, concerns about compliance with Medicare eligibility requirements, and lack of awareness of the MHB among both the public and professionals.[12] A closer look at the trend toward shorter hospice service periods shows that the average length of service (ALOS) in hospice has declined dramatically since the initial Medicare demonstration project of 1983. The median length of service (MLOS) illustrates the effect of enrollments taking place days before death, and in 2002, 34.7% of those served died in seven days or less.[8]

The trend toward shorter lengths of service, combined with the greater intensity of today's hospice services, is also creating severe financial pressures for hospice providers. The government's original reimbursement mechanism under the MHB assumed a 70-day average length of service, with a per-patient, per-day rate that spread total cost over that 70-day period. With the drop in ALOS, hospices have a shorter period of patient stability over which to spread the high front-end and back-end costs that are unavoidable with hospice care.[11]

Cost of Care

A 1994 Lewin-VHI study found that Medicare saved $1.52 in Medicare Part A and Part B expenditures for every dollar it spent on hospice. That 1995 study also showed that in the last month of life, per-patient savings totaled $3,192, "as hospice home care days often substituted for expensive hospitalizations."[13]

Other more recent studies suggest that the use of hospice and advance directives saves up to 10% in the last year of life, 10% to 17% in the last six months of life, and 25% to 40% in the patient's last month.[9] The dollar value of such savings is dramatic when one considers the staggering costs that can result from efforts to extend life futilely through hospitalization in an intensive care unit (ICU). It has been estimated that the cost of caring for certain categories of cancer patients in an ICU can range from $95,000 to as much as $450,000 per patient for each year of life gained.[13]

Methods of reimbursement for services that are outside current hospice reimbursement streams must be explored and developed. Providers should not depend on the Medicare Hospice Benefit as the only source of reimbursement. Alternative funding sources include foundation grants, research projects, physician fellowships, charitable contributions, and institutional subsidies. These must all be aggressively explored. Providers must think beyond billing income to cover costs of care and operation.[22]

The cost of caring for the terminally ill is a critically important public policy issue, given the fact that one third of all federal Medicare dollars are spent on patients who are dying.[14] However, increasing hospice referrals is not just an economic measure. Hospice provides compassionate, high-quality care with consistently high patient approval ratings. [15,16]

Public Policy Changes

Congress has recognized the need to improve access and care through adjustments to the Medicare Hospice Benefit. While recent legislative changes may not address all the concerns related to access and capacity, they should prove beneficial. In

December 2003, Congress approved a far-ranging package of Medicare reforms, the Medicare Modernization Act of 2003.

There are a number of provisions designed to improve access and make hospice care more available to patients and families earlier in their illnesses. These include an educational consult for patients who would be appropriate for hospice care but have not yet been referred, the ability for hospices to contract for core or specialized services, a provision for nurse practitioners not employed by hospice to continue caring for patients under hospice, and a rural hospice demonstration project to evaluate care delivery.

Demonstration Projects

Additional methods to improve access, capacity, and ensure financial viability could be identified through national and community demonstration projects. Demonstrations that could lift current reimbursement guidelines, offset patients with very short stays, or examine how hospice patients could benefit from higher cost treatments would provide data that would potentially improve access to care for all. Projects that explore ways in which service providers can combine hospice and disease-modifying therapies at the same time must also be examined. There has also been much debate regarding Medicare eligibility requirements—currently, a physician must certify that a patient could die within six months if the terminal illness follows its expected course. Eligibility has often been confused with limits in length of service. A better understanding of how this has become a real and perceived barrier to care should be researched, ultimately leading to improved public and professional outreach and engagement.

Public and Professional Education

Another recognized barrier to greater public education about hospice is the character of American society, with its emphasis on youth, curative treatment, and the reversal of aging.[17] While not everyone with a terminal illness may be receptive to hospice, research suggests that most Americans—including physicians—are not sufficiently educated about hospice to make an informed choice. Also, within the physician community, studies indicate an aversion to the open discussion of death with patients and a lack of medical education about end-of-life issues.[3,18,19,21] An article in the *American Journal of Hospice & Palliative Care* reported that physicians often withhold the truth of a terminal diagnosis from their patients, resulting in the patient not realizing that death is likely until the last month of life.[20]

The national Institute of Medicine published a 1997 study, *Approaching Death: Improving Care at the End of Life*, that reported "the education and training of physicians and other healthcare professionals fail to provide them the attitudes, knowledge and skills required to care well for the dying patient."[9]

Hospital-Hospice-Palliative Care Partnerships

Important opportunities for hospice providers and hospitals in the United States can be found in hospital-hospice partnerships. A report released by the National Hospice and Pallative Care Organization (NHPCO) and the Center to Advance Palliative Care, *Hospital-Hospice Partnerships in Palliative Care*,[19] explores the relationship between hospitals and hospices that actively collaborate in providing appropriate care. The report indicates that partnerships tend to move in two directions. First, an enhanced utilization of the Medicare Hospice Benefit is seen as closer relationships between the hospice and hospital develop. Also, education surrounding hospice care, the creation of in-patient units, and reduction in barriers to hospice admission are documented.

The second trend is the development of palliative care services. In April 2004, the Clinical Practice Guidelines for Quality Palliative Care[24] were released by the National Consensus Project, a consortium of five national organizations in the field intensely interested in improving care for patients and their families at the end of life. The consortium includes the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, Last Acts Partnership, and the National Hospice and Palliative Care Organization. These Guidelines describe core precepts and structures of clinical palliative care programs and are the culmination of more than two years of work. They provide guidance for the assessment and treatment of pain and other symptoms; help with patient-centered communication and decision-making; and coordination of care across settings and through serious illness and are written for any healthcare provider who is interested in a developing palliative care program. More information on these guidelines can be found at www.nationalconsensusproject.org.

> *"Nearly 90% of adults reported that they would prefer to be cared for in their own or a family member's home if they were terminally ill and had six months or less to live."*

Building on What Works

The success of hospice is well documented, yet ongoing challenges in the field are recognized. End-of-life care providers must respond and adapt to the changing environment. The general public has an awareness of hospice, but the vast majority of people lack the specific understanding and knowledge to gain full access to hospice benefits. Physicians are also reluctant to discuss the specifics of death with their patients, and they lack the comprehensive medical education in end-of-life care that would lead to more referrals (and earlier referrals) to hospice. Changing demographics will greatly impact the number of Americans who must be served and the care that must be provided at the end of life.

It is critical that hospice and palliative care providers take their full knowledge and expertise regarding care at the end of life and make it available further upstream, reaching more Americans much earlier in the course of a life-limiting illness. The hospice philosophy of care should be utilized to help patients make the transition from more aggressive therapies to holistic palliative care services. Increasingly, hospitals and critical care units are using the skills of palliative care to more appropriately serve patients in their care.

The National Hospice and Palliative Care Organization (NHPCO) is the oldest and largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. The NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their families.

More information is available at www.nhpco.org. **NCMJ**

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Palliative Care:
More than Just Care from a Friendly Relative

Richard C. Stephenson, MD

Overview

A well-meaning board member of a large home health and hospice organization once shared that he thought palliative care must mean, "care from a friendly relative." While half-heartedly playing on the words "pal" and "relative," he was not far from the truth. From a literary point of view, palliative care means care intended to "cloak" symptoms as opposed to curing disease. But most imagine it to be just comfort care only, very supportive and very hospice-like.

For more than a decade, the World Health Organization (WHO) has defined palliative care as active total care of patients not responsive to curative treatment where control of pain and other symptoms and of psychological social and spiritual problems is paramount and the goal is the best possible quality of life for patients and their families. More recently, Diane Meier, at the Center to Advance Palliative Care and others have shied away from this concept of switching from curative to palliative and embraced a concept of palliative care as interdisciplinary care that aims to relieve suffering and improve the quality of life for patients with advanced illness and their families, *offered simultaneously with all other appropriate medical treatment.*[1] From this point of view, palliative care may be present from the time of intensive care unit (ICU) admission, help manage the transition as curative therapies fail, and become the predominant mode of care as terminal illness becomes apparent.

In this issue of the Journal, Laura Hanson has done an excellent job of reviewing existing shortcomings in end-of-life care. She has also reviewed comprehensive strategies such as hospice and palliative care to address these problems and innovations to make advance directives work and other strategies to improve communication and access.[2]

In fact, palliative care may be one of the most rapidly developing service lines in United States hospitals. As Dr. Hanson points out, almost one in five hospitals now has a palliative care service and many more have plans to create them. More than 1,500 physicians are now certified in Hospice and Palliative Medicine.[3] The specialty is in the process of becoming certified by the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME). Palliative care fellowship programs are rapidly developing to meet these growing needs. Existing palliative care and hospice programs have created a more extensive body of evidence-based literature in palliative medicine and achievable, meaningful outcomes are being realized within committed institutions.

All of this must sound very exciting and academic! But from a much more practical point of view, does your institution need palliative care? What can a palliative care service actually do for you? And if you want one, how can you develop one? Many concerned healthcare providers, hospitals, and hospices are asking these same questions. Fortunately, there are tremendous resources available through the Center to Advance Palliative Care (CAPC), a national initiative supported by the Robert Wood Johnson Foundation with direction and technical assistance provided by the Mount Sinai School of Medicine.

The Center to Advance Palliative Care[4]

Diane Meier, Director of CAPC, and staff have created a wide variety of resources to assist institutions with the entire process of developing palliative care services from needs assessment to sustaining and growing existing programs. Resources include conferences, website, monographs, and leadership centers available for site visits and ongoing mentoring. These leadership centers include a variety of settings where palliative care has developed and flourished, i.e., academic medical centers, private hospitals, healthcare systems, and home health and hospice organizations. The process begins with building a case specific to the institution including needs assessment, securing support and financial considerations. While there are formulas that are specific and data driven, it is far from a "cookbook" approach. The CAPC process goes on to help design a program specific

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"Palliative care services provide 'specialized care through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services.'"

to the institution, develop a business plan, implement services, measure quality and impact, and even market the program.

Critical to the success of the CAPC process is the development of a core team, which includes a medical staff leader, nursing leader, hospice representative, and an administrative champion. CAPC is quick to point out that this is an ideal opportunity for hospital/hospice collaboration.

Is this a formula for guaranteed success? Of course not, but generally expected and accepted, evidence-based outcomes include reduction in symptom burden, improved patient and family satisfaction, and reduced costs. Other highly likely outcomes, but less evidence-based, suggest care concordant with patient/family wishes, patient/family/professional consensus on the goals of care, and improved continuity of care.[5]

Local Hospital-based Palliative Care Initiatives

Forsyth County, North Carolina, demonstrates two distinctly different approaches to palliative care programs developed with local initiative, but also tutored by CAPC programs. The local area hospice, a private, independent not-for-profit hospice and home health organization enjoys a longstanding, collaborative relationship with both the academic medical center and the large tertiary care private hospital in Winston-Salem. The hospice owns and operates a 20-bed freestanding inpatient hospice facility, and has an average daily census of 260 patients at home, in nursing homes, and in the facility. Hospice employees include a full-time medical director, a second full-time physician, and a geriatric nurse practitioner.

Over the past five years, the hospice has embraced the concepts of palliative care. Central to their view of palliative care and mission, the hospice strives to improve the quality of care for patients and families facing life-limiting illness across the continuum of care, regardless of diagnosis, prognosis, or treatment.

During this same time period, both the academic medical center and the private hospital responded to needs within their institutions and began to consider the development of palliative care services. Of interest, their approaches were distinctly different if not frankly opposite. The private hospital quickly developed a palliative care unit, whereas the academic medical center conducted a detailed needs assessment and gradually developed a consult service. However, both engaged medical, nursing, and administrative leadership as well as the hospice to collaboratively develop these diverse approaches to meeting palliative care needs within the two institutions. Each has relied on hospice expertise and, under both circumstances, representatives have attended CAPC conferences and relied heavily on CAPC developed tools.

The Acute Palliative Care Unit (APCU) at Forsyth Medical Center (FMC)

Forsyth Medical Center has been a major supporter and referrer to the Kate B. Reynolds Hospice Home in Winston-Salem. Oncologists and hospitalists at FMC became concerned by the development of a waiting list for their patients in need of inpatient hospice referral. This led to the rapid development of the Acute Palliative Care Unit (APCU) to provide quality end-of-life care for hospitalized patients and their families. Hospital staff collaborated with hospice staff in planning, development, and implementation and attended CAPC conferences together. Tools for assessment and treatment were shared, and hospice staff continues to supply clinical expertise and medical direction.

The APCU admitted over 600 patients in 2003 and has achieved superlative results in family satisfaction, while simultaneously demonstrating significant cost savings once patients are transferred to the unit. Their data reflect a cost/day saving of over $1,800 once patients are transferred into their unit from elsewhere in the hospital. In addition, APCU is the focal point for improving end-of-life care in the hospital and provides leadership for quality initiatives surrounding pain and symptom management. In direct contrast to the academic medical center, FMC quickly developed a palliative care unit to meet the needs of patients, families, and physicians. FMC is now taking steps to formally develop a consult service to identify unmet palliative care needs for patients throughout the hospital. The APCU remains one of the major referral sources for the hospice home.

The Palliative Care Consult Service (PCCS) at Wake Forest University Baptist Medical Center (WFUBMC)

The academic medical center took a different approach to meeting palliative care needs within their institution. Not surprisingly, the approach began with a detailed needs assessment to support both the educational and clinical mission of the hospital. The

Figure 1.
Palliative Care Consults by Month at WFUBMC, July 1 - May 31, 2004 = 263 pts.

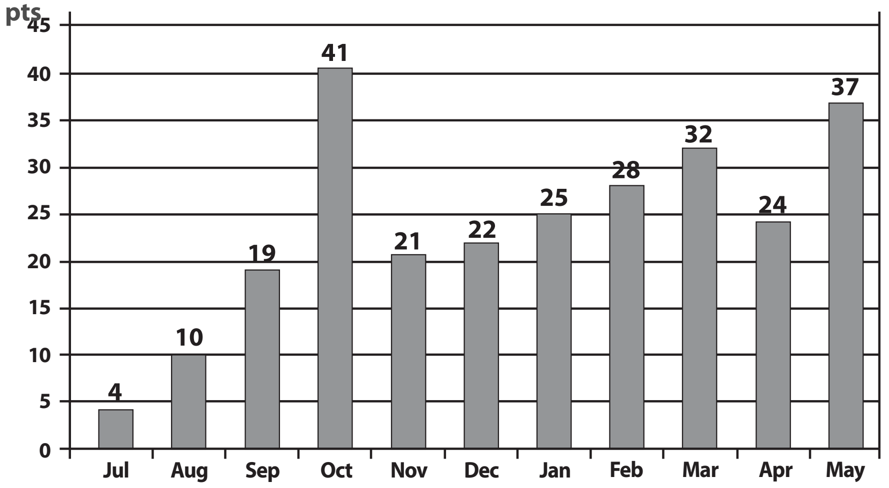


Figure 2.
Service Requesting Pallative Care Consult at WFUBMC

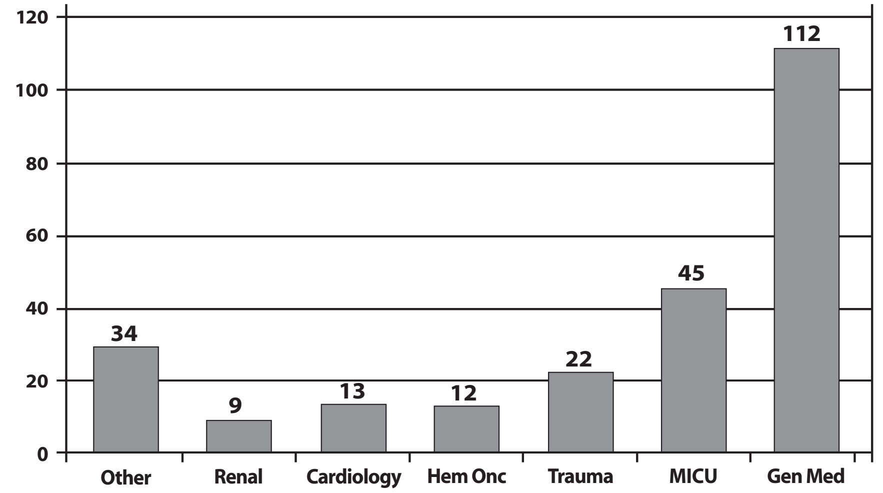
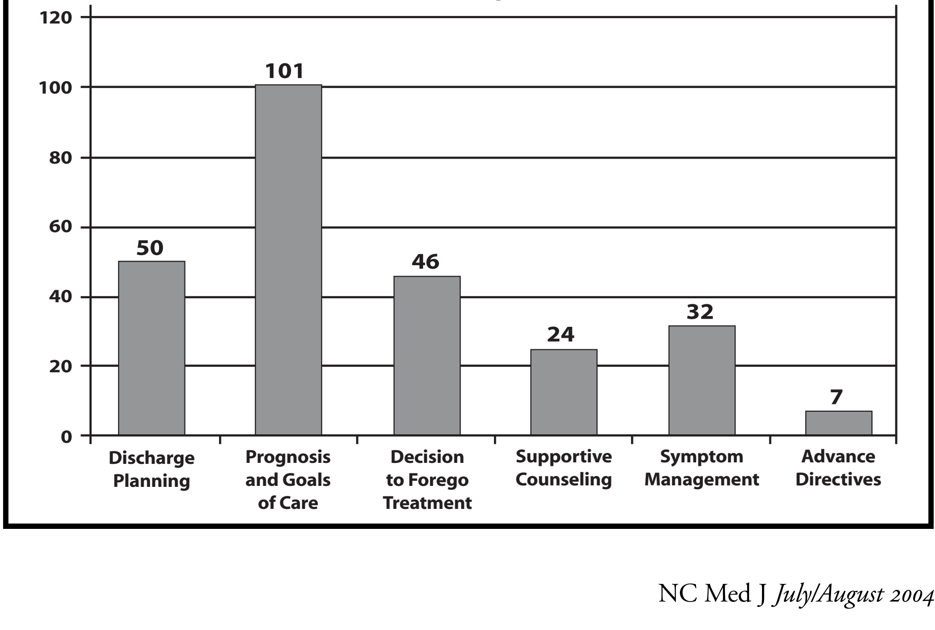


Figure 3.
Reasons Pallative Care Consults Were Requested at WFUBMC



needs assessment relied heavily on tools developed by CAPC, and medical center and hospice staff jointly attended CAPC conferences. A palliative care consult service began with voluntary attending support from the Department of Medicine and the hospice. While needs assessment progressed and administrative support was fostered, consultation progressed slowly. Within the last year, the PCCS at WFUBMC formally began with enthusiastic administrative support, including a full-time nurse coordinator and half-time support for medical direction outsourced to the hospice. Once a "face" became associated with the PCCS, the service has grown rapidly to capacity. Plans now include hiring a second nurse coordinator and additional physician resources as well as ultimate development of a palliative care unit.

The PCCS at WFUBMC demonstrates typical growth of a consult service in an academic medical center. Figure 1 demonstrates consults by month. Figure 2 shows the wide variety of services requesting palliative care consultation. While one might expect the general medical service to be the highest, it is clear that palliative care has become a regular part of ICU care. The most common reasons consultations are requested are shown in Figure 3. Communication issues such as establishing goals of care and understanding prognosis clearly lead the way. In fact, the most common interventions of the PCCS are not changes in symptom management, but family conferences. The PCCS has also demonstrated significant cost savings for WFUBMC through decreased length of stay and decreased ICU length of stay, as well as through more appropriate resource utilization. Recently an outside reviewer suggested cost savings based on the current number and type of consults per year will be at least $1 million and are more likely to approach $2 million.

Discussion

Palliative care is clearly more than "care from a friendly relative." Palliative care has unabashedly adapted and adopted principles of care firmly rooted in the hospice movement and applied them to patients with advanced illnesses and their families. Palliative care services provide "specialized care through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services."[1]

The long list of shortcomings in end-of-life care may seem daunting. With the rapid development of palliative care services across the country, it may seem like something hospitals *should* or *must* do. Indeed, developing standards from the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and other accrediting organizations may make it a "have to" in the near future. There is an old anonymous saying that suggests, "you can't do everything at once, but you must do something at once." As these two examples in Forsyth County demonstrate, it may not matter how you start, as long as you start.

There are individuals within every hospital and community who "want to" develop models and standards of care that could become palliative care services. It is important to find that core group of leaders and champions and start somewhere. A palliative care program will follow; the wheel need not be reinvented. It will become the standard of care and succeed in improving both end-of-life care and care for all seriously ill patients and their families. It may be wise to simply take a deep breath, a leap of faith, and follow the CAPC motto: "Just do it!" **NCMJ**

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COMMENTARY

Hospital-Based Palliative Care Units:
Answering a Growing Need

Anthony N. Galanos, MA, MD

The central question confronting healthcare professionals and institutions with regard to end-of-life and palliative care is: How do we relieve the suffering that patients and families experience as they struggle to know what to do with serious and possibly terminal illness when it occurs? How do they navigate a medical system that offers few options if cure is not possible, cannot prognosticate with any certainty, and does not allow for the natural ebb and flow of uncertainty in medical decision making? It would seem that "palliative care," with its attention to caring, as well as curing, and its comfort with aggressive, as well as hospice care, is the philosophy of care that can best assist patients and families as they traverse the continuum from diagnosis through symptoms and treatment to an eventual outcome that may include hospice and bereavement.

There are two ways to look at palliative care: it can be seen as the natural extension of where aggressive, cure-oriented conventional therapy ended, i.e., what do you do for people for whom no evidence-based cure or therapy is available? Or, secondly, palliative care can be conceptualized as hospice, but much further upstream. Indeed, hospice and palliative care are not mutually exclusive. Hospice is ultimate palliative care, but is defined by a time limit and regulations surrounding a Medicare benefit. Palliative care, by contrast, can begin at the time of diagnosis, or any point thereafter, when patients and families may have already begun to suffer secondary to physical symptoms, anxiety and uncertainty, and have needs outside of the traditional biomedical model of care. The clinical events that lead people into the hospital have no predetermined outcome, and there the sorting out process must begin.

As an illustration, Morrison and Meier[1] describe the case of an 85-year-old man with class IV heart failure, hypertension, and moderate Alzheimer's disease who is admitted to the hospital after a hip fracture. This is his fourth hospitalization in the past year and his 84-year-old wife feels overwhelmed by his medical and personal care needs. The question becomes what might his doctor do to address his needs, alleviate his suffering, and facilitate discharge from the hospital and subsequent care at home? While this patient may eventually choose hospice, it is his current dilemma, blossoming in the hospital, which creates the need for palliative care services.

Indeed, when problems with end-of-life care are described, reference is often made to situations that occur in the acute care hospital setting. Concomitantly, while place of death is shifting more and more away from the hospital, it still remains the most likely site of death for North Carolinians and for Americans in general. It is important to ask why the hospital is seen in such a negative light when one has a terminal illness and why there is a need for concentrated palliative care efforts in these facilities. Aren't hospitals the very places where high-quality care at the end of life would be expected?

Why the Focus on the Hospital in Discussions of Palliative Care?

Noting that as many as 50% of patients currently die in acute care hospitals, the Acute Care Hospital Working Group, one of eight working groups convened as the National Consensus Conference on Medical Education for Care Near the End of Life, delineated a host of barriers to good end-of-life care in the acute care hospital:

- Shorter lengths of stay; hence, health professionals being trained in these settings do not see the trajectory of end-stage illnesses and fail to appreciate the needs of dying patients.
- Multitude of specialist physicians, with no one seemingly responsible for the integration of care needs in a patient-centered way.
- Emphasis on the "great case" with an accent on the disease and technical procedures at the expense of the bigger picture of the impact of the illness on the patient and family.
- Subtle messages such as death as a medical failure and that physicians should not express personal emotions, and other negative attitudes about dying.

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- Lack of essential communication and symptom-control skills among supervising physicians.
- Few end-of-life educational resources available for health professionals.[2]

Why Should Hospitals Respond? And in What Ways?

Hospitals should respond because the people they serve and the people who work in them want a better response to incurable disease. Data from public opinion polls and the lay press are unequivocal. The majority of Americans (74%) expect their physicians to be confident and competent in providing them with care when they do develop a life-threatening illness.[4] The public expects that the problem of suffering has been addressed directly in medical education[5] and is not uniformly in favor of aggressive care at the expense of comfort and functional status. For example, an American Association of Retired Persons (AARP) *Modern Maturity* survey of people's attitudes about death and dying, based on 1,800 interviews of Americans 45 years of age and older found that the older you are, the less afraid you are of dying and being in pain at the end of life. In the overall sample, 71% of people believe there is a point at which costly health treatments should be stopped and the numbers were even higher among people in higher income brackets, with 77% of those who earn $50,000 or more a year agreeing that at some point aggressive treatments may do more harm than good.[6]

> *"Palliative care is not a way out, but a way* through, *and it allows patients to have hope and an opportunity to live as fully and functionally as they can for as long as they can. Hospitals are a place of miracles and cures, but when that can not be the outcome, we '...palliate often, and comfort always.' "*

Closer to home, the AARP North Carolina End-of-Life Care Survey[7] sampled AARP members age 50 and older and had a response rate of 45%. Of the end-of-life concerns, almost 90% say that total physical dependency would be worse than death, and 70% say that not being able to communicate their wishes or that living with great pain is worse than death. More than 90% had heard of hospice, though only a quarter were aware that Medicare pays for it. Among those who know about hospice, three-quarters reported they would want hospice support if they were dying.

In addition, the national Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*,[8] and policy statements from various clinical organizations, such as the American Board of Internal Medicine and the American Geriatrics Society[9,10] have advanced the argument that the public is better informed with regard to issues pertaining to end-of-life and palliative care through community organizations such as Project Compassion in Chapel Hill, North Carolina[11] or through media such as *Time* magazine,[12] the *Wall Street Journal*,[13] ABC's *NIGHTLINE* with Ted Koppel,[14] and National Public Radio.[15] One outcome of such public discussion of death, dying, and the relief of suffering is that hospitals are now being judged by their ability to provide palliative and or hospice services.[16,17,18] Ultimately, hospitals must listen to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which has issued a set of standards/guidelines regarding care at the end of life:

"The patient at or near the end of his or her life has the right to physical and psychological comfort. The hospital provides care that optimizes the dying patient's comfort and dignity and addresses the patient's and his or her family's psychosocial and spiritual needs... and staff is educated about the unique needs of dying patients, their families and caregivers."[19]

This last comment regarding "staff" is significant. Caregivers in the hospital need support and guidance as they care for patients for whom there is no cure. Nurses and physicians have voiced concerns over the lack of patient involvement in treatment decisions and the overuse of mechanical ventilation, dialysis, and resuscitation.[20] Our own research at a tertiary care teaching center has shown that among attending physicians, house officers, nurses, and family members, no two of these four groups saw the last week of life in the hospital in the same way, and levels of satisfaction differed among the four groups.[21] It behooves hospitals to provide better advice and support to those front-line professionals responsible for caring for the terminally ill. A palliative care team can provide the support needed for end-of-life care and aggressiveness of care.

How Should the Hospital Respond? Is the Hospital-based Palliative Care Team Part of the Answer?

In response to the 1998 American Hospital Association Survey, 30% of hospitals that responded to the survey reported having a hospital-based palliative care program with another 20% planning to establish one.[23] Palliative care programs have been based primarily in medical oncology or general medicine divisions and a consultation service was the most common clinical entity. Another report based on the same data concluded that, given the need, palliative care services were slow to be institutionalized in the hospital setting.[24] As Hanson concludes elsewhere in this issue of the *North Carolina Medical Journal*,[30] there are multiple models of palliative care services affiliated with hospitals and the process is "not yet standardized," but outcome data are now starting to build.[25,26]

The Essentials of Palliative Care

Palliative care, by definition, is an interdisciplinary team event. Depending on available resources, most palliative care teams have a nurse practitioner as the hub of the team to assure continuity of care. The nurse practitioner is backed up by an attending physician and, in some centers, a geriatric medicine or oncology fellow. It should be noted that there are roughly 43 active or emerging United States fellowships in palliative medicine and Duke University Medical Center will offer a program as of July 1, 2005.[25] Critical members of a palliative care team include a chaplain, a social worker, and rehabilitation specialists if increased function is needed for quality of life. In some cases, a psychiatrist may be needed to address issues such as depression and delirium if the team is not comfortable with the complexity of these issues at the end of life. It is not the composition of a palliative care team that is important, but rather that personnel with appropriate skills are available to meet the needs of a particular patient at a particular time in his/her continuum of care. The most important player on the team will vary by the patient and by patient need. "No man can be rendered pain free whilst he still wrestles with his faith. No man can come to terms with his God when every waking moment is taken up with pain or vomiting."[28]

Some potential roles of the clinical palliative care team include offering advice and support to the patient's caregiving team on symptom control and psychosocial and existential issues. This kind of support is clearly needed for the patient's family as well. Another role is educating hospital staff (pursuant to the JCAHO standard) and serving as a liaison between the hospital, hospice, or other facets of the continuum of care. This role would suggest that the palliative care team is present to reduce symptoms and suffering, to meet family and patient preferences, and to help negotiate goals of care. Meeting these needs should lead to improved patient and family satisfaction, as well as that of the hospital staff, while improving utilization of hospital resources, e.g., length of stay, number of intensive care unit (ICU) days, readmission rate, unnecessary emergency room use, and the timing and appropriateness of hospice referrals.

Institutions that have a designated geographic area and a defined palliative care unit have demonstrated incredible outcomes.[26] Having the designated area allows for total management of the patient, and for an atmosphere of enlightened patient-centered care. A step down from this level of care that still allows primary care of the patient, but does not entail a separate palliative care unit, is the "scatter-bed" model. In hospitals where beds may be at a premium, the "scatter-bed" model allows the palliative care team to take over the patient's primary care in the same bed that he or she was residing in at the time of initial consultation. In other words, when the palliative care consult team visits a patient in the hospital and finds that the needs of the patient can be better met by the palliative care team, then the patient will stay in that unit bed, but the primary care will be provided by the palliative care team. While it has its disadvantages, one clear advantage of the "scatter-bed" model is that multiple units in the hospital are exposed to and learn the fundamental principles of palliative care. In some arenas, primary care of patients may not be an option, so a "consult-only" service is the best mode of operation.

Whatever model of care is feasible at a particular institution, it is important not to approach the staff with an attitude of "we are here to show you how to do it, because you have been doing it poorly," but rather to provide added value to what is in place. Our experience has shown us that once nurses, chaplains, and physicians working on the unit understand the palliative care clinical team's role and purpose, they welcome our intervention and often participate with us in family meetings and discussions of care goals. While these activities clearly lead to better patient, family, and staff satisfaction, we are collecting data on cost savings to the institution. As in the example of the palliative care unit at Medical College of Virginia,[26] to collect data on patients that are matched on diagnosis and other variables, and then to compare cost and other data for those with and without palliative care intervention, can be a powerful argument to hospital administration and to those who may not be familiar with this type of care.

In essence what we have been talking about is that an either/or (cure or not) approach to medicine does not work for patients, families, and hospital staff. We can expand the options and choices of the people we serve by employing palliative care in the hospital. That way, we relieve suffering and change the

Sources Relevant to Initiating a Hospital-based Palliative Care Unit/Program

The Hospital and Healthsystem Association of Pennsylvania has expanded its Hospital-Based Palliative Care Consortium to serve hospitals nationwide and can be accessed via its website at http://www.hbpcc.org.The Center to Advance Palliative Care, a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine, has produced an outstanding monograph:"The Case for Hospital-Based Palliative Care," that outlines the rationale for starting such a program with an emphasis on data that would appeal to hospital administrators.[22] Readers are directed to the Center to Advance Palliative Care (CAPC) website where voluminous amounts of information are available, eg, "Palliative Care in Hospitals: Making the Case," www.capcmssm.org.

focus from the hospital, to the patient and those close to him or her. It is the patient and family who have come to the hospital for answers to their conundrum. In response, the hospital-based palliative care team does not emphasize what will be taken away, but what will be done *for* the patient and family despite a life threatening illness. Palliative care is not a way *out*, but a way *through*, and it allows patients to have hope and an opportunity to live as fully and functionally as they can for as long as they can. Hospitals are a place of miracles and cures, but when that can not be the outcome, we "...palliate often, and comfort always."[29] **NCMJ**

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COMMENTARY

A Brief Review of North Carolina's Law on Dying[1]

Anne Dellinger, JD, and Aimee Wall, JD, MPH[1]

Ten years after Oregon voters first approved the "Death with Dignity Act,"[2] contentious debate continues throughout the country regarding the legal and ethical issues surrounding end-of-life care, particularly on the issue of assisted suicide.[3] Just last year, the North Carolina General Assembly considered legislation proposing to criminalize assisted suicide.[4] The bill did not pass, but the issue is likely to arise in future legislative sessions. In considering how North Carolina should approach end-of-life issues, it is useful to review our state's current law and policy regarding life-sustaining treatment, euthanasia, suicide, assisted suicide, and pain relief. The summaries below are not intended to be comprehensive, but rather provide a basic overview of the legal environment surrounding each of these important issues.[5]

Life-Sustaining Treatment

Refusal, withholding, and withdrawal of life-sustaining treatment all are legal choices under federal and state law. A patient has long had the ability to express his or her wishes regarding life-sustaining treatment orally or in the form of a written document often referred to as an "advance directive" or "living will." Refusal of life-sustaining treatment and advance directives are governed primarily by state law, but the federal government has weighed in on a few important points. While not directly stating it, the United States Supreme Court seems to acknowledge that competent people have a constitutional right to refuse medical treatment.[6] Also, Congress recognized the concept of advance directives in 1991 when it enacted the Patient Self-Determination Act.[7] The law requires health facilities, as a condition of Medicare or Medicaid participation, to ask every patient about advance directives and to explain the options available under state law for creating them. The law does not require providers to comply with advance directives, but they must at least initiate conversations with patients about their wishes.

North Carolina's history of recognizing patient autonomy in end-of-life decisions goes back even further. The state enacted the Right to Natural Death Act[8] in 1978, not so much to create new rights related to advance directives as to recognize existing ones.[9] The law includes a form by which a person may express his or her preferences regarding extraordinary medical interventions, including artificial nutrition and hydration.[10] State law also permits residents to name an agent to make those decisions on their behalf in certain circumstances.[11] In 2001, the state enacted two laws related to patient autonomy. The first is a law that shields providers from liability if they withhold cardiopulmonary resuscitation from a person having a "portable do-not-resuscitate order" on a form developed or approved by the state.[12] The second is a law establishing a voluntary state registry for advance healthcare directives.[13]

Whether North Carolina doctors and hospitals or other facilities must carry out a patient's stated wishes is not settled. Some states require this by statute, subjecting noncompliant providers to criminal or civil penalties and/or professional disciplinary actions.[14] A North Carolina attorney general's opinion advises that a physician or a facility need not follow a patient's wishes or transfer the patient to caretakers who will. But the opinion also says that providers may be civilly liable for assault and battery if they force treatment on a patient.[15] The North Carolina Medical Board, on the other hand, states that "physicians are ethically obligated to follow the wishes of the terminally ill or incurable patient as expressed by and properly documented in a declaration of desire for a natural death" or transfer the patient to another physician's care.[16] Based on this statement, a physician could be subject to disciplinary action if he or she refuses to follow the patient's wishes and fails to transfer the patient.

Euthanasia

"Euthanasia" may be defined as "the intentional putting to death of a person with an incurable or painful disease intended as an act of mercy."[17] This act very likely is murder under North Carolina law. North Carolina's highest court has dealt very harshly with "mercy killing." For shooting his father in a

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hospital bed, a man was convicted of first-degree murder and received a mandatory life sentence, which was upheld on appeal. At trial the judge told the jury that they could infer malice[18] (though they did not have to do so) from the defendant's use of a deadly weapon, and further instructed that the defendant's knowing that his father was at the brink of death was not a defense (though they could consider that knowledge). Both instructions were challenged on appeal. The Supreme Court upheld them, but not unanimously. The chief justice urged a lesser sentence than that for first-degree murder because the son's intentions were good.[11]

Personally administering lethal medication to a patient could be first-degree murder, either as "murder by poison" or simply as deliberate and premeditated killing. Like the man who shot his father, a doctor or a nurse would likely not escape punishment because she or he meant to help the patient—not even if the patient had asked for death.

Suicide

"Suicide" is "the act or an instance of taking one's own life voluntarily and intentionally."[19] It is surprising how recently suicide and suicide attempts were crimes in this state. In fact, North Carolina was the last of the states to prosecute an attempt at suicide. In 1961 the state Supreme Court found the act criminal,[20] as it had been for centuries under the common law of England and was later in the American colonies and states. Because suicide was a crime, helping someone carry it out was as well.[21] In 1973 the North Carolina General Assembly abolished the crime of committing suicide and thereby, implicitly, the crime of attempting suicide. The status of providers' acts assisting patients to commit suicide is more complicated.

Assisted Suicide

A leading treatise on death and dying discusses at length what "assisted suicide" means and how it differs from euthanasia and homicide (if it does).[22] Much of the public and a significant minority of physicians do not distinguish meaningfully between assisted suicide and euthanasia.[23] Most people, however, continue to draw a moral distinction between responding affirmatively to "Help me kill myself" and responding affirmatively to "Kill me."[24] How to treat the two acts, and what constitutes each, are problems for all interested parties [patients, health providers, courts, district attorneys, health licensing boards, legislatures, the United States attorney general, and the Drug Enforcement Agency (DEA)]. For present purposes, though, a loose definition of "assisted suicide" may be helpful: it can be thought of as the act of providing a competent person with the means to take his or her own life.

In general, assisting someone in committing suicide is legal. That is, an ordinary person who hands a knife to a desperate stranger or holds a ladder for that person to reach a window ledge should have no legal problem. The situation can be more complicated if there is a special, legally recognized relationship between the helper and the person wanting to die. In certain relationships—such as parent and minor child or doctor and patient—one party is legally obligated to protect the other to some extent.[25] Based on the current state of the law, we simply do not know whether or when a healthcare provider in North Carolina will be seen as failing to protect a patient if she or he helps the patient die. In other words, we do not know whether a provider's decision to help a patient die will subject the provider to civil or criminal liability.

> *"Pain management is probably the most important of the end-of-life issues because of the effect of pain on dying people and the fear it engenders in nearly everyone who contemplates dying in the United States today."*

The means of assistance most often discussed is providing medication for a patient to administer to herself or himself.[26] As discussed above, Oregon law now authorizes a physician to prescribe a lethal dose of medication for a person suffering from a terminal disease if the person requests the prescription and certain other requirements are met.[27] This law came under attack recently when United States Attorney General John Ashcroft issued a directive explaining that assisting a person to commit suicide does not qualify as a "legitimate medical purpose" under the Controlled Substances Act (CSA) and therefore a physician who prescribes, dispenses, or administers a controlled substance for such a purpose would be in violation of federal law.[28] The attorney general directed the DEA to enforce the CSA in Oregon despite the existence of the state law authorizing such prescriptions. In May of this year, however, a federal court of appeals invalidated the attorney general's directive on the grounds that Congress did not provide him with the authority to make such an expansive interpretation of the CSA.[29]

While it appears (for the time being) that terminally ill Oregon residents may be allowed to request physician assistance for suicide, many other states have expressly prohibited providers from providing such assistance.[30] The United States Supreme Court has upheld such prohibitions in two states, finding in both cases that the state laws did not infringe upon constitutional rights.[31] It is not clear, however, how North Carolina courts would interpret and apply this state's law in such a situation. No law expressly prohibits assisted suicide, as was proposed this past legislative session. In laws governing living wills, however, the North Carolina General Assembly declared that the state does not "authorize any affirmative or deliberate act or omission to end life other than to permit the natural process of dying."[32] The state courts have not been called upon to review this statement, but it may be possible to infer from the language that suicide assistance by a healthcare provider is illegal in this state.

It is also possible that a physician or pharmacist providing medication to assist a suicide could be found in violation of the state's controlled substances law. Like the federal CSA, the state law provides that a prescription must be for a "legitimate medical purpose."[33] While the recent federal court of appeals decision invalidated Attorney General Ashcroft's interpretation of that language, it did not place any limits on the states' ability to interpret and apply the same or similar language in their own laws. The North Carolina Department of Justice has not released a formal opinion on this issue.

Based on the policies, position statements, and resolutions adopted by many national and state professional organizations, it appears that many members of the medical profession in this country object to the principle of assisting a person in committing suicide.[34] While these policies do not have the force of law, they are likely to be persuasive to healthcare professionals in states, such as North Carolina, where clear legal guidance is lacking. In some instances, such policies could form the basis for disciplinary action by licensing boards.

Pain Management

Pain management is probably the most important of the end-of-life issues because of the effect of pain on dying people and the fear it engenders in nearly everyone who contemplates dying in the United States today. Despite efforts from several directions to clarify the legality of giving pain-relieving medication that may shorten life or even kill, the matter is not yet clear enough.[35] Health professionals know that a number of drugs may depress breathing, especially opioids (derivatives of opium or similar, synthetic narcotics), which are among the most effective painkillers. They also know that relieving pain is among the highest goals of their professions, that United States medicine has been widely criticized by its practitioners and others for failing in that regard,[36] and that a major malpractice suit for failure to relieve pain succeeded in North Carolina. In that case a Hertford County jury returned a verdict of $15 million against Hillhaven Corporation for a nursing home's refusal to administer pain medication ordered by a physician for a man dying of cancer.[37]

There is clear support for pain management at the federal level. Federal law encourages the use of controlled substances to relieve pain, even if doing so jeopardizes the patient's life. The law requires doctors who prescribe medication for purposes of treating a drug addict to register with the DEA,[38] but regulations state that the act is not meant to limit a physician who prescribes opioids for intractable pain when no relief or cure is possible or has been found after reasonable effort.[39] In his 2001 directive, Attorney General Ashcroft reiterated the distinction between assisted suicide and "providing sufficient dosages of pain medication necessary to eliminate or alleviate pain."[40] National professional organizations, such as the American Medical Association and the American Nurses Association, also support and encourage active management of pain in dying patients.[41]

At the state level, the scope and type of legal guidance related to pain management varies. Many states expressly approve the use of pain-relieving medication, even though it may shorten life.[42] Some states do this by amending their controlled substances laws while others enact freestanding statutes. North Carolina has done neither. In the absence of state law on the issue, providers may rely on guidance from their licensing boards. In the fall of 1999, North Carolina's Boards of Nursing, Pharmacy, and Medicine issued a joint statement on pain management in end-of-life care. The statement identified issues of concern to members of the three professions. Of particular interest is the section of the statement directed toward physicians. It expressly provides that:

> "Opioid use... is appropriate if the responsible physician is familiar with and abides by acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan. Because the Board is aware of the inherent risks associated with effective pain relief in such situations, it will not interpret their occurrence as subject to discipline by the Board."[43]

The Medical Board also adopted two other statements discussing opioid use for the management of pain; one applies to pain during end-of-life care[44] and the other applies to chronic non-malignant pain.[45] The Board took care to assure physicians that they will not be disciplined for pain management, saying "no physician need fear reprisals from the Board for appropriately prescribing...even large amounts of controlled substances indefinitely for chronic non-malignant pain."

Even in the absence of state statutes or regulations on the issue, these strongly worded position statements from professional licensing boards should go a long way toward encouraging healthcare providers in North Carolina to provide adequate pain relief in end-of-life care. Without further action by the North Carolina General Assembly, though, providers (and their attorneys) will likely continue to be concerned about potential liability under the state controlled substances law and basic tort law.

Conclusion

North Carolina is clear on a few issues related to end-of-life care: an individual has the right to refuse life-sustaining treatment; euthanasia (or "mercy killing") would likely be considered murder; and suicide is not a crime. The law related to two of the most controversial issues—assisted suicide and pain management—is less clear. Healthcare providers, patients, advocates, and policymakers interested in continuing to develop the state's legal landscape related to end-of-life care have a tremendous opportunity to provide guidance and clarity in these essential components of patient care. **NCMJ**

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regulations (incorporated into the state's code at 10A N.C. Admin. Code 26E .0301) provide:

> A prescription for a controlled substance to be effective must be issued for a legitimate medical purpose by an individual practitioner acting in the usual course of his professional practice. The responsibility for the proper prescribing and dispensing of controlled substances is upon the prescribing practitioner, but a corresponding responsibility rests with the pharmacist who fills the prescription. An order purporting to be a prescription issued not in the usual course of professional treatment or in legitimate and authorized research is not a prescription within the meaning and intent of section 309 of the Act (21 U.S.C. 829) and the person knowingly filling such a prescription, as well as the person issuing it, shall be subject to the penalties provided for violations of the provisions of law relating to controlled substances.

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North Carolina Voluntary State Registry of Advance Healthcare Directives

In 2001, the North Carolina General Assembly passed legislation authorizing the NC Secretary of State to create a voluntary on-line registry of advance healthcare directives for the benefit of the citizens of the state and their healthcare providers under circumstances where immediate access to such directives would be needed. Citizens wishing to register their notarized directives may place three types of healthcare directives and an organ donor card on the Internet web site maintained by the Office of the Secretary of State at the following Internet location:

http://www.secretary.state.nc.us/ahcdr/

Those wishing to take advantage of this service by filing their information by mail may get information to facilitate their registration by calling 1-919-807-2000. Forms are provided for:

- Health Care Power of Attorney
- Declaration of Desire for Natural Death (Living Will)
- Advance Instruction for Mental Health Treatment
- Organ Donor Card

COMMENTARY

Spiritual Care at the End of Life:
What Is It and Who Does It?

Keith G. Meador, MD, ThM, MPH

The inclusion of "spirituality" in medical practice and research has become increasingly commonplace in recent years. Although clarity as to exactly what is meant by this term continues to be elusive, acceptance of its significance in the care of patients has increased as we continue to gain a better understanding of its role and develop related standards of practice. End-of-life care has incorporated some consideration of spiritual care since the advent of the modern hospice movement within the vision of Dame Cicely Saunders in England approximately 40 years ago.[1] Her vision of a community of caring that would attend to the spiritual needs of dying patients, along with addressing their pain management and other medical needs in a more humane fashion, was the foundation for the modern hospice movement. Although much of current end-of-life care has evolved from the challenge extended by Saunders regarding appropriate care of the dying, her commitment to meeting the spiritual needs of dying patients continues to be a challenge for healthcare providers.

These challenges grow out of a number of exacerbating factors concerning the diverse understandings of spirituality in a culturally pluralistic society, as well as the complexities of contemporary healthcare delivery systems. While recent evidence[2] indicates that both patients and their families consider spiritual care to be important in end-of-life care, the understanding of what this means varies considerably. The breadth of expectations expressed by this desire for spiritual care is expansive. It can include the spectrum from some sense of an emotionally sensitive care of the "human spirit" to a highly ritualized religious care incorporating very specific rites for the dying and a multitude of possibilities in between. Even those healthcare providers most sensitive to the inclusion of spiritual care at the end of life may be daunted by the thought of engaging such a fluid and somewhat nebulous expression of need.

Dr. Hanson's description of palliative care and its significance as a practice of medicine in the lead article of this issue[3] lays the groundwork for our considering the role of spiritual care at the end of life. Two primary aspects of palliative care are (1) an understanding of the virtue of caring (in contradistinction to curing) as a practice of medicine and (2) an appreciation of the art of listening well in the care of patients. Both of these resonate with the provision of spiritual care to the dying, and their central roles in palliative care speak to the potential for palliative medicine to remind all of us of the importance of listening and caring as essential aspects of practice throughout all of medicine, not just with the dying. The resolution of who can best provide intentional listening, as well as interpret the stories and struggle faced by those considering their mortality while reviewing their lives for a sense of purpose and closure, is not the same for every person. Those who render such care must examine themselves regarding their capacities and willingness to engage the rich and textured complexities of those for whom there are no illusions of cure, but who none the less need their undivided attention at the junction of life and death. The development of the skills and capacity to do such work has not been a standard part of medical education in the past and we, as well as our patients, have suffered for this inadequacy. Arthur Frank comments in *The Wounded Storyteller* that, "One of our most difficult duties as human beings is to listen to the voices of those who suffer."[4] I fear that we do not adequately equip ourselves as physicians and other healthcare providers to fulfill this "duty" and all that it entails.

Voices of suffering—especially the voices of those who know they are dying and their families—become poignantly focused. Along with asking challenging questions regarding prognosis and other "medical" inquiries, they become seekers and purveyors of "spiritual" understanding and wisdom. The language used for such communication will frequently be very specific to a particular cultural or religious tradition. While considerable strides are being made in improving communication skills for physicians in the care of the dying, lack of familiarity with such tradition—specific language and metaphors through which a dying person expresses her "soul"—can limit the capacity of the physician or other provider to listen well. This lack of familiarity is not a fault in the provider, but acknowledgement of this lack and seeking the assistance of someone more versed in the tradition of the dying patient can be crucial for providing

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meaningful spiritual care. Awareness of one's lack of familiarity with the religious or cultural tradition and language of a patient may not be readily evident, and patients may be hesitant to point out such gaps of understanding. Only through our attentiveness to the patient's story and the humility to discern our own inadequacies will we best serve the communication needs central to providing optimal spiritual care for dying patients.

The best spiritual care for the dying patient is most likely to be delivered in the same way other types of care are best provided, through partnerships within the team of persons caring for the patient. Although much of medicine is best practiced within a context of teamwork, palliative care particularly denotes a team approach,[5] and vital to a palliative care team is the clergy member of the team or the chaplain. While many physicians, nurses, and social workers have substantial gifts to offer to the spiritual care of patients, the role of a clergy member on the team to give leadership in providing spiritual care cannot be overstated. The other providers on the team may have a greater appreciation of the particular faith tradition of a patient and may serve as the more trusted spiritual confidant and care provider, but the clergy member of the team brings an interpretive, liturgical, and communal sense of spiritual care from her or his pastoral formation unique to that vocational formation. The optimally-trained and wise chaplain provides pastoral services within the entire community surrounding the dying patient and fosters a sense of care for one another that acknowledges the interdependency of the providers, the family, and the dying person in this work of living and dying.

"Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honor the privilege of intentional and reverent caring for the dying."

We healthcare providers rarely fully attend to the role of this interdependency in forming the health of the community, which ultimately determines how we care for the suffering and dying among us. Wendell Berry provides insight into the shared communal underpinnings of spiritual and palliative care when he says, "Health is not just the sense of completeness in ourselves but also is the sense of belonging to others and to our place; it is an unconscious awareness of community, of having in common."[6] Mindfulness of our interdependence allows us to be less captive to consumerist expectations and their distortion of caring relationships, while nurturing a greater sense of gratitude within an awareness of the limitations and finitude of healthcare. Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honor the privilege of intentional and reverent caring for the dying.

Good spiritual care is not just calling the chaplain for last rites or prayer with the bereaved family near the time of death. Although these are both valued and legitimate aspects of spiritual care, they fall short of the vision for spiritual care indicated by a comprehensive strategy for palliative care. Spiritual care should inform the practice of palliative care throughout the course of treatment.

There is no substitute for time to do the work of a "good death." While the interpretation of a good death may vary by tradition and culture, most consider the opportunity for a good death to include adequate pain management and the time to make peace with one's neighbor and with God while supported emotionally by family or friends. Adequate spiritual care helps provide the context for such a death for the dying person with an attentiveness to that individual's particular needs. Spiritual care as part of a comprehensive strategy for palliative care provides the opportunity and support to narrate one's story in such a way as to provide a legacy and memory of a "good death" for the family and broader community. The spiritual legacy of such a narrative can be a gift for generations to come and reframes the inevitable experience of loss within death as a reminder of the gift of the life that has been lived.

The importance and value of well-trained clergy as partners in providing the hope of a "good death" and its legacy is evident, but the lack of availability of such persons is all too common. Recent collaborative efforts between the Pastoral Services Department at Duke University Medical Center and the Duke Institute on Care at the End of Life to train specialist chaplains in end-of-life care are an attempt to address this issue. While the equipping of more specialized chaplains for tertiary care centers is helpful, the large numbers of persons dying in smaller hospitals without staff chaplains require our consideration. If we are convinced of the value of spiritual care as a part of palliative care and believe clergy to be important in the rendering of that care, we are challenged to consider how to best address this void of spiritual care providers in smaller hospitals and communities. The Caring Communities Program of Duke Divinity School and The Duke Endowment provides one response to this need in the Pastoral Care in Community program, which offers a curriculum certifying local clergy as Pastoral Care Specialists and equipping them to serve as volunteer chaplains in local hospitals. Although most of these clergy have visited regularly in the hospitals in the past, they are now receiving education in order to more ably partner with healthcare providers as part of palliative care teams in the provision of spiritual care to suffering and dying patients.

Spiritual care is still finding its place as a practice in healthcare.

Standards of practice for spiritual care have not been developed and we are still unsure as to just who should be engaging in its practice. Spiritual care has been part of end-of-life care since the start of the modern hospice movement, but it continues to evolve in content and form in response to increasingly pluralistic societies in the United States and western Europe. Providing spiritual care with integrity to the faith tradition of the dying patient can be challenging, but such care cannot be viewed as an optional luxury within the developing discipline of palliative care. The substantive shared commitments of good spiritual care and palliative care bear witness to spiritual care being inherently constitutive of palliative medicine rightly construed. Support for intentional spiritual care as an integral part of quality end-of-life care should come from many quarters, but support and commitment to spiritual care's place in palliative care at the end of life *must* come from physicians and administrative leaders in palliative care. The health of us all depends on it. **NCMJ**

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COMMENTARY

Opioids in End-of-Life Care:
Promises and Problems

Richard C. Stephenson, MD

Introduction

On the surface, it would seem that appropriate utilization of opioid analgesics to relieve suffering at the end of life is a "no-brainer." Concerns about addiction, diversion, tolerance, and other side effects might impede the use of these powerful medications in chronic nonmalignant pain, but certainly terminal pain and suffering must override these concerns. Tragically, nothing could be further from the truth.

For years, the American Alliance of State Cancer Pain Initiatives has presented convincing data showing that the undertreatment of cancer pain at the end of life is a public health crisis.[1] What an interesting and descriptive phrase, "public health crisis!" Why not tragedy, shame, or outrage? A public health crisis implies the scope of the problem is huge, that it is of concern to us all, and that effective preventive therapies and treatment strategies are available, but are simply not being utilized.

A quick look at the numbers is alarming. More than half a million people will die of cancer each year in this country. About two thirds of patients with advanced cancer have significant pain. Numerous studies confirm that almost half of these patients have unrelieved pain. Clearly these numbers are of public health crisis proportions. But even more poignantly, most experts in pain management would quickly agree that more than 95% cancer pains could be effectively treated with the right medication at the right dose at the right time.

Unfortunately it isn't just cancer pain at the end of life that is under-treated. The well-known and often quoted Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, SUPPORT, clearly showed that more than half of very sick hospitalized patients were in serious pain during their final days.[2] Unrelieved pain is incapacitating—interfering with the ability to eat, sleep, interact with others, and achieve a satisfactory quality of life.[3] Nothing could be more diametrically opposed to our fundamental promise as physicians, to cure sometimes and to relieve suffering always.

How can we all do a better job and keep the promise? It seems simple enough. Terminally ill patients present with complaints of severe pain and healthcare providers respond by diagnosing and treating with appropriate analgesic medication. So simple that hospice, palliative care programs, and others have applied a set of ABC's to pain management at the end of life (See Table 1). Perhaps thorough reflection on this "simple" process will demonstrate both the barriers and potential solutions to adequate pain relief at the end of life.

Table 1.
ABC's of Pain Management

ASK	about pain regularly; ASSESS systematically.
BELIEVE	the patient and family in their reports of pain and what relieves it.
CHOOSE	pain control options appropriate for the patient, family, and setting.
DELIVER	interventions in a timely, logical, and coordinated fashion.
EMPOWER	patients and their families; ENABLE them to control their course to the greatest extent possible.

Ask and Assess

All too often it seems we fail to ask patients with serious illness about pain. Paradoxically, healthcare providers are expecting patients to complain, while patients are waiting for their provider to ask.[4] A long list of potential reasons cancer patients may not complain about increasing pain can be easily generated. Pain may well have sinister implications, including spread of disease, failure of therapy, lack of further therapies, and imminent death. Pain may interfere with the doctor-patient relationship. Patients in pain may feel burdensome to their doctor if they complain of pain not adequately managed, even fear their pain may distract physicians from the business of curing their cancer.

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After all, patients fundamentally like and respect their doctors and want the same in return. They may not want to be considered weak, whiney, drug-seeking, ungrateful, or even a therapeutic failure to their physician.

Physicians share some of these same concerns that lead to a failure to ask. In addition, pain evaluation and management are not well taught in most medical schools and residency programs. One recent survey reported the average amount of time spent on teaching pain management in American medical schools is one hour; with just four hours for nurses.[5] Failure to ask may also reflect insecurity about what to do with poorly controlled pain and fears of regulatory scrutiny when prescribing controlled substances. Weber and Huber showed that oncologists in a busy clinic setting documented pain severity and opioid dose only 25% of the time in patients known to have significant pain (see Table 2).[6]

Table 2.
Documentation of Severe Pain, Opioid Doses, and Opioid-related Side Effects *adapted from Weber and Huber*[6]

Finding	Frequency Documented
Pain Severity	24.6%
Opioid Dose	26.9
"Rescue" Dose	4.8
Bowel movements	1.6
Laxative Rx	4.2

Asking is a great place to start, but a more formal pain assessment and regular utilization of a pain assessment tool have been shown to improve pain management. While one might argue that various tools are too long, complicated, time-consuming, or subjective, studies repeatedly show that choosing and consistently using one is far better than using none.[7] Most pain scales and tools are actually quite simple, often done by the patient, and easy to incorporate into regular visits. Even patients with mild-to-moderate dementia can respond to at least one of these simple tools.[8] The simplest of tools are scales. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) now "recommends" the regular use of pain scales to assess pain severity and relief. The two most common scales are either verbal (none, mild, moderate, severe, or excruciating) or numerical (0-10 where 0 indicates no pain and 10 the worst pain you can imagine).[9]

> *"Unrelieved pain is incapacitating—interfering with the ability to eat, sleep, interact with others, and achieve a satisfactory quality of life."*

In some settings and with some patients, particularly at initial assessment, more detailed tools like the two listed below are helpful. Neither of these tools is new and both have been validated in a variety of settings and many different countries. Many more are available and their use is encouraged.

The Memorial Pain Assessment Card (MPAC)

The MPAC[10] uses a 10-cm Visual Analogue Scale to rate not only pain but also relief and mood. A Visual Analogue Scale (VAS) is a simple 10cm line labeled 0 (none) at one end and 10 (severe) at the other. The patient marks the point on the scale that best indicates the severity of the symptom. A VAS can be used to assess any symptom including pain, nausea, dyspnea, anxiety, depression etc. The patient's response to the card also indicates global symptom distress.

The Wisconsin Brief Pain Inventory (BPI)

The BPI[11] comes in both a long and short form. The long form lends itself to initial pain assessment and the short form to follow-up. Both forms establish pain at its recent worst, least, average, and now using a 0-10 scale. They provide descriptive language about the quality of the pain as well as a body diagram to locate and separate pains. The BPI also asks patients to grade their overall pain relief efforts and quantify interference with mood, sleep, and relationships.

One element that has received recent media attention is incorporating pain as the "fifth vital sign." In reality, this may become the standard of care. The United States Department of Veterans Affairs (VA) has initiated an ambitious program to include pain as the fifth vital sign in not only all of its medical facilities, but all patient encounters. A positive pain score then triggers further assessment, prompt intervention, and follow-up evaluation.[12]

Believe

Patients and their families often note that no one seems to believe in their complaint of pain. Physicians are often stuck in a medical model of care that demands a specific diagnosis before treatment. Treatment may be delayed until proof is found by diagnostic testing or even further delayed if our tests fail to confirm a clear etiology of the pain, e.g., a positive bone scan. Hospice nurses often express considerable frustration that patients with diseases like lung cancer, at high risk for painful metastases, often do not receive adequate pain medications until testing proves the existence of disease spread. With proof in hand, most physicians are then more than willing to prescribe whatever is necessary.

It is abundantly clear that many physicians are very concerned about prescribing opioid medication without "proof" of definitive disease. It is appropriate to be concerned; there are patients trying to scam us. Diversion, abuse, and misuse happen, but fears and concerns about these possibilities should not prevent appropriate prescription of pain medications for patients who need them. This is easy enough to say, but with all the media attention and legal activity surrounding opioid diversion and misuse, fear of regulatory scrutiny, and even legal prosecution, often thwarts adequate pain management.

Few physicians will forget the picture of a Florida physician that appeared in papers all across the country with the caption, "Doctor is sentenced in Oxycontin deaths." Careful review of the article clearly showed that this was a "dishonest doctor" dispensing oxycontin for profit. Unfortunately few people get beyond the headlines. Within just the last year, an equally alarming legal advertisement appeared in the *Winston-Salem Journal* that read, "OXYCONTIN: If you have been prescribed Oxycontin for more than six (6) months for something other than cancer, call...(telephone number)...Prescription users only."

It is precisely for these reasons that the Drug Enforcement Administration (DEA) and 21 health organizations felt compelled to issue a Joint Statement Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act (see page 234).[13] This joint statement clearly reassures us that,

> *"Preventing drug abuse is an important societal goal, but there is consensus, by law enforcement agencies, healthcare practitioners, and patient advocates alike, that it should not hinder patients' ability to receive the care they need and deserve."*

This consensus agreement goes on to enumerate the following facts.

- Undertreatment of pain is a serious problem in this country.
- For many patients opioid analgesics are the most effective and often the only treatment that provides significant relief.
- Opioids are controlled substances and necessarily regulated.
- Drug abusers obtain these medications by diversion.
- Abuse is a serious problem, but focusing only on abuse could erroneously lead to the conclusion that these medicines should be avoided when indicated—generating a sense of fear rather than respect for their legitimate properties.
- Awareness of both use and abuse will enable all of us to make proper and wise decisions regarding the treatment of pain."[13]

Similarly, state medical boards have issued statements to reassure healthcare professionals that they need not fear sanctions for adequate symptom management of seriously ill patients. In fact, just the opposite is true; physicians have been sanctioned for *undertreatment* of pain at the end of life. The North Carolina Boards of Medicine, Nursing, and Pharmacy issued a Joint Statement on Pain Management in End-of-Life Care, adopted on October 21, 1999 that serves as a model for other states.[14] This statement in part reads,

> *"The Medical Board will assume opioid use in such patients is appropriate if the responsible physician is familiar with and abides by acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan."*

The physician's fiduciary responsibility to treat pain at the end-of-life is abundantly clear. These statements serve as excellent guidelines to proceed with effective pain management. As long as physicians carefully follow the tenets of appropriate prescribing within an established doctor/patient relationship, we needn't fear regulatory or legal consequences.

Choose

A pain specialist once shared that effective pain management at the end of life was really quite simple. It comes down to using aspirin and/or opioids. There are a myriad of other potential interventions available including adjuvant medication, surgery, radiation, chemotherapy, central nervous system anesthesia, and even complementary modalities. For the vast majority of patients, pharmacologic therapy with aspirin and/or opioids will do the job. Of course aspirin means the broader class of nonsteroidal anti-inflammatory drugs (NSAIDS). And opioids means a thorough understanding of a number of appropriate opioids used at the right dose, in the right dosing form, at the right time, and by the right route. While NSAIDS have a role in pain management at the end of life, for the large numbers of patients with moderate-to-severe pain, opioids are the mainstay of pharmacologic therapy.

There is little doubt that the most important barriers to effective pain management at the end of life are poor assessment and inadequate utilization of opioid medication.[3] "Inadequate utilization" does not assign blame, but refers to a major problem with education and attitude about opioid medications. This is not just a patient or physician problem, it is everyone's problem —nurse, pharmacist, family, friend, pastor, or volunteer. We all share inadequate education and inappropriate attitudes about opioid medication.

Pain and palliative care specialists speak frequently about morphine myths. These are generally held ideas about opioids that have grown to mythic proportion without much substantial proof as to their existence. These misconceptions interfere with the appropriate utilization of opioids and include undue concerns about addiction, tolerance, and uncontrollable side effects like euphoria, vomiting, constipation, sedation and respiratory depression. Numerous studies have shown that the more firmly held the myth, the more noncompliant the patient will be with their pain regimen.[15] Patients who fear addiction resulting from simply utilizing opioids are unlikely to take them as prescribed. Likewise patients who are afraid that tolerance will develop if they start taking opioids early in the course of their disease, rather than "saving" them for when their pain gets "really bad," are unlikely to take medication appropriately. Healthcare providers must assume that these issues are on the minds of most patients as they write an initial prescription for an opioid medication and ensure appropriate education to explore and dispel the myths.

Perhaps more surprising is how these same myths affect physician attitudes about pain and opioids. A remarkable study done here in North Carolina[16] confirmed the findings of others and demonstrated widespread misconceptions among physicians about pain and opioid medications. In one study,[17] 51% of physicians felt that tolerance to opioids was a significant problem and limited their ability to control pain. Most experts would agree that most of the time tolerance is not a clinical issue. Increasing pain means an increase in cancer-related disease processes and can be relieved by increasing opioid doses and/or other measures. On the other hand, 39% of physicians felt that intolerance to adverse effects of opioids made it difficult to control pain. Interestingly, most patients become tolerant of common side effects of opioids (except for constipation), but not to their analgesic effects. An alarming 20% of these physicians felt addiction was a problem for cancer patients treated with opioids and 19% felt poorly controlled pain was inevitable in advanced cancer.

While a detailed review of specific pharmacologic treatment strategies and recommendations is beyond the scope of this article, many monographs and guidelines are readily available. The American Pain Society has recently published the fifth edition of a remarkable pocket-sized set of guidelines for both acute and cancer pain,[18] which can be ordered at http://www.ampainsoc.org/pub/principle.htm. The American Academy of Hospice and Palliative Medicine also publishes a pocket guide to palliative care with up-to-date recommendations covering both pain and a wide range of other end-of-life care issues.[19] The American Geriatrics Society has recently reissued guidelines for pain management in older persons.[20] All of these resources are clear that opioids may well be both the safest and most effective treatment strategy for persons with serious pain at the end of life. All physicians should be familiar with basic opioid pharmacology, dosing strategies, and the role of common adjuvant medications. In addition, physicians must be knowledgeable about resources and pain consultants available in their communities when pain becomes difficult to control.

"Indeed, methadone is probably the ideal opioid in end-of-life care."

Unfortunately, in a distinct minority of patients, pain isn't nearly as difficult to control as the patient and/or their family. Some patients abuse their opioids, and some families divert patients' medications. Physicians must be thoughtful, careful practitioners willing to confront these possibilities and engage the assistance of specialists who commonly deal with these challenging circumstances. Pain clinics often employ effective strategies, like contracting, to deal with these circumstances.[21] Engaging local DEA authorities may even become necessary to ensure both patient and public protection. *Tolerance* may truly be the issue in patients with a history of opioid abuse. These patients are often *tolerant* of opioid medication, in*tolerant* of both physical and emotional pain, and clearly try the *tolerance* of their healthcare providers.

Deliver

Pain interventions should be delivered in a timely, logical, and coordinated fashion. A thorough understanding of the pharmacology of opioids and other medications is essential for good pain management at the end of life. For example, many physicians dose oral opioids every four hours as needed for pain. However, for patients in pain crisis a more aggressive strategy is indicated. Since oral opioids reach maximum serum concentration within an hour, peak effects and peak side effects also occur in that time frame. As long as adverse effects of sedation or respiratory depression aren't observed, additional medication, including breakthrough doses, can be administered every one to two hours.

Similarly aggressive parenteral dosing strategies exist for patients in pain crisis presenting for inpatient care. One such successful strategy describes a dose doubling every thirty minutes.[22] In this study, cancer pain patients already on opioids as outpatients presented for emergent admission with intense pain sustained for at least six hours and escalating over days. Appropriate to their outpatient opioid dose, patients received 10-20 mg of morphine intravenously over 15 minutes. If inadequate relief and no adverse effects were observed 15 minutes later, the dose was doubled and the process repeated every 30 minutes. Satisfactory pain control without adverse events was achieved in a mean time frame of 90 minutes for all patients.

In a similar study, cancer pain patients were treated with one milligram of morphine per minute for 10 minutes, which could be repeated after five minutes if there was no relief.[23] The goal in this study was also similar; to achieve adequate relief (< 5 pain score) not necessarily with complete relief, but without excess sedation or respiratory depression. In this study, the maximum dose was 30 milligrams over 45 minutes. None of their patients required this high a dose. Once relief was achieved, an hourly dose was calculated at approximately one-third to one-fourth of the loading dose.

Both of these studies depend on a clear understanding of opioid pharmacology. Both were also done in an inpatient setting, with experienced personnel, aware of, and prepared for adverse consequences. Nevertheless, innovative or "best-practice" models like this should be carefully reviewed, adapted and adopted in settings where poor pain control is likely to be encountered and effective pain management expected by patient, family, and providers.

A broader view of delivering interventions in a timely, logical and coordinated fashion suggests taking a harder look at what patients and their families need to achieve pain control. A recent review[24] suggests seven areas of difficulty in putting a pain regimen into practice. The primary difficulty is the cost of medication, but also of major concern are accessing information about the medication, tailoring the prescription to meet individual needs, and managing side effects like constipation. Anticipating these concerns is highly likely, and addressing them with all patients will clearly improve pain management. If opioid cost is an issue, methadone must be an option. While methadone has complex dosing problems and should only be prescribed by those thoroughly familiar with them, oral methadone costs only about a penny per milligram. Topical fentanyl patches for severe pain at 150mcg/hour applied every 72 hours may cost as much as $30/day, whereas an equianalgesic dose of methadone may cost as little as 45 cents/day. In addition, methadone has very specific analgesic properties that make it a more potent and effective opioid for complex, chronic cancer pain. Recent reviews of methadone[25] are essential reading for any practitioner providing care for patients with significant pain at the end of life. Indeed, methadone is probably the ideal opioid in end-of-life care.[26]

Empower and Enable

Unrelieved pain is incapacitating, interfering with the ability to eat, sleep, interact with others, and achieve a satisfactory quality of life.[3] Healthcare providers need to empower patients and their families and enable them to control their course to the greatest extent possible. Information is power. Resources abound to provide patients and their families with information with which they can better manage pain at the end of life. From drug companies[27] to end-of-life care advocacy groups,[1] print and Internet resources are readily available. Hospices cover every square inch of North Carolina and probably the entire continental United States. Palliative care services exist in many hospitals and all regions of the country. Both are committed to effective pain management. Use your local hospice and consult your palliative care service.

JCAHO standards, at least the pain control standards, are terrific guidelines and are the rules we must live by in many settings. As much as we often rebel against "have to" standards, these are worth embracing and implementing. Most guidelines and standards "suggest" that institutions should promise excellent pain control, express it clearly in statements of patient's rights and responsibilities, and put mechanisms in place to live up to the promise. One such statement reads,

"As a patient at Rockford Memorial Hospital, you can expect:

- Information about pain and pain relief measures.
- A concerned staff committed to pain prevention.
- Health professionals who respond quickly to reports of pain.
- State-of-the-art pain management.
- Dedicated pain relief specialists.
- Pain expressions will be believed.

As a patient at Rockford Memorial Hospital, we expect that you will:

- Ask your doctor or nurse what to expect.
- Discuss pain relief options with your doctors and nurses.
- Work with you doctor and nurse to make a pain relief plan.
- Ask for pain relief drugs when pain first begins.
- Help the doctor and nurse measure your pain.
- Tell the doctor or nurse about any pain that will not go away.
- Not worry about getting "hooked" on pain medication."[28]

This may not be the exact statement our institutions choose, but it is a great place to start. Individual and organizational commitment to pain relief is truly powerful. Education, attitude, passion, and compassion will overcome all of the barriers to adequate pain relief at the end of life, fulfilling our promise as concerned healthcare providers. **NCMJ**

> *"Paradoxically, healthcare providers are expecting patients to complain, while patients are waiting for their provider to ask."*

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A JOINT STATEMENT FROM 21 HEALTH ORGANIZATIONS
AND THE DRUG ENFORCEMENT ADMINISTRATION

Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act

As representatives of the health care community and law enforcement, we are working together to prevent abuse of prescription pain medications while ensuring that they remain available for patients in need.

Both healthcare professionals, and law enforcement and regulatory personnel, share a responsibility for ensuring that prescription pain medications are available to the patients who need them and for preventing these drugs from becoming a source of harm or abuse. We all must ensure that accurate information about both the legitimate use and the abuse of prescription pain medications is made available. The roles of both health professionals and law enforcement personnel in maintaining this essential balance between patient care and diversion prevention are critical.

Preventing drug abuse is an important societal goal, but there is consensus, by law enforcement agencies, health care practitioners, and patient advocates alike, that it should not hinder patients' ability to receive the care they need and deserve.

This consensus statement is necessary based on the following facts:

◆ Undertreatment of pain is a serious problem in the United States, including pain among patients with chronic conditions and those who are critically ill or near death. Effective pain management is an integral and important aspect of quality medical care, and pain should be treated aggressively.

◆ For many patients, opioid analgesics – when used as recommended by established pain management guidelines – are the most effective way to treat their pain, and often the only treatment option that provides significant relief.

◆ Because opioids are one of several types of controlled substances that have potential for abuse, they are carefully regulated by the Drug Enforcement Administration and other state agencies. For example, a physician must be licensed by State medical authorities and registered with the DEA before prescribing a controlled substance.

◆ In spite of regulatory controls, drug abusers obtain these and other prescription medications by diverting them from legitimate channels in several ways, including fraud, theft, forged prescriptions, and via unscrupulous health professionals.

◆ Drug abuse is a serious problem. Those who legally manufacture, distribute, prescribe and dispense controlled substances must be mindful of and have respect for their inherent abuse potential. Focusing only on the abuse potential of a drug, however, could erroneously lead to the conclusion that these medications should be avoided when medically indicated – generating a sense of fear rather than respect for their legitimate properties.

◆ Helping doctors, nurses, pharmacists, other healthcare professionals, law enforcement personnel and the general public become more aware of both the use and abuse of pain medications will enable all of us to make proper and wise decisions regarding the treatment of pain.

American Academy of Family Physicians

American Academy of Hospice and Palliative Medicine

American Academy of Pain Medicine

American Alliance of Cancer Pain Initiatives

American Cancer Society

American Medical Association

American Pain Foundation

American Pain Society

American Pharmaceutical Association

American Society of Anesthesiologists

American Society of Law, Medicine & Ethics

American Society of Pain Management Nurses

American Society of Regional Anesthesia and Pain Medicine

Community-State Partnerships to Improve End-of-Life Care

Drug Enforcement Administration

Last Acts

Midwest Bioethics Center

National Academy of Elder Law Attorneys

National Hospice and Palliative Care Organization

Oncology Nursing Society

Partnership for Caring, Inc.

University of Wisconsin Pain & Policy Studies Group

Addressing Pain Management and Palliative Care:
The Official Position of the North Carolina Medical Board

Charles E. Trado, MD, FAPA

Dr. Hanson has addressed the subject of palliative care in end-of-life situations, expertly documenting the definitions, statistics, and strategies for dealing with such care.[1] She has made notable references to these issues as confronted by North Carolinians, references that will prove educational to physicians, nurses, and other healthcare providers in our state. It is comforting to know that we in North Carolina are attending to this important issue with some institutional awareness and program implementation such as the Pain and Symptom Care Program at UNC Hospitals. Obviously more needs to be done by our statewide medical community.

Palliative care is a comprehensive approach to end-of-life issues and all aspects of this care need be addressed as discussed by Dr. Hanson. Alleviation of suffering should be a major goal of healthcare providers and should include not only the physical, but also the psychological, spiritual, emotional, and family suffering that takes place in this difficult life situation.

> *"...substance abuse in this country has little or nothing to do with the proper practice of pain management in palliative and end-of-life care. Studies indicate that only approximately one to four percent of patients are addicted iatrogenically."*

I would direct your attention to the physical suffering that dying patients more often than not experience. For at least the last 10-to-15 years the medical community has been made aware that adequate pain management in the dying patient has been a continuing problem. It has been reported in several studies over the years that 25-to-30% of cancer patients suffer severe pain and 40-to-50% suffer moderate to severe pain. This despite the fact that 90% of cancer pain can be relieved with current pain management protocols. One such protocol is presented comprehensively in The Clinical Practice Guideline, "Management of Cancer Pain," published by the Agency for Healthcare Research and Quality (AHRQ).[2] This publication is readily available to professionals and to the public alike from AHRQ. This is only one of many resources available to help us address this ongoing problem.

Hospice, introduced to this country in the 1970's, alerted our medical community to the need for sensible pain control in the dying patients and, even in its rudimentary protocols, opened our eyes and minds to the unmet needs of our patients. Palliative care programs will take us another important step in the right direction through its comprehensive approach.

But, as noted above, we are still not doing a good enough job in overall pain management. We can't lay the blame for our shortcomings in this area entirely on the medical community. Patients have every right to refuse adequate pain control even if that refusal is based upon faulty beliefs or assumptions. Many patients see themselves as weak or certainly non-heroic if they "give in" and use medication to control their pain. Others fear that using any kind of pain reliever will identify them as an "addict" to the public and to family members. Others fear that pain relievers have such mysterious power that they will automatically be addicted by the first dose. For patients who think and feel this way, the medical community needs to put more effort into assuaging their fears and improving their understanding of the proper and appropriate use of these medications.

Unfortunately, patients are not the only ones either misinformed or under educated about this issue. Too many, but thankfully not a majority, of physicians hold outdated and or prejudicial views about the use of pain relievers. Many of those views mirror those held by patients. As younger physicians who

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have more current and focused training in pain management become the majority care givers in our communities, this problem should continue to ameliorate.

Physician pain specialists and formal, structured pain treatment centers have afforded our patients up-to-date, comprehensive approaches to pain management. These highly trained specialists and their treatment teams tend, by necessity, to deal with outpatients who experience a full range of acute and chronic pain symptoms. All modalities of treatment are considered and applied with the goal of adequate pain relief for the patient in the safest and least noxious manner.

However, it is my observation that pain-treatment centers have to be preoccupied with the specific population mentioned above and do not routinely become involved with the dying patient. I mention this not to be critical, but to suggest that those who are taking care of the dying patient not overlook these valuable specialty programs and consultations when appropriate. This, too, in my opinion, should be part of a comprehensive palliative care program for our patients.

If it is true that some of our medical community, specifically physicians, either are improperly trained or inordinately under informed or incomprehensibly prejudiced with regard to appropriate pain management, then what, if anything, can or should be done about the problem? Please note that I said "some" of our physicians, not a majority, fall into this category. Also note that this minority of physicians have charge of the treatment of a significant number of dying patients and thereby influence decisions about their palliative care.

"Facilitating a 'good death' is what any humane and civilized society must demand for its citizens."

What can be done to help these physicians practice pain management according to more currently acceptable guidelines? In the mid-1990s, the North Carolina Medical Board, while trying to deal with "over-prescribing" of pain medication by some physicians, observed that these same medications were being "under-prescribed" by other physicians. There was a heightened awareness of the inadequacy of pain treatment prevalent in the country at that time and the Board examined the findings of several studies of this issue. It discovered that many physicians were afraid to prescribe adequate pain relief, especially opioids, for fear of being sanctioned by the Board. This was the state of affairs at that time, not only in North Carolina but throughout the nation, which led to national debate among licensing and disciplinary boards about what position boards should take in the matter.

The North Carolina Medical Board elected to write and publish a "position statement" on the topic for the purpose of letting physicians know about the problem, to educate physicians about the kind of protocol to follow in using these medications, and hopefully to help alleviate fears of being sanctioned by the Board for prescribing these medications appropriately. Reassurance to physicians was provided in the following paragraph taken from the position statement:

> *"No physician need fear reprisals from the North Carolina Medical Board for appropriately prescribing as described above, even large amounts of controlled substances indefinitely for chronic non-malignant pain."*
>
> The last paragraph of the statement is as follows:
>
> *"Nothing in this statement should be construed as advocating the imprudent use of controlled substances."*

The entire position statement by the North Carolina Medical Board is meant to address what we felt might be an impediment to proper pain management by North Carolina physicians and is especially applicable to formal palliative care programs and caregivers.

It is generally accepted that we have a drug problem in this country, and that citizens hold strong and varied opinions about what should be done about the problem. These strong and diverse opinions can and, in some instances do, have an impact upon pain management decisions made by caregivers.

In my opinion, substance abuse in this country has little or nothing to do with the proper practice of pain management in palliative and end-of-life care. Studies indicate that only approximately one to four percent of patients are addicted iatrogenically.[1] If caregivers have any role to play in the "drug problem" it is likely to be in the area of diversion of prescription drugs for illicit sale and use by recreational drug users and hardcore addicts. The latter group will find their supply by whatever means possible, and their addictive behavior should not be allowed to compromise quality of care for any of our patients, especially those in a palliative care program.

End-of-life issues have rightfully captured our attention and demand continued study by our profession. We are miles from where we were just a few decades ago and articles such as Dr. Hanson's will help point the way to the future of this important life event. A good life is what we all wish for our loved ones. Facilitating a "good death" is what any humane and civilized society must demand for its citizens. **NCMJ**

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North Carolina Medical Board Position Statement on

MANAGEMENT OF CHRONIC NON-MALIGNANT PAIN

It has become increasingly apparent to physicians and their patients that the use of effective pain management has not kept pace with other advances in medical practice. There are several factors that have contributed to this. These include a history of relatively low priority given to pain management in our healthcare system, the incomplete integration of current knowledge in medical education and clinical practice, a scarcity of practitioners specifically trained in pain management, and the fear of legal consequences when controlled substances are used—fear shared by physician and patient. There are three general categories of pain.

Acute Pain is associated with surgery, trauma, and acute illness. It has received its share of attention by physicians. Its treatment by various means is widely accepted by patients, and it has been addressed in guidelines issued by the Agency for Health Care Policy and Research (AHCPR) [now the Agency for Healthcare Research and Quality (AHRQ)] of the United States Department of Health and Human Services.

Cancer Pain has been receiving greater attention and more enlightened treatment by physicians and patients, particularly since development of the hospice movement. It has also been addressed in AHCPR/AHRQ guidelines.

Chronic Non-Malignant Pain is often difficult to diagnose, often intractable, and often under-treated. It is the management of chronic non-malignant pain on which the North Carolina Medical Board wishes to focus attention in this position statement.

The North Carolina Medical Board recognizes that many strategies exist for treating chronic non-malignant pain. Because such pain may have many causes and perpetuating factors, treatment will vary from behavioral and rehabilitation approaches to the use of a number of medications, including opioids. Specialty groups in the field point out that most chronic non-malignant pain is best managed in a coordinated way, using a number of strategies in concert. Inadequate management of such pain is not uncommon, however, despite the availability of safe and effective treatments.

The Board is aware that some physicians avoid prescribing controlled substances such as opioids in treating chronic non-malignant pain. While it does not suggest those physicians abandon their reservations or professional judgment about using opioids in such situations, neither does the Board wish to be an obstacle to proper and effective management of chronic pain by physicians. It should be understood that the Board recognizes opioids can be an appropriate treatment for chronic pain.

It is the position of the North Carolina Medical Board that effective management of chronic pain should include:

- thorough documentation of all aspects of the patient's assessment and care;
- a thorough history and physical examination, including a drug and pain history;
- appropriate studies;
- a working diagnosis and treatment plan;
- a rationale for the treatment selected;
- education of the patient;
- clear understanding by the patient and physician of methods and goals of treatment;
- a specific follow-up protocol, which must be adhered to;
- regular assessment of treatment efficacy;
- consultation with specialists in pain medicine, when warranted; and
- use of a multidisciplinary approach, when indicated.

The Board expects physicians using controlled substances in the management of chronic pain to be familiar with conditions such as:

- physical dependence;
- respiratory depression and other side effects;
- tolerance;
- addiction; and
- pseudo addiction.

There is an abundance of literature available on these topics and on the effective management of pain. The physician's knowledge should be regularly updated in these areas.

No physician need fear reprisals from the Board for appropriately prescribing, as described above, even large amounts of controlled substances indefinitely for chronic non-malignant pain.

Nothing in this statement should be construed as advocating the imprudent use of controlled substances.

(Adopted 9/13/96)

North Carolina Medical Board Position Statement on
END-OF-LIFE RESPONSIBILITIES AND PALLIATIVE CARE

Assuring Patients

Death is part of life. When appropriate processes have determined that the use of life-sustaining or invasive interventions will only prolong the dying process, it is incumbent on physicians to accept death "not as a failure, but the natural culmination of our lives."*

It is the position of the North Carolina Medical Board that patients and their families should be assured of competent, comprehensive palliative care at the end of their lives. Physicians should be knowledgeable regarding effective and compassionate pain relief, and patients and their families should be assured such relief will be provided.

Palliative Care

There is no one definition of palliative care, but the Board accepts that found in the *Oxford Textbook of Palliative Medicine*: "The study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life." This is not intended to exclude remissions and requires that the management of patients be comprehensive, embracing the efforts of medical clinicians and of those who provide psychosocial services, spiritual support, and hospice care.

A physician who provides palliative care, encompassing the full range of comfort care, should assess his or her patient's physical, psychological, and spiritual conditions. Because of the overwhelming concern of patients about pain relief, special attention should be given to the effective assessment of pain. It is particularly important that the physician frankly, but sensitively, discuss with the patient and the family their concerns and choices at the end of life. As part of this discussion, the physician should make clear that, in some cases, there are inherent risks associated with effective pain relief in such situations.

Opioid Use

The Board will assume opioid use in such patients is appropriate if the responsible physician is familiar with and abides by acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan. (See the Board's position statement on the Management of Chronic Non-Malignant Pain for an outline of what the Board expects of physicians in the management of pain.) Because the Board is aware of the inherent risks associated with effective pain relief in such situations, it will not interpret their occurrence as subject to discipline by the Board.

Selected Guides

To assist physicians in meeting these responsibilities, the Board recommends *Cancer Pain Relief: With a Guide to Opioid Availability, 2nd ed* (1996), *Cancer Pain Relief and Palliative Care* (1990), *Cancer Pain Relief and Palliative Care in Children* (1999), and *Symptom Relief in Terminal Illness* (1998), (World Health Organization, Geneva); *Management of Cancer Pain* (1994), (Agency for Health Care Policy and Research, Rockville, MD); *Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain*, 4th Edition (1999)(American Pain Society, Glenview, IL); *Hospice Care: A Physician's Guide* (1998) (Hospice for the Carolinas, Raleigh); and the *Oxford Textbook of Palliative Medicine* (1993) (Oxford Medical, Oxford).

(Adopted 10/1999)

*Steven A. Schroeder, MD, President, Robert Wood Johnson Foundation.

RELATED STATEMENT

Joint Statement on Pain Management in End-of-Life Care

(Adopted by the North Carolina Medical, Nursing, and Pharmacy Boards)

Through dialogue with members of the healthcare community and consumers, a number of perceived regulatory barriers to adequate pain management in end-of-life care have been expressed to the Boards of Medicine, Nursing, and Pharmacy. The following statement attempts to address these misperceptions by outlining practice expectations for physicians and other healthcare professionals authorized to prescribe medications, as well as nurses and pharmacists involved in this aspect of end-of-life care. The statement is based on:

- the legal scope of practice for each of these licensed health professionals;
- professional collaboration and communication among health professionals providing palliative care; and
- a standard of care that assures on-going pain assessment, a therapeutic plan for pain management interventions; and evidence of adequate symptom management for the dying patient.

It is the position of all three Boards that patients and their families should be assured of competent, comprehensive palliative care at the end of their lives. Physicians, nurses, and pharmacists should be knowledgeable regarding effective and compassionate pain relief, and patients and their families should be assured such relief will be provided.

Because of the overwhelming concern of patients about pain relief, the physician needs to give special attention to the effective assessment of pain. It is particularly important that the physician frankly, but sensitively, discuss with the patient and the family their concerns and choices at the end of life. As part of this discussion, the physician should make clear that, in some end-of-life care situations, there are inherent risks associated with effective pain relief. The Medical Board will assume opioid use in such patients is appropriate if the responsible physician is familiar with, and abides by, acceptable medical guidelines regarding such use, is knowledgeable about effective and compassionate pain relief, and maintains an appropriate medical record that details a pain management plan. Because the Board is aware of the inherent risks associated with effective pain relief in such situations, it will not interpret their occurrence as subject to discipline by the Board.

With regard to pharmacy practice, North Carolina has no quantity restrictions on dispensing controlled substances including those in Schedule II. This is significant when utilizing the federal rule that allows the partial filling of Schedule II prescriptions for up to 60 days. In these situations it would minimize expenses and unnecessary waste of drugs if the prescriber would note on the prescription that the patient is terminally ill and specify the largest anticipated quantity that could be needed for the next two months. The pharmacist could then dispense smaller quantities of the prescription to meet the patient's needs up to the total quantity authorized. Government-approved labeling for dosage level and frequency can be useful as guidance for patient care. Health professionals may, on occasion, determine that higher levels are justified in specific cases. However, these occasions would be exceptions to general practice and would need to be properly documented to establish informed consent of the patient and family.

Federal and state rules also allow the fax transmittal of an original prescription for Schedule II drugs for hospice patients. If the prescriber notes the hospice status of the patient on the faxed document, it serves as the original. Pharmacy rules also allow the emergency refilling of prescriptions in Schedules III, IV, and V. While this does not apply to Schedule II drugs, it can be useful in situations where the patient is using drugs such as Vicodin for pain or Xanax for anxiety.

The nurse is often the health professional most involved in on-going pain assessment, implementing the prescribed pain management plan, evaluating the patient's response to such interventions, and adjusting medication levels based on patient status. In order to achieve adequate pain management, the prescription must provide dosage ranges and frequency parameters within which the nurse may adjust (titrate) medication in order to achieve adequate pain control. Consistent with the licensee's scope of practice, the RN or LPN is accountable for implementing the pain management plan utilizing his/her knowledge base and documented assessment of the patient's needs. The nurse has the authority to adjust medication levels within the dosage and frequency

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ranges stipulated by the prescriber and according to the agency's established protocols. However, the nurse does not have the authority to change the medical pain management plan. When adequate pain management is not achieved under the currently prescribed treatment plan, the nurse is responsible for reporting such findings to the prescriber and documenting this communication. Only the physician or other health professional with authority to prescribe may change the medical pain management plan.

Communication and collaboration between members of the healthcare team, and the patient and family are essential in achieving adequate pain management in end-of-life care. Within this interdisciplinary framework for end-of-life care, effective pain management should include:

- thorough documentation of all aspects of the patient's assessment and care;
- a working diagnosis and therapeutic treatment plan including pharmacologic and non-pharmacologic interventions;
- regular and documented evaluation of response to the interventions and, as appropriate, revisions to the treatment plan;
- evidence of communication among care providers;
- education of the patient and family; and
- a clear understanding by the patient, the family, and healthcare team of the treatment goals.

It is important to remind health professionals that licensing boards hold each licensee accountable for providing safe, effective care. Exercising this standard of care requires the application of knowledge and skills, as well as ethical principles, focused on optimum patient care while taking all appropriate measures to relieve suffering. The healthcare team should give primary importance to the expressed desires of the patient tempered by the judgment and legal responsibilities of each licensed health professional as to what is in the patient's best interest.

(10/1999)

Both of these statements can be found on the North Carolina Medical Board web site at http://www.ncmedboard.org/pos2.htm.

COMMENTARY

Guiding the Decisions of Physicians and Families in End-of-Life Care:

The Case of Long-Term Feeding Tube Placement

Ethical and Judicial Affairs Committee, North Carolina Medical Society

The issue of long-term feeding tube placement for patients near the end of life who are unable to make decisions with regard to their own care is a complex issue for physicians and families. There is controversy about how appropriate the placement of percutaneous endoscopy gastrostomy (PEG) tubes might be in specific cases, and physicians have felt a need for clearer guidelines for their use. Consequently, the North Carolina Academy of Family Physicians asked that the 2001 House of Delegates of the North Carolina Medical Society (NCMS) undertake efforts to educate policymakers about the inappropriate use of long-term feeding tubes and to seek and support legislative and/or administrative actions supporting the adoption of the following language into law:

"Before placement of any long-term feeding tube, in a mentally incompetent patient, the hospital or nursing home ethics committee (whichever is appropriate) would have to review the case and render a non-binding written opinion. This opinion would have to be presented to the responsible parties. The rationale for this non-binding opinion would have to be explained to the responsible parties in easily understood layman's terms."

Resolution 1-2001 was referred for study to the Ethical and Judicial Affairs Committee of the NCMS, whose members undertook to develop an educational statement for physicians about the efficacy of long-term feeding tubes and then to convene a larger task force that would include representatives from external interest groups to develop a consensus on the statement.

"Tube feeding does not necessarily provide medical benefit to the dying patient by enhancing quality of life nor by reducing suffering."

A subcommittee was appointed and charged with developing a set of guidelines for physicians. The committee members were: Janelle Rhyne, MD, Chair; Darlyne Menscer, MD; Glenn Pickard, MD; Douglas Nelson, MD; Richard Stephenson, MD; and Lance Stell, PhD. The subcommittee met a number of times and produced a draft statement in the summer of 2003.

Given the sensitivity of the subject matter and the central role of patients and their families or loved ones in deciding whether a long-term feeding tube should be placed, the subcommittee also decided to promote the importance of patient and family education.

A task force, which included the subcommittee as well as representatives from nursing homes, hospitals, hospice, home health, elder law, speech pathology, the Medical Directors Association, was convened in September 2003. Members of the task force agreed that educational information was definitely needed on this issue for providers and patients alike. After significant discussion, the task force approved the following draft with some modifications. The task force also agreed that educational pieces for patients and their families should be promoted. The statement was subsequently approved by the House of Delegates of the North Carolina Medical Society in November 2003 and is presented here with the hope that it will be of value to physicians and families struggling with these issues in the care of patients and family members in these complex situations. **NCMJ**

Long-Term Feeding Tubes: Ethical Issues in Physicians' Decision Making

Statement Adopted by the North Carolina Medical Society House of Delegates, November 2001

When a decisionally incapable patient who suffers from a chronic, progressive illness develops swallowing difficulty, physicians, families, nurses, and other care providers have, with increasing frequency, elected non-oral nutritional support. However, recently accumulated outcome data make dubious a reflexive decision in favor of tube feeding in this setting.

- Feeding tube placement is associated with an in-hospital mortality of 15-25%, and a one-year mortality of 60%.
- Co-factors associated with increased risk of mortality include: advanced age, CNS pathology (CVA, advanced dementia), cancer (except early stage head/neck cancer), disorientation, and low albumin.
- Aspiration occurs in up to 50% of patients being tube fed.
- For patients with advanced dementia, feeding tubes have not proven effective in prolonging life, in preventing aspiration, or even in providing adequate nourishment.[1]

David Weissman, MD, has outlined the *tube feeding death spiral*:[2]

1. Hospital admission for complications secondary to brain failure or other predictable end organ failure due to primary illnesses (e.g. Urosepsis in the setting of advanced dementia)
2. Inability to swallow documented and/or direct evidence of aspiration and/or weight loss associated with low or no p-o (by mouth) intake
3. Swallowing evaluation followed by a recommendation for nonoral feeding.
4. Feeding tube placed followed by increasing patient agitation, resulting in feeding tube dislodgement.
5. Re-insertion of feeding tube; restraints placed.
6. Aspiration pneumonia
7. Intravenous antibiotics and pulse oximetry.
8. Repeat steps 4-6 two or more times.
9. Family conference.
10. Death

- The specter of aggressive, over-treatment was a major factor motivating the patients' rights movement.
- Legal and ethical standards have been developed to support an informed decision to withhold or withdraw any medical intervention, including tube feeding.[3]
- North Carolina does not prejudice with unique restrictions the medical decision of whether or not to place a feeding tube.
- There is no ethical or legal warrant for the physician to evaluate differently a decision to withdraw tube feeding from a decision to withhold tube feeding.[4]
- Advance care directives, such as living wills, healthcare powers of attorney, etc., enable decisionally capable patients to anticipate and plan for the contingency of losing their ability to communicate healthcare decisions, including a decision whether to withhold or withdraw tube feeding.
- Persons authorized to give informed consent to feeding tube placement on a patient's behalf may also make an ***informed refusal*** of tube placement.
- In the absence of advance care directives, a surrogate's decisions regarding feeding tube placement or removal should be based, whenever possible, on what the patient would choose in the circumstances. Otherwise, the surrogate's decisions should be guided by considering the patient's best interests.

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The physician should not bias a discussion of the pros and cons of tube feeding with an implicit assumption that nursing home residents would prefer tube feeding in the event they cannot swallow. On the contrary:

- A study of 421 randomly selected, competent persons living in 49 nursing homes found that only one-third would favor feeding tube placement if they were unable to eat because of permanent brain damage. Sixty-one percent opposed tube feeding. Of those who initially favored tube placement, 25% changed their preference when they learned that physical restraints might be necessary to facilitate feeding tube use.[5]
- The desire for tube feeding decreases as the hypothetical degree of cognitive impairment increases.[6]

Tube feeding does not necessarily provide medical benefit to the dying patient by enhancing quality of life nor by reducing suffering.

- Tube feeding is associated with increased agitation and may reduce quality of life and dignity because it increases the need for physical restraints;[7]
- Typically, dying patients do not experience hunger or thirst;
- Malnutrition, a concomitant of the natural dying process, should not be confused with "starvation";
- While dry mouth commonly occurs in dying patients, tube feeding does not relieve it;
- Complete relief from symptoms associated with dry mouth may be achieved with ice chips, moist sponge, sips of liquid, lip moisteners, hard candy, and mouth care."[8]

Recommendations:

- Prior to feeding tube placement in a decisionally incapable patient, it is the physician's ethical responsibility to determine whether the patient has executed an advance directive whose provisions may apply to the placement decision. Otherwise, the physician should take the lead in discussing with the patient's surrogate decision maker the pros and cons of long-term tube feeding.
- The physician should be prepared to address the common tendency to confuse "malnutrition" (a concomitant of the natural dying process) and "starvation."
- The physician should relate decisions about tube feeding +/- to achievable goals of care. A summary of discussions regarding tube feeding should be documented in the medical record.
- The goals of care should be reviewed regularly to determine whether, or to what degree, tube feeding promotes or contradicts them.
- Consultation with hospice or with a palliative care service facilitates setting realistic goals of care.
- Since tube feeding has not proven beneficial in patients with advanced dementia, but on the contrary, is associated with significant increased morbidity, mortality, and indignity, physicians may, in good conscience, recommend that it be withheld or withdrawn in these circumstances.
- In the event a valid decision is made to forego tube feeding, the physician should enter in the patient's medical record an order "Do Not Tube Feed."
- Patients who are genuinely hungry should be allowed to eat anything they please.

This document was written with adult patients in mind; issues facing pediatric patients were not discussed by the authors and are not addressed herein.

FEEDING TUBES—continued on page 245

FEEDING TUBES—continued from page 244

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COMMENTARY

Current End-of-life Issues:
A Practicing Physician's View

Phillip A. Sellers, MD

As a third-year internal medicine resident in the 1960s, I visited the small North Carolina Cancer Hospital in Lumberton, NC. To my amazement patients received no blood transfusions or nutritional supplementation; the only medication provided was morphine for pain. With my newly developed and up-to-date scientific knowledge about how to prolong life, I was disturbed by the predominant treatment philosophy in this facility. This was not the standard of care accepted by the medical community at that time, or now. Over the last 40 years, however, a new set of concepts has gradually been accepted by the healthcare delivery system and, more importantly, by most of the public.

End-of-life health policies have been slow to evolve. Living wills, healthcare power of attorney documents, Do-Not-Resuscitate (DNR) orders, as well as the so-called "yellow sheet" DNRs have all been made legal by the North Carolina General Assembly. The use of feeding tubes increased rapidly, but has now receded after studies have shown that feeding tubes used in the chronically ill are not as beneficial as we originally thought.[1] It is now clearly recognized that IV fluids and "hydration" are not indicated at the end of life. Dehydration and malnutrition do not cause symptoms or discomfort. The passing is easy. As the old-time practitioner always knew, pneumonia and infection frequently can be "the dying person's friend." Antibiotics may be contraindicated at the end.

The above changes include both good and bad concepts of care. Hospice care and the rapidly emerging new medical specialty of palliative care have better defined the concepts and how they should be applied. I would like to explore some of these from the perspective of the practicing physician.

Comfort Care

The concept of comfort care has developed over the last several years. The primary goal of comfort care treatment is to make the patient comfortable, which includes relieving the patient's pain and other symptoms. No other treatment is provided to sustain life. Medication such as sleeping pills, tranquilizers, and narcotics, as well as food and fluid by mouth, are appropriate to assure comfort. This is an excellent option for the chronically ill, severely demented, immobile nursing home patient, as well as for the less debilitated terminally ill cancer patient. In addition, for the competent patient who has verbally and unequivocally let it be known—and who has signed the appropriate legal papers such as a living will and a DNR order—comfort care is appropriate. For the incompetent patient who has a healthcare power of attorney who knows the patient's desire for comfort care only, it is also appropriate, especially if the appropriate papers were signed earlier.

Many have interpreted a living will or a DNR to mean comfort care only. This is not true. The living will is effective only when the patient has lost his or her competency to make her or his own decisions. The same is true for the Health Care Power of Attorney. Competency of the individual is the critical factor. A DNR order is only effective if the patient is not breathing or does not have a heart beat and therefore is not responsive. If there is a heart beat and the patient is breathing, the healthcare providers (emergency medical technicians, hospital and nursing home nurses, emergency room physicians, etc.) are obligated to treat unless the patient is competent and refuses treatment. This policy has resulted in many individuals receiving treatment they did not desire in hospitals, emergency rooms, nursing homes, and at home. An available, effective, and legal comfort care physician's order

> *"A trusting relationship between a terminally ill patient and her or his physician is the most important basis for realistic and good decision making."*

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would have averted the unwanted treatment. The patient could stay in the nursing home or at home and receive comfort care treatment without having their wishes exceeded.

Problems

Today some healthcare givers assume the presence of a living will or a DNR order is also a comfort care only order. It clearly is not. Many healthcare providers—including doctors, nurses, patients, and families—are unclear about the difference. At times there is a tendency for the care-giving medical staff to assume it is okay for the patient to die if there is a living will and/or a DNR order. The staff may not be as attentive to that patient's needs and complaints as they would be to patients having no living will or DNR order. Indicated and beneficial treatment may be delayed or not instituted.

Under comfort care orders, the decision not to treat with antibiotics frequently poses a dilemma. Do you treat reversible and easily curable urinary infections or skin infections? Some would argue treatment of an easily curable infection is a component of comfort care. But not all agree. There is no clear-cut answer to this question. A competent patient can make the decision at the time, but the incompetent need better-defined advanced directives.

The care of the patients with ultimately fatal medical illnesses, such as congestive heart failure or chronic obstructive pulmonary disease, is much more difficult to address from a comfort care or palliative care approach. To be comfortable, these patients will continue to need medication for treatment of their disease. Decision making and medication management are much more complicated and require more than the usual palliative or comfort measures. Prognosis is much more difficult to predict and instead of living for months the patient may live for years. I am concerned that the hospice principles will be applied too soon to some now receiving palliative care for chronic, slowly progressive medical illnesses. It may be detrimental to some patients.

Some in our community feel we make dying too easy and, subsequently, resist hospice care. Others believe that earlier application of hospice care services and principles give families of these patients much needed respite and enable them to better cope with the possibly long trajectory of illness and death.

> *"Recent efforts to involve team members—nurses, chaplains, social workers and psychologists—in educating both the patient and the family about end-of-life issues are very helpful."*

Team Care

The expansion of hospice and palliative care to include multiple other caregivers—such as physician's assistants, nurse practitioners, chaplains, nurses, social workers, and counselors—has been necessary and good. The personal doctor or specialist cannot do it all. The team is able to give the patient more comprehensive care.

Problems

My concern is that the personal or primary care physician is frequently left out of the loop. I would argue that the care can be just as good if the primary care doctor is involved and head of the team, so long as he or she functions as a "team member." Consistent attention to the needs of the patient is something the primary care physician can provide. The personal physician should know the patient better than any other care giver. The patient's own "doc" should not abandon the patient in his time of greatest need or as he approaches death. I realize my view is in the minority these days. In fact, many primary doctors are happy to turn their patients over to the hospice or palliative care team. Their view is that terminal care takes too much time for too little reimbursement. I think the reason goes deeper than this. Unfortunately, some physicians do not want to deal with the difficult management and emotional issues associated with dying. This is not good for long-term physician-patient-family relationships. I personally find helping a long-term patient die a good death is one of most beneficial things I do.

Family Relationships

Recent efforts to involve team members—nurses, chaplains, social workers and psychologists—in educating both the patient and the family about end-of-life issues are very helpful.

Problems

Frequently a family's understanding of the process of death and its variability is difficult. Much time must be expended in elucidating the diagnosis, deciding between treatment or non-treatment, and expected course. Families are vastly more knowledgeable about medical illnesses than in the past. But they may not fully understand the jargon in an experienced medical sense. A little knowledge may lead to great expectations both realistic and unrealistic. With their increased Internet-derived medical knowledge, families can reasonably challenge the physician's decision making. This more easily happens if family members have not been around the patient recently and have not experienced the patient's recent physical and mental decline.

Trust

A trusting relationship between a terminally ill patient and her or his physician is the most important basis for realistic and good decision making. It is even better if the trusting relationship extends to the family. A long-time physician-patient-family relationship in which all parties are comfortable and are free to express themselves in a trusting environment makes the care for all much easier. Primarily the patient needs to be comfortable and able to clearly communicate her or his wishes whenever the he or she wants. Compassionate caregivers must communicate with honesty, modified by prudence and fidelity to the patient's wishes.

Recommendations to Improve the Possibilities of a "Good Death"

POST - Physicians Orders for Scope of Treatment

The North Carolina General Assembly should approve the use of the POST form (as developed in West Virginia) as a legal upgrade to the currently approved North Carolina DNR Yellow Sheet. The proposed new "pink-sheet" or POST form has been approved by the West Virginia State Legislature for use in that state. The current North Carolina "yellow-sheet" DNR only addresses the patient with no pulse or who is not breathing. The new POST form addresses the patient with no pulse and not breathing plus offering options for comfort care only, not being hospitalized or moved, as well as decisions on whether or not to receive antibiotics or tube feedings. It fully defines the patient's desires and is reinforced by state law. For terminally ill or severely demented patients, it clearly defines for families, nursing homes, emergency medical technicians, and emergency room physicians, what should be done and not done. The POST forms are physician orders that will stay with the patient all the time and can be changed anytime, but only by a physician's order. You can learn more about POST at the West Virginia Center for End-of-Life Care at http://www.hsc.wvu.edu/chel/wvi/ContactUs.asp.

Patient-Physician Relationships

Physicians who know their patients well should continue to follow and be involved in critical decisions at the end of life. They should participate in the team approach to terminal illness and receive reasonable reimbursement for it.

Trust

For multiple reasons, trust in the healthcare system is becoming more difficult to achieve at the end of life. Physicians must see that patient trust is maintained to the end, and they must not abandon their patients.

So, we have indeed learned a lot from the time I visited the North Carolina Cancer Hospital in the 1960s about the appropriate treatment for those of us who are about to die. But we can always make it better. **NCMJ**

REFERENCES

1 Care of Patients Near the End of Life. American Medical Association, ACP-ASIM Section 2. Access at: www.ama-asn.org/ama/pub/article/print/7665-4827.html.

COMMENTARY

Why the Patient Self-Determination Act Has Failed

Dee Leahman

Deciding when and how to cross the bridge from curative to palliative care is both complicated and simple. Complicated by clashes in perspective and values: Opinions differ as to what is best for the patient, how quality of life should be defined, who is best qualified to make these important decisions.

Simple? Sometimes as simple as asking, "What would the patient want?" But what if they can't express themselves?

Over a decade ago the Patient Self-Determination Act (PSDA) was passed. If designed to give patients the right to refuse unwanted treatments before the fact so that tragedies like the family of Nancy Cruzan and Terri Schiavo faced would disappear, then the PSDA has not worked.

> *"Why are we still dying in places we would not choose, in ways we do not want, surrounded by strangers, our wishes undocumented, unknown and, therefore, often not honored?"*

Today, only about 30% of Americans have advance directives. Living Wills are the simplest, most common and least effective type. Healthcare Powers of Attorney require that you appoint a healthcare agent, tell that agent which treatment options you would choose under what circumstances, document your choices and wishes, make sure all the right people have copies of the document... Whoa!! Talk about complicated. Most people respond: "We'll get around to that later—when we need it." Discussion deferred.

As Dr. Laura Hanson points out in this edition's lead article,[1] "Patients and their families say they prefer terminal care at home, but four of five deaths in the United States take place in hospitals and nursing homes." In other words, about 80% of us would rather die in a home-like setting, but that only happens 20% of the time. What we say we want is NOT what we get. Why are we still dying in places we would not choose, in ways we do not want, surrounded by strangers, our wishes undocumented, unknown and, therefore, often not honored?

A cancer patient who was active in her church taught me the answer. Asked if she had talked with her doctor about her disease, she replied: "Oh, no! He's much too busy." I asked, "What about your minister?" "Lord, no," she replied. "This kind of talk makes him really uncomfortable." Her perceptions may not have been accurate but they kept her from helpful information and support she needed.

I agree with Dr. Hanson when she says "patients generally welcome these conversations, and many are willing to record their wishes in some form." I also believe that most patients, physicians, and family members are reluctant to *initiate* the conversation. Once given permission and some coaching, discussion flows freely. But permission to talk about these care options is often implicitly denied.

Most of us know clearly what kind of treatment we want near life's end. Few of us are comfortable and skilled when approaching the subject. Avoiding discomfort now, we invite confusion, conflict, and permanent damage to relationships later. Documented wishes are often too vague to be of much help once patients cannot speak for themselves. The only fail-safe I know is thorough and early conversations about these tough decisions.

We have failed in implementing the Patient Self-Determination Act because we have allowed documents to speak for us, and paper can't talk. We don't say the right things to the right people at the right time in the right place. We have failed both organizationally and personally.

Organizationally

Organizations receiving Medicare funding are mandated to distribute advance care documents and information about them. *Wrong place!*

Information about living wills and healthcare powers of

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attorney is given to patients upon admission to healthcare facilities along with a mix of other material about the facility. ***Wrong time!***

Healthcare facility admissions personnel seldom have time to facilitate in-depth advance care planning discussions and often don't have answers to questions that should be asked. ***Wrong person!***

Admissions staff ask, "Yes or No: Do you have an advance directive?" Most of the time that is translated to the easier default: "Do you have a Living Will?" Healthcare Powers of Attorney are more complicated and confusing. Time is limited. Seldom is the patient asked to identify their healthcare agent. Most patients don't bring a copy of the document with them. Many medical records that have the "yes" box marked do not contain copies of advance care documents that are easy to access and understand. Even completed documents clearly marked on the medical record do not give physicians much direction. They are often vague and open to interpretation. That is not a good thing in the presence of difference of opinion. ***Wrong mechanism!***

Personally

Focus has been on documents rather than on the all-important conversation. Time, skill, and comfort level are in short supply all around when talking about treatment options and end-of-life care decisions. Parents don't want to upset children; children don't like talking to their parents about life's end. Patients expect the physician to bring it up. Physicians hope the patient will. In short, the conversation doesn't happen, at least not in the way it should.

The Carolinas Center for Hospice and End of Life Care, in collaboration with the North Carolina AARP and the Life's End Institute in Missoula, Montana, conducted a survey of North Carolina AARP members that revealed interesting facts about the way they approached (or did not approach) discussions about end-of-life care.

Ninety-two percent of respondents reported they wanted honest answers from their physician; 88% wanted to understand treatment options; 74% feared dying painfully. Even so, only 11% had spoken to their physician about their concerns.

Eighty-three percent said it is very important to be at peace spiritually (this number was 93% among African American respondents); 62% said it is very important to have comfort from spiritual or religious persons. Still, only six percent had talked with their clergy about these issues.

What an Incredible Disconnect!

Instead of using the documents as a catalyst to promote conversation, they have been used as a shield to protect us from having the conversation. The formal documents leave out the personal touch.

Two of my most memorable conversations about advance directives and end-of-life care, one with an aging relative, the other with my closest friend, taught me a lot about how important the details of the conversation can be and how void of meaning and direction the documents alone are.

Mamie was practically blind and deaf. She knew she didn't have much longer to live. She was bed ridden and dependent on others but mentally alert. As we talked about her future, she said, "I can't hear, I can't see. I can hardly move. But I can still smell. Can we get some flowers and scented candles in here?" I couldn't find that request anywhere in her formal documents.

I asked my friend: "What's on your list of the kind of care you'd like near the end of life?" He said quickly and matter-of-factly, "I want my pain controlled. I'd like to be with people I love. And I want music."

"Fine," I said. "I can help make that happen." We changed the subject. A few days later I realized I had failed to ask something important: What ***kind*** of music did he want? I assumed I knew, knowing what he listened to all the time. I asked, "Classic Rock, right?" He replied, "No, Celtic Harp." Lessons learned: it's in the details; ask the right questions.

You would think that healthcare professionals would have protected themselves and those they love by selecting a healthcare agent and documenting their wishes. They will have expressed to their agent and those in their important "inner circle" details about the setting, care, treatment options, and personal details they'd like someone to handle when they can no longer speak or act for themselves. Knowing that such a conversation makes it more likely that their wishes will be honored, they will have recorded their wishes and made them easily accessible to the right people. Not so. A clear majority of most audiences of physicians, nurses, social workers, clergy, and attorneys I speak to have not adequately dealt with these issues.

I maintain that it is difficult, if not hypocritical, to encourage patients to do advance care planning unless we have done it ourselves. It is appalling that so many of us are willing to subject our patients, our families, and ourselves to "pot luck" when it comes to end-of-life care.

So What Can We Do?

1 Normalize the conversation. Talk about the taboos early, prior to diagnosis or crisis. Ask about the kind of care they want. Take enough time or make a referral to someone who can.

I like the familiar model of the "consult." If my primary care physician discovers I have a cardiac problem, she calls for a cardiac consult. If I'm in respiratory distress, she may ask for a pulmonary consult. Why not call for an advance care planning consult if a patient needs assistance discussing and documenting one's end-of-life care wishes?

2 With terminal diagnoses, help the patient and family redefine hope. Rather than avoiding the truth, creating false hope, and delaying the inevitable, help patients and families focus on hope for comfort and maximizing quality of remaining life. As Dr. Hanson points out, identifying the point in time to transition from curative to palliative care and helping the patient and family manage that transition well is one of the central dilemmas of end-of-life care. I like her mention of compassionate communication. She states, *"Absent this skill, physicians will be unable to help patients decide on appropriate treatments, assess physical symptoms, or address emotional and spiritual suffering. Meaningful and compassionate communication is the core skill in end-of-life care. Patients facing the crisis of their own mortality require time to express fears and to seek reassurance of physician attention to their needs, in addition to medical aspects of their care."*

3 Use the documents as a vehicle to foster discussion about treatment options and preferences rather than viewing them as the desired outcome

4 Encourage policy change by sponsoring consumer and physician-friendly statutes such as Oregon's POLST (Physician Orders for Life-Sustaining Treatment) or West Virginia's POST (Physician Orders for Scope of Treatment). Become a process improvement activist in institutions having difficulty with advance directive documentation, tracking, and education. Help create an organization recognized for patients' wishes being known, documented, and honored wherever possible.

5 Spend time talking with patients' families about the whole person, not just the medical components of the disease. An unsolicited, positive outcome of this kind of trust-building dialogue is risk reduction. Well informed families who feel the physician has been caring, compassionate, and open are less likely to litigate.

6 Help "relocate" advance directives. Move them out of the acute care setting and "upstream" to physicians' offices, ministers' studies, estate planning sessions with attorneys, and kitchen table conversations.

7 Break the barrier of silence by bringing the subject of advance care planning into routine intake and assessment appointments. Add questions related to selection of a healthcare proxy to paperwork completed during the initial visit.

Linda Lewis, former hospice chaplain and currently Project Coordinator for *Faith In Action* End of Life Care Ministries at the Hospice & Palliative CareCenter in Winston-Salem, North Carolina, sums it up well:

> *"What used to be the moment of death when life ended fairly abruptly and quickly, has now become, in many cases, the season of death. Ventilators, feeding tubes, artificial hydration, dialysis, and even antibiotics can prolong the inevitable, meaning that the dying process may take weeks or months, or as in Terri Schiavo's case, even years.*

The dialogue has to be more than, "I don't want to live like a vegetable." What is it that makes life meaningful? What would I want my family and other decision-makers to know about me should I be unable to communicate my wishes? Encouraging people to complete Advance Directives is important, but these documents are of little use unless open and reflective conversation has taken place with those who may be faced with making crucial decisions in a time of crisis.

This is not just about "autonomy," the ethical principle that has guided most of the discussion around these issues in recent years. It is not just about "what I want." Who will be the one to speak for me when I cannot speak for myself? What does that person need to know about my values and my feelings about life? How can I have conversations now that will pave the way for wholeness and community when a crisis occurs? Personal wishes need to be discussed in the context of community, recognizing that others will be involved in carrying out wishes and will be affected by decisions that are made. Meaningful conversations with loved ones before a crisis not only help make medical decisions easier down the road; they can also strengthen relationships and create bonds as life values are shared openly and honestly."

Too many people are dying in ways they would not choose simply because they did not talk about it ahead of time. Physicians can only honor patients' wishes if they know what those wishes are. Encourage the conversation.

REFERENCES

1 Hanson, LC. Palliative Care: Innovation in Care at the End of Life. *North Carolina Medical Journal* 2004:65(4): 202-208.

Running the Numbers

A Periodic Feature to Inform North Carolina Healthcare Professionals
About Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
www.schs.state.nc.us/SCHS

Deaths Among North Carolinians Age 85 and Older

According to the United States Census Bureau, the nation's population age 85 and older is projected to increase from 4.5 million in 2002 to 9.6 million in 2030. North Carolinians also are living longer and dying later in life than in the past. In 2002, there were 17,739 deaths of North Carolina residents age 85 and older. This represented 25% of all 71,780 deaths of North Carolina residents during 2002. By comparison, deaths to persons age 85 and older were 14% of all deaths in 1980.

In 2002, there were 1,938 deaths of persons at exactly age 85, and the number declined steadily at each single year of age, with 238 deaths of persons age 99. There were 461 deaths of persons age 100 and older in 2002, with the oldest reported age at death being 113 (one death).

Of the deaths of persons age 85 and older, 70% were female and 30% were male. Seventy-four percent were widowed and 19% were married at the time of death. Men age 85 and older who died were much more likely to be married than women: 48% compared to 6%. For deaths of North Carolina residents of all ages, 51% were female and 49% were male; 38% were widowed, 40% were married, 11% were never married, and 10% were divorced. Fifty-eight percent of decedents age 85 and older had less than a high school education, compared to 47% of decedents of all ages.

Persons age 85 and older are much more likely to die in a nursing home. Among deaths of those age 85 and older, 42% occurred in a nursing or rest home, 39% in a hospital, and 16% in the home or not in an institution. For deaths of North Carolina residents of all ages in 2002, the comparable percentages are 20%, 50%, and 23%. Cremation occurred for 15% of the deaths of persons age 85 and older, compared to 19% for North Carolina resident deaths of all ages.

Following are the ten leading causes of death in 2002 for persons age 85 and older:

Cause of Death	Number of Deaths	% of Total Deaths
Heart disease	5,616	32%
Stroke	2,005	11%
Cancer	1,987	11%
Alzheimer's disease	1,124	6%
Pneumonia and influenza	863	5%
Chronic lung disease	711	4%
Diabetes	411	2%
Nephritis and nephrosis	394	2%
Non-motor vehicle unintentional injuries	384	2%
Septicemia	305	2%
All other causes	3,939	22%
TOTAL	17,739	100%

For persons age 85 and older, heart disease and stroke accounted for 43% of the total deaths in 2002, compared to 33% for persons of all ages. Cancer deaths were 11% of the total for persons ages 85 and older, compared to 23% for deaths of persons of all ages. Alzheimer's disease accounted for 6% of deaths of persons age 85 and older, compared to 3% of deaths in the total population.

Contributed by Paul A. Buescher, PhD
State Center for Health Statistics, North Carolina Division of Public Health

Letters to the Editor

Infant Mortality in North Carolina

To The Editor:

I have just reviewed the May/June 2004 issue on Infant Mortality. It is very well done. In particular, the article on folic acid by Robert Meyer and Anna Bess Brown was of particular interest. It is nice to know that some of one's efforts pay off. I chaired the Food and Drug Administration (FDA) Food Advisory Committee (FAC) that recommended folic acid fortification of cereal grains. This was a very controversial issue for two reasons. The first concerned the principle of whether the FDA should order the "artificial" modification of "natural" foods. The second was more substantial and was concerned with how much folic acid should be added. The issue was to not increase it so much that Vitamin B12 deficiency was masked in the elderly since the elderly consume more cereal grains than young women. Hence, the final level will not meet the 40mcg. needed in young women. In spite of this final decision, it is clear that folic acid fortification of cereal grains is having an effect.

Edward N. Brandt, Jr. MD, PhD
Regents Professor
Health Sciences Center
University of Oklahoma
Oklahoma City, OK

(The writer was Assistant Secretary for Health, United States Department of Health and Human Services under President Ronald Reagan.)

To The Editor:

I read with interest the article, "Demand for CME Programs on Cancer Care Among Primary Care Physicians in North Carolina," published in the May/June 2004 issue of the *North Carolina Medical Journal.* As a Continuing Medical Education (CME) provider for one of the North Carolina Area Health Education Centers (AHEC) organizations, we survey physicians in the 16-county western region of the state each year, and our survey results support the findings of Dr. Anderson, Dr. Torti, and their research associates and assistants at Wake Forest University School of Medicine.

In response to our regional survey in the fall of 2003, we began last spring to plan a CME conference to address primary care physicians' concerns and the clear need for updated information. I am pleased to report that the Lineberger Comprehensive Cancer Center at UNC-Chapel Hill responded to our need, and the conference is scheduled October 8 and 9 at Fairfield Mountains, Lake Lure, NC.

Dr. Beverly Mitchell, Associate Director of the Lineberger Comprehensive Center, is serving as the medical course director of Early Detection, Screening, and Detection of Malignancies—A Cancer Update for Primary Care Providers. She will be joined by six of her colleagues, and the topics will include updated information on cancer of the breast, colon, lung, prostate, and skin, as well as discussions on hematological and central nervous system malignancies.

I encourage interested primary care physicians who would benefit from the October conference to visit our website www.mtn.ncahec.org for more information.

I extend my thanks to you for highlighting a pressing educational need in your journal.

Sincerely,
Irene D. Jurczyk,
Co-Director Continuing Medical Education
Mountain Area Health Education Center (MAHEC)
Asheville, NC

> *"It is nice to know that some of one's efforts pay off... it is clear that folic acid fortification of cereal grains is having an effect."*

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Since January 2002,
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In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the North Carolina Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The North Carolina Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 when the North Carolina Medical Society reached the decision to cease support for its publication. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The Journal provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The Journal makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy

North Carolina Institute of Medicine

Coming in the Sept/Oct 2004 issue of the

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a look at

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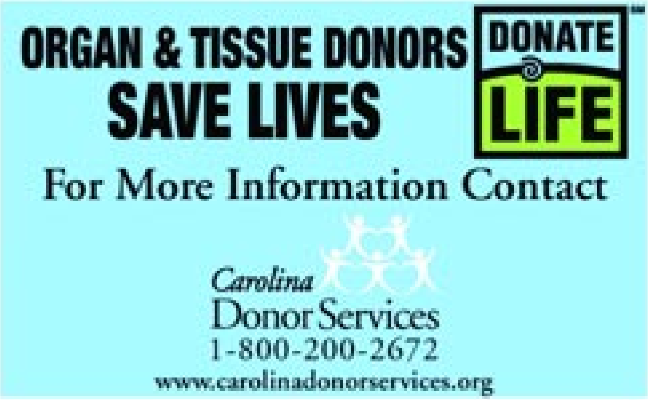
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- North Carolina's Family Caregiver Support Program can provide help for caregivers of persons 60 or older.
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North Carolina Medical Journal: Call for Papers

Herbert G. Garrison, MD, MPH
Scientific Editor, North Carolina Medical Journal

North Carolina is blessed with some of the finest medical research institutions in the world. The work of the medical scientists that labor in our research facilities becomes complete (in many ways) and public when it is published in peer-reviewed journals.

While medical researchers in North Carolina have many journals to which they can submit their manuscripts, we want them to consider keeping their work here at home. To be more specific, we invite the authors of our state to submit their papers to the *North Carolina Medical Journal*.

The *Journal* seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

An editor reviews all papers received and those of sufficient quality are peer-reviewed. As with any journal of merit, only papers of high quality will be published. Papers printed in the Journal are indexed in the National Library of Medicine's MEDLINE public database.

The *North Carolina Medical Journal* is published six times a year. It is distributed free of charge to the members of the North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina College of Internal Medicine, the North Carolina Academy of Physician Assistants, the North Carolina Board of Pharmacy, the North Carolina Association of Pharmacists, the North Carolina Division of Public Health, the North Carolina Association of Health Plans, and the Medical Review of North Carolina. The *Journal* is available by subscription to others.

For guidance on manuscript preparation, authors should consult the "Author Guidelines," which can be found at www.ncmedicaljournal.com.

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For more information, contact Jill Blalock at jblalock@ncqio.sdps.org, or 919-380-9860, ext. 2004, or visit our website at www.mrnc.org.

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