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End-of-Life Care in a Rural State

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Dying with Dignity

By Tony L. Berg, MD
SDSMA President

Everybody dies, but not always with dignity. All too often, members of our community live out their last days of life confused by medical issues, stunned by health care expenses, in physical and/or emotional pain, and alone.

According to research conducted by LifeCircle South Dakota, an interdisciplinary organization home-based at the Sanford School of Medicine of The University of South Dakota, the five critical elements in the practice of end-of-life care are pain management, non-pain symptom management, spiritual issues, advance directives and family support.

As physicians, our patients and their family members often look to us for answers and guidance to help them through the final stages of life. I think this is especially true in our more rural areas where physicians are often viewed as leaders in their community and where multi-disciplinary teams, designed to help those reaching end of life, are not as readily available.

To assist you in caring for patients who are reaching or already receiving end-of-life care, I encourage you to read this special issue of *South Dakota Medicine*. Within this issue, you will find articles on hospice and palliative care, advance directives, pain management, end-of-life ethical and legal issues, and bereavement.

Thank you, and congratulations to the SDSMA staff, the South Dakota Department of Health and the contributing physicians who have worked so hard to create this special issue of *South Dakota Medicine*.

Tony L Berg MD

Dear South Dakotans:

On behalf of the Department of Health, it is my pleasure to recognize this very special issue of *South Dakota Medicine*.

End-of-life care, the focus of this issue, is a subject with the potential to touch each one of us on a very personal level. Whether we are caring for a loved one with a terminal illness or confronting our own mortality, end-of-life issues such as pain management, advance directives and family support are critically important.

When we find ourselves in these situations we naturally turn to our physicians for support and guidance. This special issue is dedicated to giving physicians the information and resources they need to better prepare for that difficult role. The intent is to help physicians help their patients live out their last days with dignity and compassion.

The Department of Health congratulates the South Dakota State Medical Association, the South Dakota Alliance for Advance Directives and all other partners involved on their efforts to address the difficult but important issue of end-of-life care. We are pleased to have played a part in developing this issue, and we are confident it will benefit both physicians and the patients in their care.

Sincerely,

Doneen B. Hollingsworth

Doneen B. Hollingsworth
Secretary of Health

Dear Reader,

I would like to welcome you to the first special edition of *South Dakota Medicine*. These special editions are designed to explore in more detail an important area of health care affecting South Dakotans. Appropriately, this first edition evaluates end-of-life care, which affects all of us in multiple ways including our patients, families and ourselves. In this edition we have gathered articles from leaders in end-of-life care throughout the state and region.

This compendium of manuscripts begins with a paper on the causes of mortality throughout the life-cycle in South Dakota. Articles then address ethical, moral and legal issues involving end-of-life care and the importance of discussing these issues with our patients who are affected with life-threatening illnesses. The focus then shifts to explore palliative care and the effect of cultural, spiritual and age-related differences. These are well-written manuscripts that remind us of the diversity among our patients and the importance of considering age, culture and spirituality as we provide care. Also included in this issue is commentary that explores assessment and management of pain and non-pain symptoms at the end of life. This special edition finishes with a discussion of hospice care (an often underutilized service), as well as the appropriate use of artificial hydration and nutrition.

I hope you find *End-of-Life Care in a Rural State* educational and a good resource for clinical practice. I want to thank our authors who dedicate their energies to caring for patients during this critical time and who, through this special edition of our journal, share their expertise with our readership.

Sincerely,

Keith A. Hansen, MD

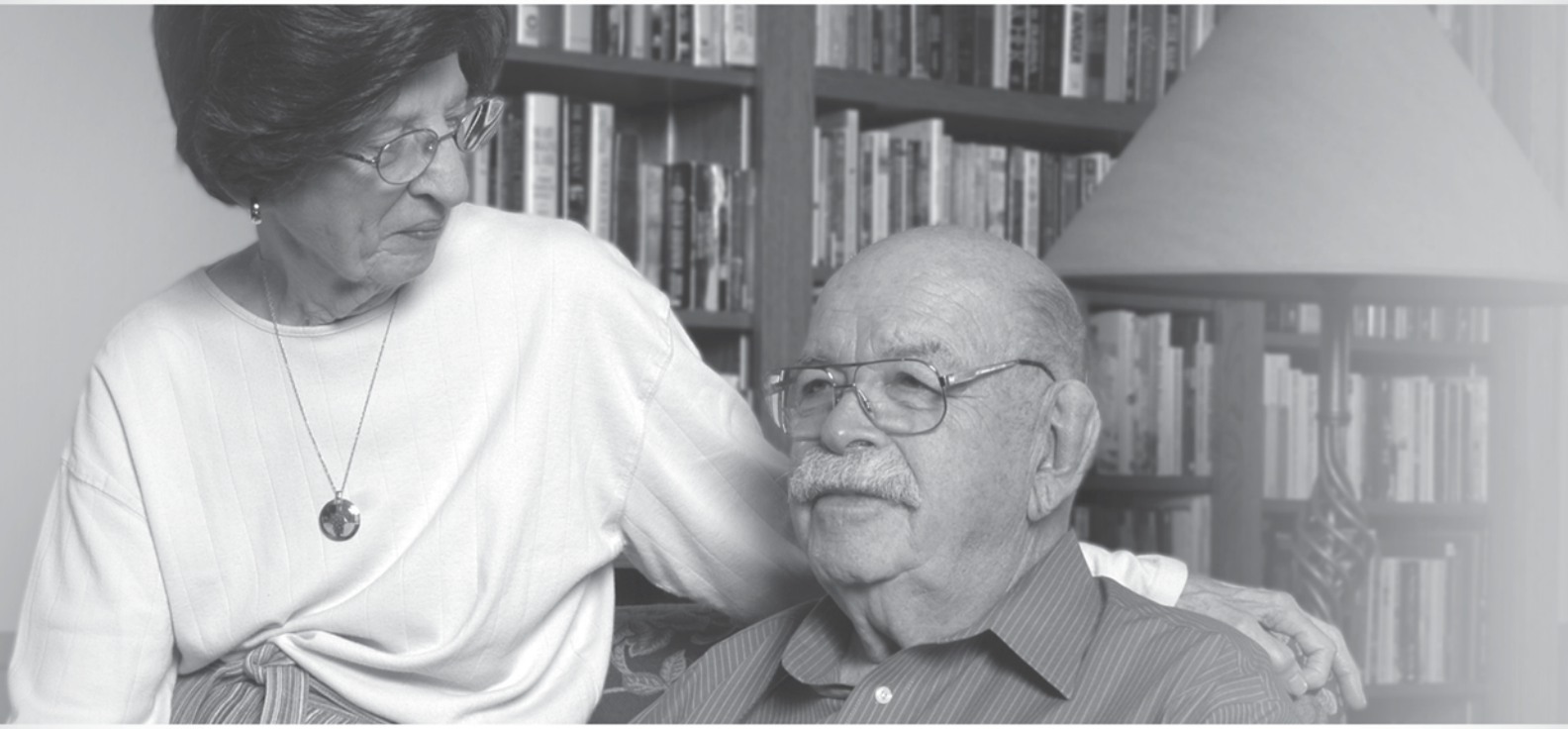
Co-Editor, *South Dakota Medicine*

SPECIAL EDITION 2009

Anti-Tobacco

What Tobacco is Doing to South Dakota's Children

A COMMUNITY OF CARE



Lenore is a retired nurse educator.
George is a retired college professor and administrator.

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Dying in South Dakota: Causes of Mortality

By Lon Kightlinger, PhD, MSPH; Mark C. Gildemaster, MS

Abstract:
This article reviews South Dakota's historical death rates and reports recent death rates (2000-2006) and leading causes of death by gender, race, age and county. The recent leading causes of death in South Dakota were heart disease, cancer, stroke, chronic lower respiratory diseases and accidents. Accidents were the second leading cause of death for American Indians and the third leading cause of death for South Dakota males. Accidents were the leading cause of death for individuals between the ages of 1 and 44. Sixty-three percent of deaths were among the elderly 75 years old and older. The age-adjusted death rate for South Dakota residents was lower than the national rate.

The South Dakota Department of Health (DOH) is legally responsible for the registration of deaths in the state. The cause of death and demographic details are determined and documented by a local physician or coroner who submits the death certificate to the DOH. Death or morbidity statistics are reported annually by demographic stratification as aggregate numbers, crude death rates (deaths per 100,000 population), age-adjusted death rates (an age standardization used to compare different populations as deaths per 100,000 population) and death percentages.[1]

South Dakota's death rate is lower than the national death rate. The most recent published national data (2002-2004[2]) report the average annual age-adjusted death rate for South Dakota as 770 deaths per 100,000 population, which is lower than the national rate of 826 deaths per 100,000 population. South Dakota's 2002-2004 age-adjusted death rate was the eleventh lowest in the country (Figure 1). Hawaii had the lowest age-adjusted death rate with 647, and Mississippi had the highest with 1,011 deaths per 100,000 population. South Dakota's white residents had the third lowest death rate, 728, in the country for white people, behind only Minnesota and North Dakota. South Dakota American Indian residents had the highest age-adjusted death rate of any race/ethnic group in the country with 1,542 deaths per 100,000 population.

Historically, the annual crude death rate in South Dakota over the past century ranged from 700 to 1,180 deaths per 100,000 population (Figure 2). The years with the highest

Figure 1. Age-adjusted death rates by state, United States, 2002-2004 (deaths per 100,000 population)[2]

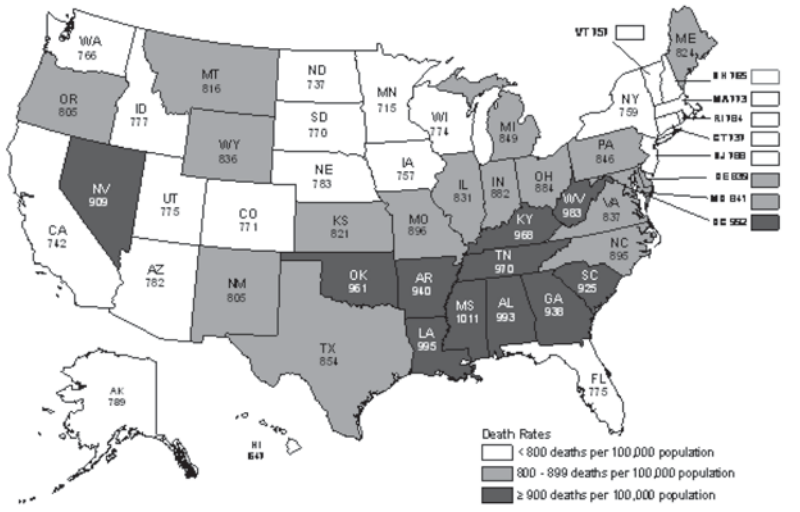


Figure 2. Crude death rate, South Dakota, 1906 – 2006 (deaths per 100,000 population)

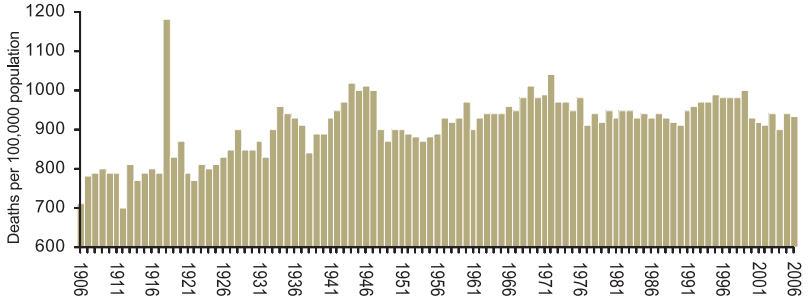


Table 1. Leading causes of death, number of deaths and annual average crude death rate*, South Dakota residents, 2000-2006[1]

Cause of Death	Number	Crude death rate*	Percent of deaths
Total deaths	48,847	892.4	100.0
1. Heart disease	13,246	242.0	27.1
2. Malignant neoplasms (cancer)	11,138	203.5	22.8
3. Cerebrovascular diseases (stroke)	3,456	63.1	7.1
4. Chronic lower respiratory diseases	2,716	49.6	5.6
5. Accidents (unintentional injuries)	2,680	49.0	5.5
6. Alzheimer's disease	1,557	28.4	3.2
7. Diabetes mellitus (diabetes)	1,510	27.6	3.1
8. Influenza and pneumonia	1,451	26.5	3.0
9. Intentional self-harm (suicide)	762	13.9	1.6
10. Nephritis, nephrotic syndrome, nephrosis (kidney disease)	698	12.8	1.4
All other causes	9,633	176.0	19.7

*Average annual crude death rates are per 100,000 population, based on the 2006 population estimate, U.S. Census Bureau.

crude death rates were 1918, with 1,180 deaths per 100,000 population (the year of the Great Influenza Pandemic), and 1972, with 1,040 deaths per 100,000 population (the year of the Rapid City flood).

Since the new millennium, 2000-2006, there have been 48,847 South Dakota resident deaths reported (median 7,014 deaths per year; mean 6,978, range 6,811 – 7,109).

The overall leading causes of death in South Dakota during this period are reported in Table 1. The two leading causes of death, heart disease and cancer, accounted for half of South Dakota deaths.

For both South Dakota men and women, heart disease and cancer were the leading causes of death (Table 2). The accident death rate among South Dakota men, 63.4 per 100,000, was nearly double the rate among women, 34.6, and was the third leading cause of death for men, but sixth for women. The Alzheimer's death rate among South Dakota women, 41.2, was nearly three-times the rate as among men, 15.7. Suicide was the seventh leading cause of death among men, but does not rank among the top 10 for women.

In South Dakota, 92.2 percent of all resident deaths were among whites, 7.2 percent among American Indians and 0.5 percent among other races during the 2000-2006 interval. This compares to a population breakdown of 88.7 percent white, 9.0 percent American Indian and 2.3 percent for other races. For both whites and American Indians heart disease was the leading cause of death (Table 3). The top causes of death in the white population mirrored the full population, with the addition of "unspecified dementia" being the ninth leading cause. It is notable that more American Indians died of accidents than of cancer. Included in the top 10 leading causes of American Indian death were chronic liver disease, cirrhosis, suicide and homicide.

Table 2. Leading causes of death by gender, number of deaths and annual average crude death rate* (CDR), South Dakota residents, 2000-2006[1]

Males	Deaths	CDR
Total deaths	24,497	896.0
1. Heart disease	6,683	244.4
2. Cancer	5,953	217.7
3. Accidents	1,733	63.4
4. Chronic lower resp. diseases	1,530	56.0
5. Stroke	1,376	50.3
6. Diabetes	714	26.1
7. Intentional self-harm (suicide)	638	23.3
8. Influenza and pneumonia	609	22.3
9. Alzheimer's disease	429	15.7
10. Kidney disease	358	13.1
Females	**Deaths**	**CDR**
Total deaths	24,349	888.8
1. Heart disease	6,563	239.6
2. Cancer	5,185	189.3
3. Stroke	2,080	75.9
4. Chronic lower resp. diseases	1,186	43.3
5. Alzheimer's disease	1,128	41.2
6. Accidents	947	34.6
7. Influenza and pneumonia	842	30.7
8. Diabetes	796	29.1
9. Unspecified dementia	485	17.7
10. Kidney disease	340	12.4

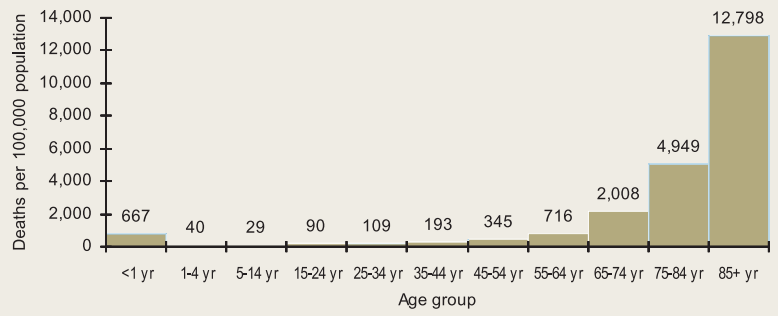
*Average annual crude death rates are per 100,000 population, based on the 2006 population estimate, U.S. Census Bureau.

Table 3. Leading causes of death by race, number of deaths and annual average crude death rate* (CDR), South Dakota residents, 2000-2006[1]

White	Deaths	CDR
Total deaths	45,043	931.1
1. Heart disease	12,546	259.3
2. Cancer	10,585	218.8
3. Stroke	3,326	68.8
4. Chronic lower resp. diseases	2,606	53.9
5. Accidents	2,079	43.0
6. Alzheimer's disease	1,541	31.9
7. Influenza and pneumonia	1,364	28.2
8. Diabetes	1,263	26.1
9. Unspecified dementia	680	14.1
10. Kidney disease	628	13.0
American Indians	**Deaths**	**CDR**
Total deaths	3,530	756.4
1. Heart disease	638	136.7
2. Accidents	561	120.2
3. Cancer	504	108.0
4. Chronic liver disease, cirrhosis	233	49.9
4. Diabetes	233	49.9
6. Intentional self-harm (suicide)	126	27.0
7. Stroke	115	24.6
8. Chronic lower resp diseases	106	22.7
9. Influenza and pneumonia	83	17.8
10. Assault (homicide)	77	16.5

*Average annual crude death rates are per 100,000 population, based on the 2006 population estimate, U.S. Census Bureau.

Figure 3. Average annual crude death rate by age, South Dakota, 2000-2006 (deaths per 100,000 population)

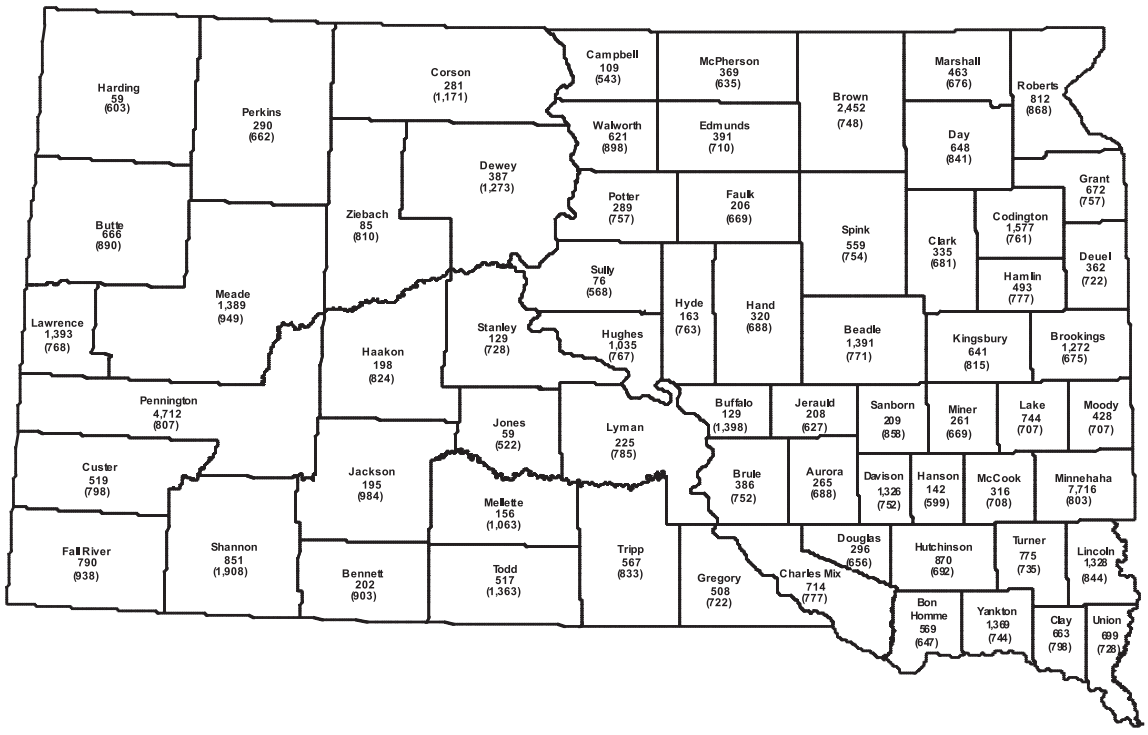


The numbers of deaths, rates and causes varied by age group. Figure 3, showing the South Dakota resident crude death rate stratified by age, reveals higher death rates among the elderly. Death among South Dakota's elderly, 75 years old and older, accounted for 63.2 percent of all deaths in the state during the 2000-2006 period. The leading causes of death by age group are reported in Table 4. The leading causes of death among the elderly were heart disease and cancer. Death among the very young, infants less than 1 year of age, accounted for 1.1 percent of deaths. The top causes of infant death were congenital malformations, deformations, chromosomal abnormalities and sudden infant death syndrome (SIDS). Accidents were the number one cause of death among children and young adults in the 1-4, 5-14, 15-24, 25-34 and 35-44 year age groups, which has similar ranking to national data.[2] Cancer was the leading cause of death for adults in the 45-54, 55-64 and 65-74 year age groups, but among the elderly, 75 years old and older, heart disease was the top cause of death. Suicide was the second leading cause of death in the 15-24 and 25-34 year age groups.

When death rates are age-adjusted the counties with the oldest populations had the lowest age-adjusted death rates. The South Dakota counties with the lowest age-adjusted death rates (Jones 522, Campbell 543 and Sully 568 deaths per 100,000) had greater than 17 percent of their populations age 65 years old and older, whereas the counties with the highest age-adjusted death rates (Shannon 1,908, Buffalo 1,398 and Todd 1,363 deaths per 100,000) had less than 7 percent of their population age 65 years old and older (Figure 4).

Although South Dakota's death rate is lower than the national death rate, disparities within the state are evident. The foremost disparity is the high rate of American Indian accidental death. Accidents were also the leading cause of death among children and young adults. Although many

Figure 4. Number of deaths and (age-adjusted death rates) by county, South Dakota, 2000-2006 (deaths per 100,000 population)



accidents are preventable with contemporary technology, current public awareness and individual responsibility are insufficient. Healthy lifestyle is crucial in reducing deaths due to cancer, heart disease, stroke and diabetes. Reducing tobacco use and obesity and increasing physical activity and healthy dietary habits should lower the numbers of premature, preventable deaths.

Table 4. Rank order of leading causes of death by age, number of deaths, annual average crude death rate* (CDR) and percent of deaths, South Dakota residents, 2000-2006[1]

	Deaths	CDR	Percent
Ages under 1 year: total deaths	535	666.7	
1. Congenital malformations, deformations and chromosomal abnormalities**	155	193.2	29.0
2. Sudden infant death syndrome	78	97.2	14.6
3. Disorders related to short gestation and low birth weight, not elsewhere classified	48	59.8	9.0
4. Accidents***	32	39.9	6.0
5. Newborn affected by maternal complications of pregnancy	23	28.7	4.3
6. Newborn affected by complications of placenta, cord and membranes	22	27.4	4.1
7. Atelectasis	18	22.4	3.4
8. Cardiovascular disorders originating in perinatal period	11	13.7	2.1
9. Intrauterine hypoxia and birth asphyxia	10	12.5	1.9
10. Hydrops fetalis not due to hemolytic disease	8	10.0	1.5
10. Respiratory distress of newborn	8	10.0	1.5
All other causes of death	122	152.0	22.8
***Includes congenital malformations of heart, 34; Congenital malformations and deformations of musculoskeletal system, limbs and integument, 21; Congenital malformations of genitourinary system, 15; Anencephaly and similar malformations, 14; Patau's syndrome, 11; Edward's syndrome, 11.*			
****Includes accidental suffocation and strangulation in bed 12.*			
Ages 1-4 years: total deaths	122	40.2	
1. Accidents	61	20.1	50.0
2. Congenital malformations, deformations and chromosomal abnormalities	14	4.6	11.5
3. Assault (homicide)	13	4.3	10.7
4. Cancer	5	1.6	4.1
All other causes of death	29	9.6	23.8
Ages 5-14 years: total deaths	211	28.8	
1. Accidents	122	16.6	57.8
2. Cancer	18	2.5	8.5
3. Intentional self-harm (suicide)	16	2.2	7.6
4. Congenital malformations, deformations and chromosomal abnormalities	11	1.5	5.2
5. Heart disease	6	0.8	2.8
5. Septicemia	6	0.8	2.8
7. Disorders of sphingolipid metabolism and other lipid storage disorders	3	0.4	1.4
7. Cerebral palsy	3	0.4	1.4
7. Influenza and pneumonia	3	0.4	1.4
7. Stroke	3	0.4	1.4
All other causes of death	20	2.7	9.5
Ages 15-24 years: total deaths	742	89.7	
1. Accidents	396	47.9	53.4
2. Intentional self-harm (suicide)	170	20.6	22.9
3. Cancer	35	4.2	4.7
4. Assault (homicide)	32	3.9	4.3
5. Heart disease	14	1.7	1.9
6. Congenital malformations, deformations and chromosomal abnormalities	11	1.3	1.5
7. Cerebral palsy	10	1.2	1.3
8. Epilepsy	7	0.8	0.9
8. Stroke	7	0.8	0.9
10. Events of undetermined intent	6	0.7	0.8
All other causes of death	54	6.5	7.3

Table 4. Rank order of leading causes of death by age, number of deaths, annual average crude death rate* (CDR) and percent of deaths, South Dakota residents, 2000-2006[1]

	Deaths	CDR	Percent
Ages 25-34 years: total deaths	722	108.5	
1. Accidents	276	41.5	38.2
2. Intentional self-harm (suicide)	132	19.8	18.3
3. Cancer	72	10.8	10.0
4. Heart disease	46	6.9	6.4
5. Assault (homicide)	25	3.8	3.5
5. Chronic liver disease and cirrhosis	25	3.8	3.5
7. Congenital malformations, deformations and chromosomal abnormalities	15	2.3	2.1
8. Events of undetermined intent	14	2.1	1.9
9. Stroke	11	1.7	1.5
10. Diabetes	7	1.1	1.0
All other causes of death	99	14.9	13.7
Ages 35-44 years: total deaths	1,359	193.4	
1. Accidents	311	44.3	22.9
2. Cancer	230	32.7	16.9
3. Heart disease	187	26.6	13.8
4. Intentional self-harm (suicide)	142	20.2	10.4
5. Chronic liver disease and cirrhosis	89	12.7	6.5
6. Stroke	39	5.5	2.9
7. Assault (homicide)	33	4.7	2.4
8. Diabetes	32	4.6	2.4
9. Mental and behavioral disorders due to alcohol use	21	3.0	1.5
9. Events of undetermined intent	21	3.0	1.5
9. Influenza and pneumonia	21	3.0	1.5
All other causes of death	233	33.2	17.1
Ages 45-54 years: total deaths	2,760	345.5	
1. Cancer	781	97.8	28.3
2. Heart disease	623	78.0	22.6
3. Accidents	316	39.6	11.4
4. Chronic liver disease and cirrhosis	156	19.5	5.7
5. Intentional self-harm (suicide)	136	17.0	4.9
6. Diabetes	102	12.8	3.7
7. Stroke	86	10.8	3.1
8. Chronic lower respiratory diseases	43	5.4	1.6
9. Mental and behavioral disorders due to alcohol use	41	5.1	1.5
10. Influenza and pneumonia	40	5.0	1.4
All other causes of death	436	54.6	15.8
Ages 55-64 years: total deaths	4,178	715.8	
1. Cancer	1,587	271.9	38.0
2. Heart disease	996	170.6	23.8
3. Accidents	217	37.2	5.2
4. Chronic lower respiratory diseases	209	35.8	5.0
5. Diabetes	161	27.6	3.9
6. Stroke	135	23.1	3.2
7. Chronic liver disease and cirrhosis	125	21.4	3.0
8. Intentional self-harm (suicide)	59	10.1	1.4
9. Kidney disease	41	7.0	1.0
10. Influenza and pneumonia	40	6.9	1.0
10. Septicemia	40	6.9	1.0
All other causes of death	568	97.3	13.6

Table 4. Rank order of leading causes of death by age, number of deaths, annual average crude death rate* (CDR) and percent of deaths, South Dakota residents, 2000-2006[1]

	Deaths	CDR	Percent
Ages 65-74 years: total deaths	7,359	2,008.0	
1. Cancer	2,721	742.4	37.0
2. Heart disease	1,821	496.9	24.7
3. Chronic lower respiratory diseases	585	159.6	7.9
4. Stroke	351	95.8	4.8
5. Diabetes	283	77.2	3.8
6. Accidents	179	48.8	2.4
7. Influenza and pneumonia	103	28.1	1.4
8. Chronic liver disease and cirrhosis	95	25.9	1.3
9. Kidney disease	86	23.5	1.2
10. Aortic aneurysm and dissection	85	23.2	1.2
All other causes of death	1,050	286.5	14.3
Ages 75-84 years: total deaths	13,771	4,948.9	
1. Heart disease	3,722	1,337.6	27.0
2. Cancer	3,556	1,277.9	25.8
3. Chronic lower respiratory diseases	1,129	405.7	8.2
4. Stroke	1,114	400.3	8.1
5. Diabetes	454	163.2	3.3
6. Alzheimer's disease	443	159.2	3.2
7. Influenza and pneumonia	370	133.0	2.7
8. Accidents	340	122.2	2.5
9. Kidney disease	238	85.5	1.7
10. Parkinson's disease	206	74.0	1.5
All other causes of death	2,199	790.3	16.0
Ages 85 years and older: total deaths	17,088	12,797.6	
1. Heart disease	5,824	4,361.7	34.1
2. Cancer	2,133	1,597.5	12.5
3. Stroke	1,709	1,279.9	10.0
4. Alzheimer's disease	1,043	781.1	6.1
5. Influenza and pneumonia	859	643.3	5.0
6. Chronic lower respiratory diseases	728	545.2	4.3
7. Unspecified dementia	520	389.4	3.0
8. Diabetes	468	350.5	2.7
9. Accidents	430	322.0	2.5
10. Kidney disease	299	223.9	1.7
All other causes of death	3,075	2,302.9	18.0

**Average annual crude death rates are per 100,000 population, based on the 2006 population estimate, U.S. Census Bureau.*

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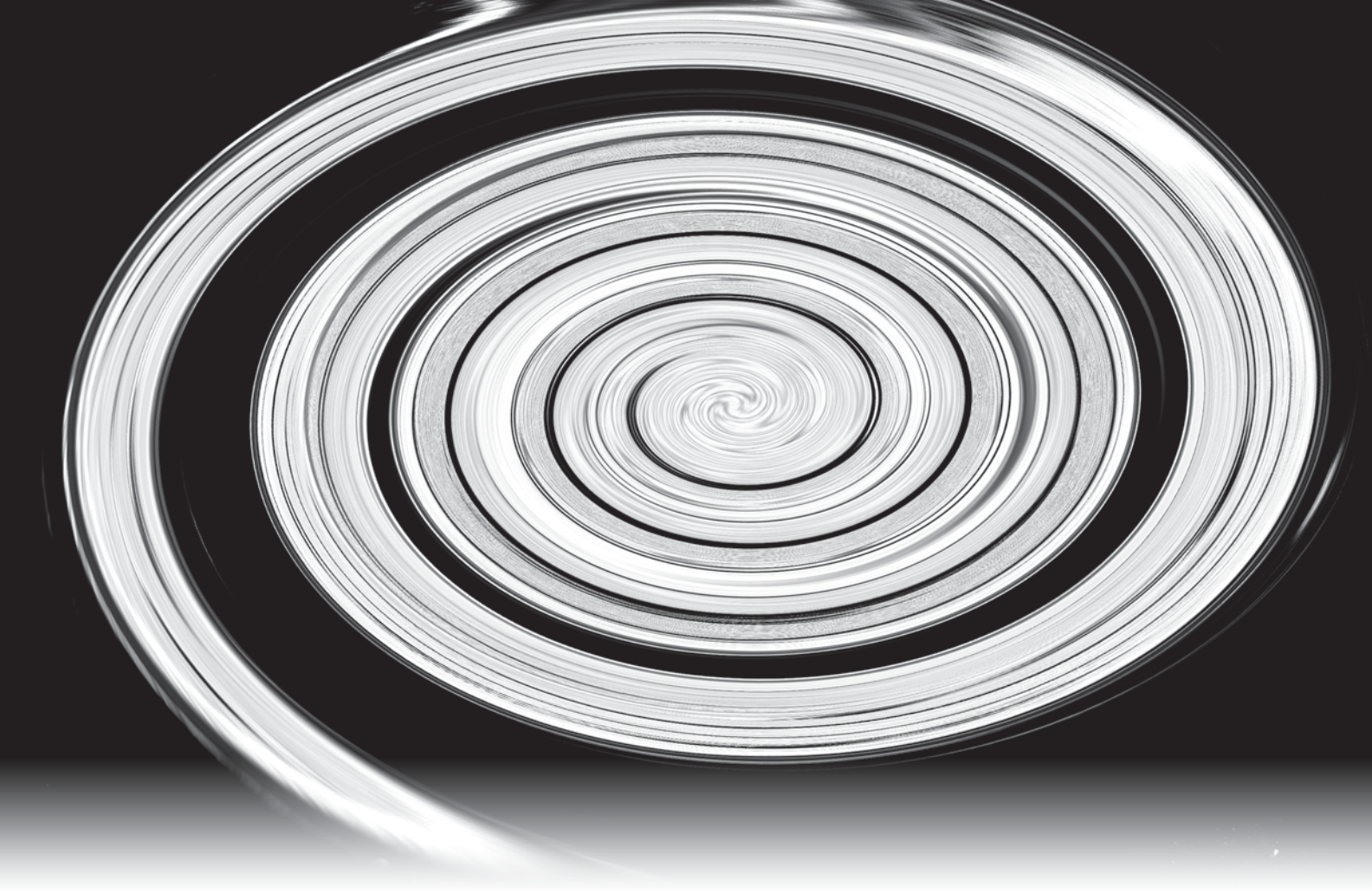

Advance Care Planning

By LuAnn M. Eidsness, MD; Ellen L. Schellinger, MA; Sandy Young, RN; Joann Bennett, DO

Talking about death doesn't make it happen. Whether it is with our family or our patients, many of us will shy away from this conversation, even though as practitioners we are in the best position to recognize its value. Timeliness is important; it may seem like there will always be tomorrow, but tomorrow may come too late. If a crisis occurs prior to the discussion, families and physicians are left wondering what the person would have wanted. Clear communication about wishes at the end of life will not solve all potential problems, but it can certainly diminish them.

The process of advance care planning (ACP) encourages dialogue. Whether the wishes are on paper or not, it is the discussion itself that is important and provides direction. Lack of discussion and reflection can increase the potential for conflict regarding personal care and treatment options.

Through ACP, a person makes his desires known about the care he would want to receive in the event he is incapable of communicating. These wishes are based on personal values and preferences and shared verbally or in writing with family and health care providers. Joan Teno has described the goals of ACP to encompass the following:[1]

1. Ensure clinical care consistent with patient preferences when capacity is lost
2. Improve decision-making process
   - Facilitate shared decision-making process
   - Allow proxy to speak on behalf of patient
   - Respond with flexibility
   - Provide education
3. Improve patient's well-being by reducing frequency and magnitude of over or under treatment
4. Reduce patient's concern regarding possible burden placed on family and others

What Are Advance Directives?

An advance directive is a legal document that provides written evidence of a person's health care goals and preferences. In South Dakota, there are essentially three advance-directive legal documents that are recognized by statute:[2] the durable power of attorney for health care (Chapter 59-7), the living will (Chapter 34-12D), and the DNR directive (Chapter 34-12F, Comfort One). Advance directives are legally recognized throughout the United States, and most directives are transferable from state to state. The original laws governing health care advance directives in South Dakota were passed in 1990-1991 and revised in 2007.

Although a person can complete an advance directive without physician input, the physician can provide information about the various options including the types of life-sustaining treatments that are available. If the advance directive is developed after the diagnosis of a life-limiting illness, then the dialogue about appropriate treatment is based upon the patient's diagnosis. If this conversation occurs during a routine visit, the discussion includes deciding what types of treatment the patient would or would not want if diagnosed with a life-limiting illness or after a sudden life-threatening event.

Durable Power of Attorney for Health Care

As long as a person has decision-making capacity, he can make decisions for himself. If this capacity is lost, a surrogate decision-maker must make decisions based on the person's preferences. This surrogate decision-maker is identified through a durable power of attorney for health care (DPOAHC) or the Health Care Consent statute (see below). In a DPOAHC, the individual appoints a person as health care agent (or surrogate decision-maker), who is authorized to make medical decisions. The agent should be someone the patient knows well and trusts and will be comfortable accepting this sort of responsibility. Usually this person is a spouse or family member, but may be a close relative or a personal friend.

The South Dakota statute for a DPOAHC is in Chapter 59-7 and states the following: "The attorney-in-fact or agent may make any health care decisions for the principal which the principal could make individually if the principal had decisional capacity. However, all such decisions shall be made in accordance with accepted medical standards. Whenever making any health care decision for the principal, the attorney-in-fact or agent shall consider the recommendation of the attending physician, the decision that the principal would have made if the principal then had decisional capacity, if known, and the decision that would be in the best interest of the principal."

The attorney-in-fact or agent cannot authorize the withholding or withdrawal of comfort care from the principal. In addition, South Dakota statute has specific requirements regarding artificial nutrition and hydration. The agent may authorize that artificial nutrition or hydration be withheld or withdrawn if one or more of the following exist:

1. Artificial nutrition or hydration is not needed for comfort care or the relief of pain and the attending physician reasonably believes that the principal's death is imminent; or
2. Artificial nutrition or hydration cannot be physically assimilated by the principal; or
3. The burden of providing artificial nutrition or hydration outweighs its benefit, provided that the determination of burden refers to the provision of artificial nutrition or hydration itself and not to the quality of the continued life of the principal; or
4. There is clear and convincing evidence that the principal expressed the desire that artificial nutrition or hydration be withheld, or refused artificial nutrition or hydration prior to the loss of decisional capacity; or
5. The principal expressed in the document creating the power of attorney that artificial nutrition or hydration be withheld; or
6. The principal expressly authorized, in the writing creating the power of attorney, the attorney-in-fact or agent to direct the withholding of artificial nutrition or hydration. (Chapter 59-7-2.7)

South Dakota does not have a DPOAHC document in statute. There are several forms available online (see Appendix A), through health care systems, physician offices or an attorney. When the directive is completed, it should be witnessed and notarized.

Living Will

A living will is an instructive advance directive. The individual is not appointing someone to make decisions but rather indicating in writing what wishes the individual has regarding treatment at the end of life. By statute, "a living will declaration becomes operative when the declarant is determined by the attending physician to be in a terminal condition, death is imminent, and the declarant is no longer able to communicate decisions about medical care" (Chapter 34-12D-5). In the revision during the 2007 legislative session, only the attending physician, "who has primary responsibility for the treatment and care of the

patient" (34-12D-1), is necessary to declare a person terminal.

The South Dakota Living Will statute is in Chapter 34-12D, and it includes a suggested format which was revised in the 2007 legislative session to make it clearer and consistent with the other health care statutes. (A copy of this document is included in Appendix B.)

While allowing individuals to decline artificial nutrition and hydration at end of life, the living will statute offers these provisions regarding artificial nutrition and hydration:

> If an individual's declaration contains a directive to provide treatment or artificial nutrition and hydration under any circumstances, any health care provider who has responsibility for the treatment and care of the individual must provide the directed treatment or artificial nutrition and hydration in those circumstances so long as it is technically feasible. A health care provider who objects to providing such treatment may instead transfer the individual to a health care provider willing to honor the declaration, but must continue to provide the treatment or care until the transfer is effectuated. (Chapter 34-12D-12)

Instructions to Patients After Completing a Living Will or DPOAHC

After an advance directive is completed, the document should not be locked up in the safety deposit box. The patient should be instructed to keep the original in a safe place where it can be easily found. A copy is given to the physician(s), the power of attorney (agent and alternate agents if appropriate), any involved family member, the health care facility and a lawyer, if the patient has one. When sharing a copy, there should be a discussion of its contents – providing a copy is not enough.

Health Care Consent

If the attending physician has determined that a patient is incapable of giving informed consent and in the absence of a durable power of attorney for health care, a court-appointed guardian, or if neither the attorney-in-fact nor guardian is available to consent, then health care providers turn to the Health Care Consent Act, Chapter 34-12C, to determine who will make decisions for that person.

The surrogate decision-maker is guided by statute in decision-making: "Any person authorized to make a health care decision for an incapacitated person shall be guided by the express wishes of the incapacitated person, if known, and shall otherwise act in good faith, in the incapacitated person's best interest, and may not arbitrarily refuse consent. Whenever making any health care decision for the incapacitated person, the person available to consent shall consider the recommendation of the attending physician, the decision the incapacitated person would have made if the incapacitated person then had decisional capacity, if known, and the decision that would be in the best interest of the incapacitated person" (Chapter 34-12C-3).

Until 2007, this list included only members of the patient's family. Many in health care recognize that for some, the closest person may not be a blood relative. For this reason the list was expanded to include "close friend." The legislature has defined a close friend "as any adult who has provided significant care and exhibited concern for the patient, and has maintained regular contact with the patient so as to be familiar with the patient's activities, health, and religious or moral beliefs" (Chapter 34-12C-1). What is missing from the list is "domestic partner" who includes not only gay and lesbian partnerships, but also common-law marriages, which South Dakota does not recognize. The resolution for people in these situations is a DPOAHC.

A health care decision for an incapacitated person may be made by the following persons or members of the incapacitated person's family who are available to consent, in the order stated:

- The spouse, if not legally separated
- An adult child
- A parent
- An adult sibling
- A grandparent or an adult grandchild
- An adult aunt or uncle, adult cousin, or an adult niece or nephew
- Close friend (Chapter 34-12C-3)

If a person declines to accept the responsibility, he may "delegate the authority to make a health care decision to another family member in the same or succeeding class" (Chapter 34-12C-3).

Cardiopulmonary Resuscitation Directives

A Cardiopulmonary Resuscitation Directive, also known as "out of hospital DNR," is found in South Dakota's Codified Laws:

> [It is an] advance medical directive pertaining to the administration of cardiopulmonary resuscitation, which is a medical order based on informed consent, signed by or on behalf of an individual and must be signed by a physician, a physician assistant, or a nurse practitioner, directing emergency medical services

> personnel to not perform resuscitative measures in the event of a respiratory or cardiac arrest or malfunction. (Chapter 34-12F-1)

This statute was originally adopted in South Dakota in 2004 and then amended in 2005 to require the signature of a health care professional. South Dakota uses the "Comfort One" EMS Cardiopulmonary Resuscitation Directive, which originated in Montana. It allows EMS personnel to withhold or withdraw certain treatment, requires them to provide comfort care and protects EMS personnel from liability for following the patient's wishes.

An EMS cardiopulmonary resuscitation directive also applies when a person is admitted to a health care facility (hospitals, hospices and nursing homes) and a do not resuscitate (DNR) "shall be implemented as a physician's order … pending any further order by a physician" (34-12F-6). Having a "Comfort One" in place can alleviate confusion about code status that can occur when patients transfer from a skilled nursing facility to a hospital and back.

To execute a "Comfort One" directive, a standard form must be used and is available through the Department of Public Safety's Web page (see appendix A). The "Comfort One" form is a two-sided, triplicate document. The white copy of the form is kept by the individual and a copy is sent to Department of Public Service and one to the physician. The reverse side of the form gives instructions to EMS on what they can do and cannot do if the patient has a "Comfort One."

In order for EMS personnel to recognize and respond appropriately to a "Comfort One" directive, persons with a cardiopulmonary resuscitation directive must present a signed copy of the standardized form or wear a bracelet obtained from the South Dakota Emergency Medical Services identifying the person as "Comfort One." And, like other advance directives, "An EMS cardiopulmonary resuscitation directive may be revoked at any time by the person who is the subject of the directive or by any other person who is, pursuant to the laws of this state or any other state, authorized to make medical treatment decisions on behalf of the person who is the subject of the directive" (Chapter 34-12F-8).

Physician Responsibility in Advance Care Planning

Some physicians may worry that a discussion about wishes at the end of life will provoke anxiety and be stressful, especially for elderly patients. A study in Ohio found that "Elderly outpatients experienced no adverse emotional or attitudinal effects following a physician-initiated advance directive discussion … patients strongly endorse physician-initiated discussions about preferences for life-sustaining therapies."[3] A 1992 study in the *Archives of Internal Medicine* found that "involvement of these patients in decision-making appeared to have no adverse effects, and, for some, it was therapeutic, possibly through enhancement of personal control."[4] A more recent study in 2001 reaffirmed that "chronically ill patients are more satisfied with their primary care physicians and the care they deliver when advance directives are discussed."[5] The elderly are receptive to talking about end-of-life concerns; it is likely physicians' own uncertainties that inhibit the discussion of end-of-life issues.

ACP should be considered a routine part of annual medical exams when patients are less likely to be acutely ill. Physicians should initiate the conversation with all adults. How the conversation is structured will depend on the patient's health status, but if it is not done during an emergency there will be time to explore the patient's values. When the discussion is left to occur in a semi-urgent situation or crisis, the focus of the conversation is often limited to treatment possibilities and end-of-life concerns, leaving little opportunity to reflect on the patient's goals, values and beliefs. The physician actively initiating dialogue can help the patient make decisions consistent with his wishes and answer questions regarding treatments and prognosis.

Also, ACP does not stop with completion of an advance directive document.[6] It should be reviewed periodically to discuss any changes. A review of a declaration should definitely occur after key life events, such as retirement, marriage/divorce or any major illness. The competent patient can make changes by writing a new directive and/or revoking an existing advance directive.

We know from the SUPPORT study[7,8] that physicians are often not aware of hospitalized patients' wishes. It is the physician's responsibility to be knowledgeable of a patient's advance directive and follow the directive in a thoughtful and medically appropriate way. If a patient does not have a written advance directive, the physician must clarify with the patient or surrogate decision-maker what the patient's wishes are and devise an appropriate plan of care based on this information.

"Respecting Your Choices"[9,10] is a successful community model that "treats advance care planning as an ongoing process" and "shifts the focus on end-of-life decision-

making away from completion of documents toward facilitating discussion about values and preferences."[11] The conversation could start with "If you couldn't make decisions for yourself, who would?" This can be followed with "Life can change quickly – if something suddenly happened such as an accident that left you significantly impaired, what would you want if ...?" If the discussion is held during a routine office visit, the focus can be broader and centered on the patient's overall attitude toward life, including the activities enjoyed and situations feared. Ideally, the family or health care power of attorney would be present for this discussion.

If the discussion is held after the diagnosis of a life-limiting illness or after a significant change in health, the health care provider should talk openly and truthfully with the patient about the illness. This discussion should include the decisions the patient and family will need to make. The physician may be asked for advice to help the patient make decisions. If treatment is being started for a life-limiting illness, the physician should share with the patient that if the treatment fails to provide the expected results, a new discussion will occur. A significant amount of time may need to be devoted to listening to the patient's fears and concerns. All physicians are encouraged to develop the skills to share bad news and discuss goals of care. If a physician is not comfortable with this discussion, he can seek out continuing medical education opportunities to improve his competence (Appendix A) or consult with a specialist in palliative medicine.

Many people have unrealistic expectations of what medical technology can provide. They have a misperception about the survival rate from CPR and burdens and benefits from artificial nutrition and hydration. The physician will need to gently educate the patient and family about realistic expectations. Also, when appropriate, discuss hospice care. It can be difficult to prognosticate life expectancy of six months. It may help to ask the question, "Would I be surprised if this person died in less than 12 months?" If not, the patient is likely appropriate for hospice care.

The Code Status Discussion

When approaching a discussion regarding code status, practitioners often mistakenly ask, "If your heart stops do you want us to restart it?" without prefacing the issue by providing a review of the patient's illness, treatment goals, and prognosis for survival and function. Thus, often the answer is "yes" when the physician believes it should be "no" based on the patient's poor prognosis. As was noted earlier in this article, it is optimal to have this discussion prior to crisis, with a cognitively intact patient so the patient's values can be made known and the physician can then guide the patient to the appropriate medical treatment. The physician has the ethical obligation to educate the patient and/or family to the medical condition, prognosis and the appropriate course of treatment.

Based on the authors' personal experience, we have found that after a long, careful discussion of the patient's values, clarifying the medical course and prognosis with expected outcomes, a DNR is often accomplished. When there is dissension, it is often due to the patient and family having no prior conversation, no advance care planning and, therefore, unrealistic goals for a successful resuscitation or recovery.

A review of the literature can assist the physician in determining the likelihood of success of CPR in selected patients.[12,13] With this information, the expectations for survival can be shared as necessary with patients and families to guide decisions. If there is still disagreement by patient or family and the situation is futile, then consultation can be obtained with a palliative care team or ethics committee. (See also the article on futility in this issue.)

Summary

Advance care planning is important; the discussion should start early, prior to a life-threatening illness and repeated as necessary when there are changes in a patient's status. It is not necessarily the final document that is important, but the communication that occurs during the process of ACP. It is during the discussion the physician and family will learn about and understand the patient's wishes. As Teno commented, "Even the most detailed written directive is likely to be of limited value if there has been no communication among patient, provider team, and proxy decision-maker."[1] If an advance directive document is not completed, the wishes of the patient must be documented in the medical record.

We know from the 2005 South Dakota "Dying to Know" survey that only 35 percent of South Dakotans have completed an advance directive and 39 percent want their physicians to initiate the conversation.[14] South Dakota physicians can take an active role in increasing these percentages by initiating the advance directive discussion with their patients and completing their own directives. We can help our patients realize that the discussion of their values at end of life is a natural part of caring for themselves and their family.

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Appendix A: Web Page Resources

AARP End of Life page. http://www.aarp.org/families/end_life

Aging with Dignity, source of "Five Wishes." http://www.agingwithdignity.org

American Academy of Family Physicians, Advance Directives and do not resuscitate orders. http://familydoctor.org/online/famdocen/home/pat-advocacy/endoflife/003.html

American Academy of Hospice and Palliative Medicine. Educational resource for end of life care and the UNIPAC series. http://www.aahpm.org

American College of Physicians, Ethics and End of Life Care. http://www.acponline.org/ethics/eolc.htm

American Medical Association: Advance Care Directives. http://www.ama-assn.org/ama/pub/category/14894.html

Center for Practical Bioethics, Caring Conversations "is a consumer education initiative that helps individuals and their families share meaningful
conversation while making practical preparations for end-of-life decisions." http://www.practicalbioethics.org/cpb.aspx?pgID=886

EPEC: Education in Palliative and End-of-Life Care to "educate all health care professionals on the essential clinical competencies in palliative care." http://www.epec.net/EPEC/webpages/index.cfm. Sharing Bad News: http://www.ama-assn.org/ethic/epec/download/module_2.pdf

EPERC: End of Life/Palliative Education Resource Center. http://www.eperc.mcw.edu

LifeCircle South Dakota, Partners Improving End of Life Care. http://www.usd.edu/med/neurosciences/partnership/advancedirectives.cfm

National Cancer Institute Fact Sheet on Advance Directives. http://www.cancer.gov/cancertopics/factsheet/support/advance-directives

National Hospice and Palliative Care Organization, Caring Connections. Information about advance directives. http://www.caringinfo.org/AdvanceDirectives

Respecting Choices: A comprehensive advance directive education program created by the La Crosse Area Medical Centers. Information about this
program can be found at: http://www.gundluth.org/eolprograms

South Dakota Department of Public Safety, Emergency Medical Services: for information on Comfort One and ordering the form: http://www.state.sd.us/dps/EMS/EMT_Information/dnr.htm

Appendix B Living Will Declaration

http://legis.state.sd.us/statutes/DisplayStatute.aspx?Type=Statute&Statute=34-12D-3.
34-12D-3. Declaration--Sample form. A declaration may, but need not, be in the following form:

LIVING WILL DECLARATION

This is an important legal document. A living will directs the medical treatment you are to receive in the event you are in a terminal condition and are unable to participate in your own medical decisions. This living will may state what kind of treatment you want or do not want to receive.

Prepare this living will carefully. If you use this form, read it completely. You may want to seek professional help to make sure the form does what you intend and is completed without mistakes.

This living will remains valid and in effect until and unless you revoke it. Review this living will periodically to make sure it continues to reflect your wishes. You may amend or revoke this living will at any time by notifying your physician and other health care providers. You should give copies of this living will to your family, your physician, and your health care facility. This form is entirely optional. If you choose to use this form, please note that the form provides signature lines for you, the two witnesses whom you have selected, and a notary public.

TO MY FAMILY, HEALTH CARE PROVIDER, AND ALL THOSE CONCERNED WITH MY CARE:

I, _____ direct you to follow my wishes for care if I am in a terminal condition, my death is imminent, and I am unable to communicate my decisions about my medical care.

With respect to any life-sustaining treatment, I direct the following:

(Initial only one of the following options. If you do not agree with either of the following options, space is provided below for you to write your own instructions.)

___ If my death is imminent or I am permanently unconscious, I choose not to prolong my life. If life-sustaining treatment has been started, stop it, but keep me comfortable and control my pain.

___ Even if my death is imminent or I am permanently unconscious, I choose to prolong my life.

___ I choose neither of the above options, and here are my instructions should I become terminally ill and my death is imminent or I am permanently unconscious:

_____

Artificial Nutrition and Hydration: food and water provided by means of a tube inserted into the stomach or intestine or needle into a vein.

With respect to artificial nutrition and hydration, I direct the following: (Initial only one)

___ If my death is imminent or I am permanently unconscious, I do not want artificial nutrition and hydration. If it has been started, stop it.

___ Even if my death is imminent or I am permanently unconscious, I want artificial nutrition and hydration.

Date: _____ Your Signature _____

Address_____

Type or print your signature _____

The declarant voluntarily signed this document in my presence.

Witness _____ Address _____

Witness _____ Address _____

On this the _____ day of _____, _____, the declarant, _____, and witnesses

_____, and _____ personally appeared before the undersigned officer and signed the foregoing instrument in my presence. Dated this _____ day of _____, _____.

Notary Public_____ My commission expires:_____.

Ethical and Legal Issues at the End of Life

By Michael Sprehe, MD; Ellen L. Schellinger, MA; Allen Eide, JD

End-of-life issues often present conflicts between and among the medical team, patients and patient families. During these times of patient and family fear, grief and possible prognostic uncertainty, differing value systems can lead to opposing assessments of risks and benefits with respect to continued aggressive treatment, feeding and hydration, pain control, and overall decision-making. Many of these issues can be resolved at the bedside with good communication between the stakeholders. On occasion, however, third-party involvement, such as ethics consultation, is necessary. Further complicating such interactions are fears of litigation if a physician chooses an action against the wishes of some family members. This article will present frequently encountered areas of conflict and the legal underpinnings of current ethical thinking that can be applied to educate and inform decisions for patients, families and the medical team.

Surrogate Decision-Making

When a patient is unable to make his or her wishes known, a proxy source must be used to inform decision-making. These sources can be living wills or other advance directives, an agent acting under a durable power of attorney for health care (DPOAHC), or in the absence of these, family members or friends. In these situations, two questions are raised: who makes medical decisions for the patient, and how should medical decisions be made?

In 1975, Karen Quinlan was being maintained on a ventilator in a persistent vegetative state (PVS). Her parents obtained guardianship in order to discontinue the ventilator, an action which was reported to be consistent with her previously stated beliefs. The treating physician

wished to continue treatment on the basis of conforming to medical standards and traditions. Eventually, the New Jersey Supreme Court agreed with the family's position of their right to be proxy decision-makers for their daughter and, thus, gave them surrogate decision-making authority.[1] Today, the choice of medical decision-maker when the patient has not designated one is generally determined by state statute. In South Dakota, the hierarchy determining the order of surrogate decision-makers can be seen in Figure 1.

Figure 1.
South Dakota Statute of Proxy Health Decision Makers[2]

If a DPOAHC or appointed guardian is not available,

1. The spouse, if not legally separated
2. An adult child
3. A parent
4. An adult sibling
5. A grandparent or an adult grandchild
6. An adult aunt or uncle, adult cousin, or an adult niece or nephew
7. Close friend

A legally executed DPOAHC trumps all others, including spouses. If one is not available, then health care providers progress down the list until an appropriate person is found.

If two or more people exist in a single category, such as siblings, they generally share decision-making responsibility. Recently, the law has been revised to allow close friends of the patient who are familiar with the patient's health and belief system to also be eligible.[3]

Once the identity of the surrogate decision-maker is determined, one of two standards is applied to make proxy decisions for the patient. The first is generally known as "substituted judgment."[4] These decisions apply information from the patient that indicates what he or she would want in a given situation. This evidence can range from living wills at one end of the spectrum to previously stated preferences or known values of the patient at the other. It must be stressed that the decision of the surrogate in this situation is not to be the decision that the surrogate would make for himself or herself but that which the patient would make if they were able to at that moment. Living wills and other advance directives, if available, can provide great insight into the patient's wishes. Indeed, in South Dakota, the law states that the proxy decision-maker must "consider the recommendation of the attending physician, the decision the incapacitated person would have made if the incapacitated person then had decisional capacity, if known, and the decision that would be in the best interest of the incapacitated person."[3]

If there are no known preferences of the patient, one must then apply another standard for decision-making. That standard is referred to as the "best interest" (of the patient) standard. With this standard, the burdens and benefits of any intervention must be considered with the goal of minimizing the burdens, such as pain and suffering. The decision must be one that a reasonable person in the same situation might choose for him- or herself.[4]

Once a surrogate decision-maker has been identified and the standard for those decisions has been defined, emotionally challenging decisions sometimes need to be made. One of the most difficult is the decision to withhold or withdraw life-sustaining medical treatment (LSMT). This may include mechanical ventilation, antibiotics, transfusions, dialysis, pressors, and intravenous or enteral fluids and nutrition. Once started, LSMT can appear to some as more difficult to discontinue than not starting it at all. Legally and ethically, there is no difference between withholding and withdrawing LSMT.[5,6] That is not to say that they are not different psychologically for all involved parties, but from the decisional standpoint, they should be treated as equal.

Numerous legal cases have supported the surrogate's ability to advocate for withdrawal of the above LSMT. Some of the most widely known cases are the Quinlan case, the Cruzan case, the Bouvia case, and most recently, the Schiavo case. Like Karen Quinlan, Nancy Cruzan was diagnosed with PVS. She was not ventilator dependent but was being fed via a gastrostomy. After years, her parents wished to discontinue feeding that was, according to testimony, inconsistent with the patient's previously stated wishes. This was challenged by the state of Missouri, citing the state's interest in preserving life. The United States Supreme Court agreed that the state may require "clear and convincing evidence of the patient's wishes," but if available, the surrogate has a constitutional right of refusal of life-sustaining medical treatment for the patient.[1]

In 1986, Elizabeth Bouvia was a 28-year-old quadriplegic who had a feeding tube inserted against her will. She sought a court order to have the feeding tube removed. The trial court refused, siding with the medical community and citing concerns for the sanctity of life and fear of participating in suicide. The appellate court disagreed, stating in part "the right to refuse medical treatment is basic and fundamental. It is recognized as a part of the right of privacy protected by both the state and federal constitutions. Its exercise requires no one's approval. It is not merely one vote subject to being overridden by medical opinion."[7] Thus, the court agreed with Ms. Bouvia, and the

feeding tube was removed. These cases and many others have established the constitutional right to refuse any treatment, including LSMT, either by the patient or by the surrogate. South Dakota statute states "Death resulting from the withdrawal or withholding of life-sustaining treatment in accordance with this chapter does not constitute, for any purpose … a homicide on the part of the attending physician or other health care provider."[8]

What about the opposite situation? How does a practitioner approach the scenario in which the surrogate demands that life-prolonging treatment be continued at the end of life? Another article in this issue addresses the concept of "futility," so it will be discussed only briefly here. When LSMT appears to be burdensome or appears to not meet the goals of medicine yet the surrogate refuses the withholding or withdrawal of that treatment, several strategies are available. The most important is continued communication with honest assessments of the clinical situation, the goals of continued treatment, the inherent uncertainties and an appreciation of the difficult situation in which the surrogate or family finds itself. Time-limited trials of the discussed LSMT can be offered. Ethics consultation is available. Hospitals may have "futility policies" that can be applied. One state, Texas, has a futility statute.

In 1999, Texas adopted a wide-ranging law on advance directives. It is now codified as Chapter 166 of the Texas Health & Safety Code.[9] Health & Safety Code §166.046 applies when a physician refuses to honor a health care decision made by or on behalf of a patient. Subsection "e" specifically includes those situations in which the patient or the decision-maker requests life-sustaining treatment, which the physician has decided is inappropriate. Section 166.046 provides a multi-step process in these cases. First, the physician's refusal is reviewed by an ethics or medical committee, of which the attending physician may not be a member. Life-sustaining treatment continues during the review.[10] The patient or surrogate is provided with a written description of the review process and of applicable policies and procedures of the health care facility.[11] The patient or surrogate is given at least a 48-hour notice of the committee meeting (which may be waived).[12] They are also provided with a specified written statement regarding the right to transfer to another facility and a list of health care providers and referral groups that have indicated willingness to consider accepting transfer or to assist in finding such a health care facility.[13] The patient or surrogate may attend the committee meeting and shall receive a written explanation of the decision the committee reaches.[14] If the physician, patient or surrogate does not accede to the committee's decision, there is a process for transferring the patient to another physician, another care setting within a health care facility or another health care facility.[15] Life-sustaining treatment must continue to be provided for 10 days after the written decision is delivered to the patient or surrogate.[16] The patient or surrogate may seek judicial intervention.[17] Before extending the 10-day period a court must find by a preponderance of the evidence (the usual burden of proof in civil matters) that if an extension is granted there is a "reasonable expectation" that a physician or health care facility which will accept the patient can be found.[18] In South Dakota, no such law exists at present; therefore, physicians must rely on hospital policies and ethics consultation for guidance and support.

At the end of life, pain, discomfort, shortness of breath and other symptoms are often present and can greatly diminish the dying person's quality of life. The need for and practice of palliative care are growing within the country. Current practice encourages titrating doses of narcotics, such as morphine, to sufficient levels in order to alleviate pain. Many physicians remain concerned, however, that escalating doses of narcotics to treat these symptoms will cause the patient to die and, as a result, be considered murder, physician-assisted suicide or euthanasia. Certainly, death in these cases may be hastened. But within the ethics literature and in state law, using medicines appropriately to treat a symptom despite unintended but foreseeable side effects (e.g., respiratory depression) that may hasten death is both ethical and legal. The underlying presumption is that the treatment is offered to treat the symptoms, not to cause the death of the patient. This is often referred to as the Principle of Double Effect.[19] The relief of pain is a moral good, according to South Dakota statute:

> Any licensed health care professional who administers, prescribes, or dispenses medications or procedures to relieve another person's pain or discomfort, even if the medication or procedure may hasten, or increase the risk of, death, does not violate § 22-16-37, unless the medications or procedures are knowingly administered, prescribed, or dispensed with a purpose to cause death. Any licensed health care professional who withholds or withdraws a life- sustaining procedure, in compliance with chapter 34-12D or in accordance with reasonable medical practice, does not violate § 22-16-37. (SDCL 34-12D-23)[20]

Thus, the hastening of death is not intended, but also not unexpected as a possible consequence. This is not to be mistaken as "killing" or euthanasia, where the intent is the

death of the patient. What about the concern that the patient will escalate his own medicine dose with the intent of death (suicide)? Although often considered unfavorable in traditional and religious thought, suicide itself is not illegal, and in one state, Oregon, physician-assisted suicide has been legalized. In South Dakota, however, SDCL 22-16-37 prohibits aiding or abetting suicide. When a physician prescribes pain-relieving medication that might cause death, prudence dictates thorough documentation of the prescription's purpose.

In summary, numerous ethical and legal challenges may arise in end-of-life situations. Help in determining appropriate surrogate decision-makers and the standards that those decision-makers should apply is available. The withholding and withdrawing of LSMT is supported in health law and in medical ethics, including the ethics codes from medical groups such as the AMA and the ACP.[5,6] Pain and symptom control is a necessity, and state statute and ethical principles should help alleviate physician fears of "causing death," addiction or abetting suicide. Debates about "futility" and how to respond to family or surrogate requests to continue life-prolonging medical treatment at the end of life continue. Until South Dakota has a statute as does Texas, the use of ethics consultation or ethics committees can be employed to resolve these, and indeed, many conflicts at the end of life.

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Medical Futility: Balancing Patient Autonomy and Physician Integrity

By Ellen L. Schellinger, MA; LuAnn M. Eidsness, MD; Allen Eide, JD; Mary Helen Harris, MD

Autonomy, Integrity and the Goals of Medicine

In the early days of modern medicine, the physician's armamentarium against physical ills was a limited assortment of diagnostic tools and curative concoctions, and patients readily accepted what was offered. In the intervening years, scores of new techniques, treatments and technological devices have changed the prognostic outlook for many diseases once thought to be deadly, bringing a new concept to the examining table: the patient's right to refuse. Traditionally, the goals of medicine have been to heal and to relieve suffering and pain. In recent years, the principle of respecting patient choices has motivated the establishment of institutional policies that permit patients (or surrogate decision-makers) to exercise autonomy by limiting, refusing or withdrawing any unwanted intervention. The right to refuse treatment stems from our constitutionally protected "liberty interest" and, in some states, is linked to our constitutional right to privacy.[1] These policies are generally limited to situations in which patients or their proxies refuse an intervention.

Indeed, our modern, market-driven economy has created something called a "health care consumer," further confusing physician and patient roles and presenting the healing art of medicine as something that can be bought and sold on demand. Truly, there are treatments that can be either healing, such as blepharoplasty for vision obstruction, or elective, such as the same procedure to combat a common side effect of aging.

However, what if a patient or proxy requests a treatment that will not be of benefit, such as antibiotics for a virus, or may even do harm, such as CPR on a patient in end-stage

cardiac disease with multi-system failure for whom dialysis is no longer working? As is common in moral and ethical theory, there is a complementary concept that stands at counterpoint and may limit individual autonomy: respect for professional integrity.

Respect for physician integrity dictates that medical practitioners provide treatments that balance any harms they may create with the good that they are expected to do a given patient. If the likelihood of benefit is practically zero, then virtually any risk is not justified. In analyzing physician-assisted suicide to ascertain why physicians are obligated to not perform actions that predictably will not offer benefit, the following elements of professional integrity become evident:

1. The ethical goals that define medical practice include healing and curing disease, promoting health and preventing disease, and relieving suffering caused by disease symptoms. If a treatment can be reasonably predicted to accomplish none of these, requiring a physician to offer it is to require them to act contrary to their goals of practice.
2. Physicians are obligated to adhere to high standards of scientific competence. Employing a treatment that predictably will not work deviates from that standard of competence.
3. Physicians are also obligated to represent standards of scientific knowledge truthfully to the public, claiming neither more nor less than what medicine can truly deliver. Reasonable people will conclude that if a physician offers a treatment, it must have some chance of working. Thus, physicians who employ futile treatments risk becoming quacks or frauds.
4. Physicians are justified in risking harm to patients only when the possible benefit outweighs the risk. Giving in to demands for futile treatments, especially those such as CPR that can cause pain, forces physicians to become agents of harm, not benefit.[2]

It is, however, difficult to accurately define and agree on the meaning of the term "futile." Reflection on the usage of the term "futility" reveals three common usages:

1. **Physiologically Futile Treatment** in which the treatment that is requested will not produce the outcome desired.
2. **Futility Based on Scarce Resources** in which a physician or institution *may* consider a treatment that imposes enormous cost compared to the benefit it might yield.
3. **Normative futility** (which is often confused with physiologic futility) in which the burdens of treatment sought are felt, by the caregiver, to outweigh the benefits.[3]

Given that the term futility can be nuanced in so many ways, it is important to clarify what one means when making such a claim. If health care institutions attempt to create policy regarding futile interventions, they would also be advised to offer a definition of futile early on to clarify under what circumstances, exactly, such a policy might be invoked. Whereas a policy that deals only with physiologic futility might be defensible given that physicians are under no obligation to provide treatment that is not medically indicated, or a decision based on scarce resources might be defensible for a hospital with limited resources, one that ventures to justify refusal based on normative thought may be more difficult to justify.[4]

Institutional Futility Policies

An institutional policy regarding futile medical care should be designed to *supplement* rather than to *supplant* currently existing policies on limiting life-prolonging therapies and provide a conflict resolution mechanism to follow when a patient (or surrogate decision-maker) requests to start or continue an intervention that the primary attending physician assesses to be medically inappropriate (commonly referred to as "medically futile"). Such a policy affirms the value of integrity so long as appropriate, and thorough institutional review supports the determination of medical inappropriateness. It is suggested that procedures set forth in such a policy should be invoked only by the primary attending physician. Concerns on the part of other health care providers, hospital officials or family members should be addressed through other institutional mechanisms such as a biomedical ethics committee or patient ombudsperson. Before resorting to an internal, legalistic proceeding, guidelines should assure that all supportive resources – social work, behavioral health, ethics, etc. – have been utilized and that clear and compassionate communication between the attending physician and the patient/family has occurred. Communication is crucial. The primary attending physician must carefully describe: the nature of the ailment and the prognosis that includes severity of the illness and likelihood of functional recovery as well as survival; the options, including palliative care and hospice care; and the reasons that the requested intervention is considered to be inappropriate. Institutions should be willing to facilitate access to an independent medical opinion regarding the appropriateness of the intervention in question. Guidelines should provide ample opportunity for patients or their

surrogates to obtain advice or to transfer the patient to a different facility or practitioner.

An institutional policy on futile medical care that involves oversight by a group of individuals not directly involved in caring for the patient in question can provide two important checks and balances in physician management. On one hand, review and oversight can support a physician's medical determination and uphold the need to protect the vulnerable patient while upholding the integrity of the practice of medicine. On the other hand, oversight can protect against the physician's potential abuse of power and unilateral decision-making.

An institution developing guidelines for determining futile care should be cautioned to review state and federal statues. In some states, such as Texas, laws were developed specifically to deal with this issue. In South Dakota, however, statutory guidance is limited to various statements embedded in our advance directive laws. Chapter 34-12D section 19, in particular, clarifies that "This chapter does not require a physician or other health care provider to take action contrary to accepted medical standards." What those "accepted medical standards" are, however, is not further defined.

In Summary

Recognizing medical futility affirms both the traditional goals of medicine and the moral value of physician and institutional integrity in discerning the limits of medical interventions. Respect for this integrity provides the basis for the right to refuse to provide a medically inappropriate intervention. It complements the right of patient autonomy that must be given both voice and effect in any forum for medical decision-making. This appeal to integrity is generally rooted in a combination of concerns such as avoiding harm to patients, avoiding provision of unseemly care, and just allocation and good stewardship of medical resources. Institutional policy regarding medically inappropriate treatment should effectively assign responsibility, promote communication and provide a reasonable timeline.

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Spirituality and Cultural Considerations in End-Of-Life Care

By Peter Holland, DMin; J. Gordon Harris, PhD; Valerie Hearns, MD

Consideration of spiritual and cultural issues must be addressed in order to deliver effective, compassionate care to patients at the end of life. Even patients who previously had not considered themselves religious, spiritual or ethnocentric may grasp onto these concepts as they deal with their imminent mortality. Issues regarding spirituality and culture may influence decisions about medical treatment and life sustaining interventions. In some cases, patients may raise issues and in other cases patients may not feel comfortable bringing these concerns to the attention of their caretakers and medical providers. In order to better understand patients and provide better palliative care, we need to be aware of these influences and be prepared to help patients with expression of these ideals.[1]

In teaching the interdisciplinary Palliative Care Seminar, it would be relatively simple but marginally helpful to teach how to apply facts. It would miss an opportunity for usefully addressing a topic that influences patient healing and hope. Visiting patients and reflecting on the experience helps students adjust their expectations that the seminar will be simply pedagogical and didactic. Throughout, learning to improvise responses[2] within visits, by challenging students to incorporate their emotional selves into the experience has been one of the philosophies guiding the seminar. The session on "Culture and Spirituality" reinforces learning through participation in the patient's story.

As spirituality and culture are generally communicated through narrative, students are encouraged to listen to a patient's primary narrative. They are also asked to reflect upon and understand their personal parallel stories[3] as well as how their professional narratives influence their relationships to patients. The teachers in the seminar believe one can most effectively enter the life of the patient as a competent practitioner if one is aware of one's own story.

Spirituality is a popular but deliberately vague term[4] that is intended to capture how people make meaningful stories from their experience. It is broad enough to include low moods as well as excitement, while allowing for individual expression. It embraces the individual meditating alone, religious practices and exercises, and it can even embrace the dead who return as spirits.

While professionals draw on scientific knowledge so that they can assess situations consistently, patients/clients/residents/parishioners/customers live outside the world of the helping professions and tell stories to make sense of their experiences. Professionals write and speak to a professional culture, but they try to translate their knowledge into a "bedside manner" to which a layperson can relate. Clients, patients, parishioners, etc., find it in their best interest to also understand the professional cultures into which they have been thrust. In many cases, the failure to appreciate each other's culture as a relational process can produce unintended and sometimes harmful consequences that restrain rather than release opportunities for healing. Even a person from the professions becoming a patient feels intimidated by prized hierarchies, precisely timed procedures and technical language that reduce lived experience to scientific measurement. However, a patient might also emerge from their medical encounters telling a story of compassion, humor or complaint about the care they received. In the seminar we have been trying to raise awareness about how students might make use of stories to make sense of the culture and the spirituality present in the medical encounter. As an example, one of our faculty members speaks about his encounter with the medical community when his daughter, Joy, was dying. Students have been able to identify with his emotional experience and some have been able to draw the implications about professional sensitivity from his illustrations, which are told in the following account, through the eyes of his wife and mother of the dying child. The case helps us discuss how a palliative care plan impacts family relationships and teaches much about non-medical care of a dying patient. Joy lived for 30 years, most of it with the diagnosis, complications and treatment of cystic fibrosis, including dealing with a lung transplant:

A renal specialist came to inform Joy of the risks and benefits that long-term drug therapy would have on her kidneys. Joy already knew that but said nothing. The heavy drugs during the critical transplant had damaged her kidneys. Her kidneys would never survive another drug combination. They could possibly save her lungs but shut down her kidneys.

I saw interns huddled with a medical school pulmonologist outside Joy's room. Joy's husband and father arrived just in time with a friend. Soon, Joy's pulmonologist came into the room and sat down in a chair beside Joy's bed. He reported that the biopsy from yesterday's bronchoscopy was inconclusive because the tissue they were able to extract from Joy's lungs was too small.

I cannot remember much of his report on the lab cultures. He then told her they could put her on the ventilator with strong drugs to fight the infection. Joy had always said she would never go back on the ventilator, which she had experienced after the double-lung transplant.

I asked her pulmonologist if there were other options. He said the only other option would be to hook Joy to an IV that would allow her to rest comfortably and peacefully and gradually … I did not hear the rest of his words. Without hesitation Joy said that's what she wanted. I jumped from my chair and walked to the window and back. The group of doctors who had politely stood outside the walled curtains suddenly appeared and moved silently into the room. I guess that was part of their education. How do you tell a patient she is going to die? Maybe they wanted to see my reaction. I was not about to give them the satisfaction.

Joy then told her pulmonologist she wanted to go home. The doctor said he would see what could be arranged. He left with the interns. He returned shortly to report that Joy would have to be transported by helicopter air ambulance. They would try to make arrangements. He left again.

I pulled my chair to the other side of Joy's bed. So many thoughts were going through my head. Should I share them? Yes, yes. "Joy, I should be there on that bed, not you," I said as she shook her head vigorously. "I've lived my life. You are young, more gifted, so much to live for and to offer." She continued to shake her head. I continued, "Just think, you will have a new body. No more treatments. No more pain, suffering. You will see Jesus and live with Him." There was so much more I could have said, but I was still in shock. I think I told her I wanted to go with her. I wanted to say I loved taking care of you especially during those six months after transplant surgery. During the last month of June we had so much fun exploring Minneapolis and the surrounding area. Then I made a stupid comment, "You had almost three years of life after the transplant."

"But I wanted to live to 40," Joy said. Of course she did! Her love for Mike (her husband of 16 months) was complete.

Joy absolutely loved life and was willing to go the length and breadth to be used by God. But God knew better. He said, "Come to me. You are weary. I will give you rest." Joy said several times, "I'm tired." I'm tired, as if to apologize for giving up her body. She had fought hard and vigorously all her life. But it was time. I understood. She knew it and acted upon it. As I have reflected on those moments, Joy seemed to relax. The expression on her face lacked that struggled, pained look. She was at peace. Joy knew her Father. She was not afraid. He would be there to welcome her. She was willing to let go and let God take care of her.

The pulmonologist returned again and said it would be too risky to take Joy to Sioux Falls by helicopter or ambulance. The medical staff worked all the angles but could not justify it for Joy's sake. Joy accepted that. Looking back, it was the best decision.

I saw the pulmonologist in the hall. He was Joy's primary pulmonologist during and after her transplant. I knew he would be in to see Joy. I sat Joy in a chair and pulled up a second chair. He soon came in and sat beside Joy. They talked. I realized his personal feelings for Joy. He was truly touched by her life. A few weeks later he wrote in a letter to us:

… I would like to express to you what a terrible loss we all feel with Joy's death. Her spirit was an example for all of us. She did more with her ailing lungs than most of us manage to accomplish in perfect health. I enjoyed helping to take care of her, and I will miss her. Clearly, she touched many people.

As the day progressed into early afternoon, Joy asked her father to get the Bible. He found one in the room set aside for families of ICU patients. Joy asked him to read that scripture. Gordon asked, "What scripture?"

"You know," she said, "that scripture." After fishing for more information, Gordon finally figured it out – Lamentations 3:21-26. **Editor's Note:** *The Bible verses referred to here from Lamentations focus on the goodness of God, the Lord of hope, love, faithfulness, salvation and restoration, in spite of all evidence to the contrary.*

Our time in that room and hospital became a sacred place. I sat close beside Joy's bed, Mike on the other side. Joy turned toward Mike and stayed facing him. Joy kept repeating, "I'm tired," as if to apologize. Mike time and again said, "It's OK." I wanted to scream, "It's <u>not</u> OK." It was all I could do to hold my tongue. Thankfully, I said nothing.

Joy's discharge and clinic nurse and social worker came to Joy's side. The nurse hugged me for a long time. A pastor and his wife arrived. She sang the hymn, "Great is Thy

Faithfulness." How could she know this would be the theme of Joy's funeral? A colleague walked in. I was surprised to see him in the Twin Cities. He later commented that God's presence was overwhelmingly real when he walked into that room. It was heavy with God's spirit. A doctor friend sat in the room sharing in our sorrow. Close friends of Joy and Mike drove from Sioux Falls to be with Joy. Friends also called to tell Joy they would miss her. She responded, "I will miss you, too." Her sister called again.

Joy could not hold the phone by this time so I held it to her ear. They talked a long time. I do not know what was said. Joy listened; Jami talked. After Jami's phone call, Joy said she could not take any more calls.

Later in the afternoon the head nurse came in and said very abruptly, "We have to move Joy to another floor. It's hospital policy." The staff began rushing around. I could not understand and thought it disrespectful. But we complied with her directions. We were moved to another room one floor above. The nursing staff brought Joy into the room on a wheeled gurney. The doctor had decided to transfer Joy to a room with more privacy where we could be alone and rest.

I left the room and went into the hall where Mike, Gordon and friends waited. I said I just could not bear to watch them move Joy from the gurney to the bed. When they left, we all gathered in the private room to which she had been moved. Tears were trickling down Joy's cheeks. She probably was confused by the quick transport. She may have thought we had left her, abandoned her. No way. We all found places to sit. We sang hymns as Joy lay quietly.

At 10 p.m. Joy's friends indicated they had to depart. We understood. Nurses brought in cots for the four of us to sleep. All the time Joy was half sitting up, propped by pillows with eyes closed. The only medical equipment was the very slow drip from the IV. I never once saw the medication drip. It kept Joy comfortable, not struggling. I was thankful for that. But then I thought, let's stop this whole thing. Joy can come back. It's not too late. Then I realized it was too late. They're killing my baby. I knew it was indeed too late. Weeks later I shared those thoughts with Gordon. He said it was not the drug that killed Joy. It was the massive infection in her lungs. I could live with that.

We decided to take shifts. Gordon would take the first two hours. I would take the next two hours, and Mike the last hours. We each gave Joy a kiss and told her we loved her then settled down to sleep. When it was my turn, Joy lay still, so quiet and peaceful. After about two hours, Mike stirred and said he would take the next watch. I said, "It's OK. I am fine. I can sit with Joy." He repeated his request, and I finally relented. I lay on the cot where he had slept. As I rested, I heard voices. In a sleepy daze I thought Joy and Mike were talking. I did not want to disturb them and lay back down. In a flash I pulled myself up realizing Joy could not speak.

In a few minutes Mike spoke to us and said Joy had taken her last breath. I quickly was up, but Gordon was beside her bed first. Gordon said a prayer as we held hands around Joy's bed. We lingered there quietly. The nurses came into the room to check her vital signs. They clocked the time, 3:30 a.m., then left.

I looked at Joy. I was shocked. She changed so suddenly. She was gone. She had left us. So matter of fact, Mike told us what he said to Joy. "During the last moments I had with Joy, I took her hands, kissed her, and told her of my love for her. I shared that we would be OK. Your friends love you; your mom and dad love you; Jami loves you; I love you … it's OK. It's OK." Joy was waiting for her lover. It was their last good-bye, and she knew it was OK. She gave up her body and moved into the very presence of God and into the loving arms of her Savior.

Mastering the broad topics of spirituality and culture is not a function of language and concepts, but an adventure in relating to others characterized by the nature of one's presence, ability to define boundaries, openness and ability to manage anxiety.

Cultural Considerations

Changing demographics across the country and our region make it likely that health care providers will care for patients from cultural backgrounds other than our own. This could lead to difficult provider/patient interactions as providers may not understand certain patient actions or decisions that are culturally based. Challenges may also arise between cultural differences from the patient's background and traditional western medical practice. Recognizing and addressing these potential differences will allow us to work toward becoming more culturally competent.[6]

Cultural competence is defined as "A set of congruent behaviors, attitudes and policies that come together as a system, agency or among professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations." One should think of cultural competence as a journey or continuum, not a limited destination.[7]

There are four commonly recognized, essential components of cultural competency.[8]

1. An awareness of self and one's own value system;
2. An understanding of the concept of culture and its role as a factor in health and health care;
3. A sensitivity to cultural issues for each patient; and
4. An understanding and ability to use specific methods to deal effectively with cultural issues in interacting with individual patients, their families, members of the health care team and the wider community.

When speaking of diversity and providing care, we also need to be aware of variables other than race. The major diversity categories include geography, culture, gender, spirituality, language, disability, sexuality and age.[9] Each of these factors influences one's attitudes and beliefs both between and within cultures. There is a great deal of variability in preferences within ethnic minorities; therefore, it is important to learn about different cultures, but avoid stereotyping.

Being culturally competent requires knowledge and application of communication skills, use of interpreters/translators and attention to nonverbal communication. The physician may not instinctively know how to go about conducting a cross-cultural interview. There are several mnemonics that can be helpful in facilitating the interview process in a way that conveys respect, acknowledges differences, builds trust, shows interest in one's heritage, and yet elicits needed information. ETHNIC was developed by educators at UMDNJ and provides a framework for culturally competent clinical practice.[10]

E: Explanation: What do you think may be the reason you have these symptoms?

T: Treatment: What kinds of medicines, home remedies or other treatments have you tried for this illness?

H: Healers: Have you sought any advice from alternative/folk healers, friends or other people (non-doctors) for help with your problems? Tell me about it?

N: Negotiate options that will be mutually acceptable to you and your patient that do not contradict but rather incorporate your patient's beliefs.

I: Intervention: Determine an intervention with your patients. This may include incorporation of alternative treatments, spirituality and healers, as well as other cultural practice (e.g., foods eaten or avoided, in general and when sick).

C: Collaboration with patient, family members, other health care team members, healers and community resources.

In addition, cross-cultural issues for end-of-life care need to address the patient's preferences. Ask how much a patient wants to know about his or her condition. Ask who should make medical decisions. Ask which family members to speak to or not. Confirm understanding especially when using an interpreter/translator. Find out views on serious illness and treatment based on family, community and religious beliefs. If necessary, assess the patient's level of comfort in discussing issues with a provider of a different ethnic background.[11]

By addressing spirituality and cultural competency in end-of-life-care situations, patients and providers will have better satisfaction and outcomes as communication and understanding are improved. This does not mean that all of the questions will be answered or that there will be no disputes or conflicts; however, a foundation that acknowledges and respects differences while delivering high-quality, patient-centered care will be established.[12]

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Pediatric Palliative Care

By Didima Mon-Sprehe, MD; Michael R. Sprehe, MD

Children die every day. To many people, this seems unbelievable, and yet, to the families and friends of the more than 50,000 children who die each year in the United States, it is a grim reality. Just over half of these deaths occur in the first year of life, mostly from congenital anomalies and issues related to prematurity. The most common causes of death after the first year of life include unintentional injuries, congenital anomalies, cancer and intentional injuries.[1] Nearly 200 of these deaths occur in children from South Dakota each year.[2] While many of these deaths are unexpected as the result of injuries, the majority do not happen acutely. In fact, each year 500,000 U.S. children and their families cope with life-threatening illnesses.[3] Thus, there is a need and an opportunity to introduce palliative care to help children, along with their siblings and family members, better prepare for and cope with the possibility of death.

The terms palliative care and hospice are often used interchangeably and are unfortunately misconstrued by some to signify giving up hope. Palliative care is the treatment of any symptom – physical, mental or emotional. Hospice is a subset of palliative care provided to children or adults with a terminal illness. The main goal of hospice, and of palliative care, is to maximize quality of life.[4]

When we as health professionals talk about palliative care, it tends to be after all or most available medical therapies have been tried. Instead of practicing according to the traditional model, which treats people who cannot be cured only at the end of their illnesses, we should strive to practice according to the model laid out by the World Health Organization (WHO), which advocates for early involvement of palliative care services for those who are at risk of dying.[5] If curative measures do not work, then the palliative care service can begin to take a more active role. In this model, a palliative care team has been involved for some time and has been able to establish a relationship with the patient and family. This allows for more seamless care than the model in which palliative care is introduced only at the end of the illness.

In palliative care, as in all aspects of medicine, children cannot be treated simply as small adults. Most palliative care and hospice programs have been centered on adults, but children have unique needs. For example, children of all ages differ from adults and from each other in terms of their understanding of death. How children understand death depends on their developmental level as well as their families, cultures and personal experiences. A fully mature understanding of death requires integrating the principles of irreversibility (death is permanent), finality/non-functionality (all life-defining functions and emotions end at death), universality (all living things die), and causality (illnesses or events cause death). Children achieve these levels of understanding at different ages, but it is thought that children understand death as a changed state as early as 3 years of age, universality by about 6 years of age and personal mortality by about 9 years of age.[3] Thus, it is important to recognize that dying children generally know that they are dying. Avoiding the topic does not protect them, but rather it denies them the ability to talk about their feelings and breeds fear and isolation.[6] Children, like adults, have hopes and fears and dreams about the future and, ill or not, should be encouraged to share them.

Just as children are different from adults, palliative care programs for children must be different from those for adults. The WHO affirms that "palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family." It charges health providers to evaluate and alleviate a child's physical, psychological and social distress.[7] This vision of palliative care requires a multidisciplinary team (Table 1) that is best involved early in the disease process rather than when death is imminent.

Team members, while having discreet responsibilities, also share many overlapping skills and duties and need to be open to adapting to individual cases. Collectively, they can address the varied needs of children and families. Donnelly et al. suggested seven needs that are important to incorporate into a comprehensive model of pediatric end-of-life care.[11] (Table 2)

One of the primary goals of palliative care is the relief of physical suffering. Numerous symptoms may occur and can be as varied as the disease processes themselves. The ability

Table 1. Team Members for Pediatric Hospice and Palliative Care Services[8,9,10]
1. Physician director
2. Nurse coordinator/Case manager
3. Nursing
4. Social Worker
5. Child Life
6. Psychologist/Mental Health Worker
7. Respiratory Therapists
8. Pastoral care
9. Pharmacist
10. Bereavement counselor
11. Dietary
12. Physical, Occupational and Speech Therapists
13. Home care agencies
14. Family/Parental Support Volunteers

to assess for these symptoms in children of different ages is a necessary skill for the physicians and nurses. The treatment of these symptoms can be facilitated by a pharmacist with the ability to compound medicines for pediatric dosing and delivery. Common symptoms experienced by children at end of life and often requiring treatment are pain, nausea, vomiting, fatigue, anxiety, constipation, dyspnea and seizures.[10] A supply of compounded medicines, individualized for each patient, can be made available to each family for these symptoms and any others that may arise as the child's condition dictates.

It is important to note that the relief of physical symptoms is but one goal of palliative care. Palliative care and hospice can provide anticipatory guidance and shared decision-making for parents and children, as well as family-centered care to include parents, siblings, grandparents, close friends, teachers, classmates and other important members of the child's social circle.[12] Child life members serve a particularly important role by providing age-appropriate information to children and siblings using varied strategies to promote communication, understanding and memory building.

Table 2. Pediatric Needs to Be Addressed at the End of Life[11]
1. Pain and symptom management
2. Decision-making
3. Access to the medical system
4. Dignity and respect
5. Family-oriented care
6. Spirituality
7. Psychosocial issues

Child life, along with mental health counselors and social workers, can provide psychosocial and emotional support while pastoral care can address spiritual issues. Davies et al. state that spirituality, which is not the same as religion, faith or psychosocial need, has often been neglected in medical care. Spiritual needs exist independent of religion.[13] Spirituality should be addressed with the goal of "assisting individuals to find meaning and purpose in life, to continue relationships and to transcend the self."[13] In their article, numerous guidelines are provided to aid team members in addressing these issues in children, parents, siblings and grandparents.

Ongoing interactions with the family to provide psychosocial, emotional and spiritual support can continue after the child's death. This critical component of hospice, namely bereavement services, is available to families for one year after the death of their child if they were enrolled in hospice.

Palliative care provides an absolute benefit to children and families. So why are so many children not receiving these services? Numerous barriers to pediatric palliative care have been identified. (Table 3)

Table 3. Some Identified Barriers to Pediatric Palliative and Hospice Care[9,12,15,16]
1. False hope of cure among caregivers or health professionals
2. Delayed identification of need
3. Lack of understanding of pediatric palliative care
4. Lack of providers trained in pediatric palliative care
5. Distance from services
6. Disallowing concomitant chemotherapy or other treatments
7. Inadequate or fragmented follow up care after discharge
8. Poor continuity of care across hospitalizations
9. Inattention to spiritual or psychosocial issues
10. Inadequate financial support

While adult hospice and palliative care programs are well established in this country, dedicated pediatric programs lag far behind. Two major factors accounting for this are epidemiology and finances. While 50,000 pediatric deaths nationwide is a staggering number, it pales in comparison to the number of adult deaths that occur nationally each year. This smaller number, along with the reality that these children are scattered throughout the country, makes it more challenging to develop programs and resources to serve all children. Financial support is also a critical issue for many programs as reimbursement for palliative care for children often falls short of that for adults. To date, a

national uniform payment scheme (i.e., the hospice benefit with Medicare) does not exist for children. Additionally, children with complex medical needs require many medications, nutritional supplements and durable medical goods that may not typically be covered by hospice benefits.[14] Thus, programs specifically focused on children can be hard to establish and even more difficult to maintain.

One barrier to enrollment in hospice services, even where available, has been a desire to continue certain medical treatments that have traditionally been viewed as curative and, therefore, not allowed for patients who enter hospice. These treatments, which include chemotherapy, surgery, radiation or transfusions, often affect children with cancer. The desire to continue these treatments is reported to be the most common reason for not referring a child to hospice by pediatric oncologists,[15] thus depriving them the benefit of hospice services. A hospice that allows such palliative treatments, and all the aforementioned treatments, may increase the number of children and families receiving comprehensive hospice care.

As previously stated, infants and children of different ages have different needs based upon their developmental stage. There is a growing awareness of another "pediatric" group that can benefit from the provision of hospice care. With technological improvements in prenatal diagnosis, more fetuses with life-limiting anomalies or genetic disorders are being identified. For women who choose to not have an abortion, expecting that the child will die shortly after birth, the availability of a perinatal hospice can provide tremendous support. This type of hospice provides psychosocial support, information and resources to families "as they plan for both the birth and often probable death of their child,"[17] as well as opportunities for memory building. One such team in Minnesota is comprised of a nurse, a social worker, a chaplain and parent support volunteers who work with the obstetric team. Personal choice is a "central element" in the development of care plans that include the choice to terminate the pregnancy.[17]

In conclusion, as technology improves and more and more children are surviving prematurity, congenital defects and critical illnesses, it becomes easier to regard death as avoidable, yet the numbers prove otherwise. If we do not discuss the possibility of death either because we practice in this age of the technological imperative or because of our own personal discomfort, then we deny children and their families the time and support they need to prepare. Multidisciplinary palliative care teams can maximize the quality of life for ill and dying children and their families. With a growing awareness of need, improved education and resources, and a collaborative approach between health care providers, families and the palliative care team, many of the barriers to palliative care can be overcome. The challenges in pediatric palliative care are great, but the needs are much greater. It is time for us to move forward and provide the children of South Dakota and their families with much-needed pediatric palliative care.

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Palliative Practice in Indian Health

By Timothy Domer, MD; Judith S. Kaur, MD

Overview

Any discussion of palliative and end-of-life are provided to the approximately 4 million U.S. citizens who identify themselves as American Indians and Alaska Natives (AI/AN) must recognize the rich diversity of cultures, beliefs and lifestyles within this group.

In 2007 there were 560 federally recognized tribes in 35 states in the United States. The Indian Health Service (IHS) provides medical care to approximately 1.8 million AI/AN through 268 health centers, 135 health stations, 162 Alaskan village clinics and 48 hospitals. In addition, there are 34 urban centers serving AI/AN people who live outside of Reservation lands.[1]

Certain demographic differences with implications for palliative care exist between AI/AN and other white and non-white Americans. The AI/AN population is younger, with a median age of 24 years, compared to 33 for all U.S. races. Approximately 6 percent are over age 65 compared to 13 percent for all races. AI/AN are also much poorer, with a median household income 34 percent below that of the general population.[2]

The 10 most frequent causes of death for all U.S. races reported in 2004 by the Centers for Disease Control and

Prevention (CDC) National Center for Health Statistics are, in order: heart disease, malignancies, cerebrovascular disease, chronic pulmonary disease, unintentional injuries, diabetes, Alzheimer's disease, acute respiratory illness, renal disease and septicemia. Among the AI/AN population, the two leading causes are the same; however, unintentional injuries jumps to the third, diabetes fourth, liver disease sixth and suicide eighth. Alzheimer's disease does not appear until No. 15, though in the age group 65 and older it is the eighth leading cause of death.[3]

Death rates are significantly higher for: alcoholism, 638 percent greater; tuberculosis, 400 percent; diabetes mellitus, 291 percent; unintentional injuries, 215 percent; suicide, 91 percent; homicide, 81 percent; pneumonia and influenza, 67 percent; gastrointestinal diseases, 38 percent; and heart disease, 20 percent. On the other hand, malignant neoplasms overall are 1 percent lower, though some such as gastric cancer are higher. The rate of HIV disease is 43 percent less.

The result is a life expectancy nearly seven years less than U.S. Whites. The years of productive life lost (YPLL – measures the burden of premature death. It is the sum of the difference between the midpoint of the age of death in all age groups less than 65, compared to 65) is 80 percent higher than all U.S. races and 110 percent greater than U.S. Whites.[2]

While significant strides have been made in reducing death rates for many of the major causes of death since the 1970s, chronic illness has emerged as a major challenge and focus of attention in the IHS.[4] Palliative care and hospice services must be a major part of any effort to improve quality of life for patients suffering from chronic illness, yet AI/AN people lag far behind the rest of the nation in access to these services.

In its report to Congress in June 2006, the Centers of Medicare and Medicaid Services (CMS) emphasized the growth and change in Medicare's hospice benefit. Since 1983 the Medicare hospice benefit has funded most formal end-of-life services. In 2004, 31 percent of Medicare beneficiary decedents opted for hospice use, up from 22 percent in 2000.[5]

In contrast, using the Dartmouth Atlas utilization data, the New Mexico Medical Review Association (NMMRA), the Medicare Quality Improvement Organization for New Mexico, found that from 1999-2003 only 2.8 percent of Medicare patients at two IHS hospitals were enrolled in hospice when they died. This compared to a state average of 30.8 percent.[6,7]

During a meeting with reviewers in May 2007, one explanation of this dramatic difference was that perhaps Native American beneficiaries were culturally opposed to hospice care. A better explanation, however, is a lack of hospice services. For example, the authors are unaware of any formal CMS-accredited hospice program bringing services to significant numbers of patients living on Reservation lands in the Four Corners area of the United States.

Tribal and Regional Diversity

Each tribe has unique traditions, customs and beliefs. Within each tribe, however, there are variations in how families and individuals interpret and practice tribal customs.[8]

Many individuals have joined any number of faiths or denominations. The influence of these outside faiths on traditional customs and practices may vary widely within families and from individual to individual within a tribe. Because of these variations, one cannot assume anything about an individual's beliefs regarding end-of-life or palliative care issues. The only way to find out is to ask!

Numerous studies and journal articles underscore the critical role of cultural sensitivity, understanding and consideration in the success of any palliative care program.[9,10,11,12,13,14] Critical illness, injury and the end stages of chronic illness inevitably raise issues of mortality for patients and families. Cultural background and religious beliefs are central to how patients and families receive information, make decisions, and try to find meaning and direction in the face of potentially life-limiting or end-of-life situations.

A common theme in studies focusing on providing palliative and end-of-life care to ethnic or racial groups is the importance of first developing trust. A major part in developing trust is taking the time and making the effort to learn the unique customs and practices of the people to whom these services will be provided.

Under the authority of the Indian Self-Determination and Education Assistance Act[15] many tribes have exercised the option of assuming the administration and operation of clinical and health-related services and programs in their communities, rather than receiving direct services from

IHS. Cultural considerations and traditions may be more easily incorporated into programs under tribal control.

One such program is the Helping Hands palliative care program in the Bristol Bay area of southwest Alaska, an area of 46,000 square miles with 34 native villages.[9] During the early planning stages of the program, a series of focus-group discussions was held with elders and younger members of native villages. A trusted medical anthropologist facilitated the meetings.

Cultural beliefs and traditions influenced the final product at every level. One example was a concern expressed by some elders that family members who obtained training as personal care attendants would be paid for the care provided. Later, a pamphlet, in the form of a short, culturally oriented story, was prepared to introduce the Helping Hands program. Incorporated into the story was a brief discussion of why it was necessary to pay the personal care attendants and professionals who provided direct care to enrolled patients.

A similar approach was taken during the development of the palliative care program in the Pueblo of Zuni in New Mexico. Members of the planning team were not certain how to discuss dying and death in a culturally appropriate way. A Cultural Advisory Committee was therefore established. Members of the committee were authoritative members of the Zuni Tribe who gave planners guidance on cultural practices surrounding the end of life.[12]

The Tohono O'odham Hospice is a new program being developed through the Tohono O'odham Nursing Care Authority in southern Arizona. The tribe oversees a skilled nursing facility and originally worked with a local accredited hospice agency. Because cultural issues were inadequately addressed, the tribe has now started its own hospice program. Areas of cultural concern included the need for extended family involvement in decision-making, specific language and words used around end-of-life issues and death, the traditional concepts of time, and the role of silence. The CMS accreditation process for the tribal hospice program is underway.

In Cherokee, North Carolina, palliative care is provided by local hospice agencies that come onto the Reservation. Within Cherokee Indian Hospital two rooms were renovated to better provide hospice care. The project grew out of the desire expressed by many patients who wanted to pass in the hospital, rather than at home, but also wanted to remain on their own land. Similar to the experiences described previously, a committee, which included authoritative tribal members, was formed to guide the culturally appropriate development of the program and rooms. Money for the renovations came from several sources, including sales of baskets, carvings and other artwork by local community artists. In addition, the family of a patient who received hospice services donated money toward the rooms. On December 19, 2006, the first room was opened. The room is called Ne gi I yv, translated as: "Over there," a phrase chosen by native members.

In summer 2005 the Fort Defiance Home Based Care (HBC) program at the Fort Defiance Indian Hospital on the Navajo Nation in Fort Defiance, Arizona, admitted its first patient. The HBC program grew out of the need to provide post-acute hospital care, sub-acute and chronic care of certain high-risk outpatients, and to provide hospice and palliative care in the home. There are no other formal home care or hospice programs near Fort Defiance. Prior to the start of the program, patients requiring these services were either kept in the hospital for long periods, were transferred far from home or simply did not receive these necessary services.

The program is patterned on the Medicare Hospice Benefit interdisciplinary team approach, with some features of the Medicare Program for All-inclusive Care for the Elderly (PACE).[16,17] Several years before the program was initiated, a presentation was given to the Dine' Medicineman's Association to seek their guidance on traditional considerations and practices. This distinguished group of native healers voted unanimously to support the program, stating that the Navajo people needed these end-of-life services.

The HBC program includes full-time social workers (all of whom are Navajo), nurses, physicians and a cultural liaison. One cultural issue that had to be addressed was how to discuss "code status" with some of our patients. Talking directly about dying and death, particularly about CPR, is a taboo for many.[14] The social workers developed a gentle, indirect statement which patients and families can read and sign: "The Fort Defiance Indian Hospital Home Based Care Program would like to help you make a choice regarding your wish to die naturally with dignity and respect. In signing below, I acknowledge that when that time comes, when my last breath leaves me, I choose to die in peace to meet

shi'dyin (deity)." This approach has been well accepted. In the hospice portion of the program there have been 30 deaths. Because of cultural reasons many patients and families do not want death to occur in the home, yet eight (27 percent) of these deaths have occurred in the home at patient and family request.

Formalizing Palliative Care

An organized process to advance palliative care services on a wider basis within the IHS started in 2001 and is detailed elsewhere.[18]

A national conference funded by the IHS, "Talking Circle: Palliative and End-of-life Care for American Indian Communities," was held in Albuquerque, New Mexico, in March 2001. Participants of the conference strongly agreed that there was a desperate need for these services throughout IHS. The recommendation was made for formal training in palliative care to be made available to IHS staff.

The first training session was held the following year, attended by 50 participants from 22 IHS sites. Since that time, formal training conferences have been held annually. For the past three years the conferences have been hosted by the Alaska Native Tribal Health Consortium in Anchorage, Alaska. From 2005 through 2007, a total of 527 individuals have participated from across IHS. Disciplines represented include physicians, nurses, social workers, midlevel providers, administrators, spiritual counselors and pharmacists.

In 2004, at the national conference supported by the Spirit of EAGLES, Special Populations Network, breakout sessions on palliative care and hospice were attended by about 75 individuals. A smaller group of leaders met to discuss the strongly voiced need for improving palliative care in native communities. A white paper was produced for the IHS following the conference. Dr. Bruce Finke, Indian Health Service Elder Care Director, was able to identify a young Native American physician to spearhead the writing of guidelines. The publication of *Guidelines for Palliative Care Services in the Indian Health System* occurred in December 2006.[19]

These guidelines cover structure, process, physical, psychiatric, psychological, social and spiritual aspects of palliative care. Care of imminently dying patients and ethical/legal issues are also covered. The guidelines were based in large part on the Clinical Practice Guidelines for Quality Palliative Care from the National Consensus Project for Quality Palliative Care.[20] Experts within and outside the IHS contributed to the final product. The strong hope is that service areas and programs within and outside the IHS will use these guidelines to help develop culturally sensitive palliative care services.

The most current effort to further quality end-of-life care for IHS beneficiaries is a collaborative project between the National Cancer Institute (NCI) and IHS to use the Education in Palliative and End-of-Life Care™-Oncology (EPEC-O) curriculum to train IHS staff in palliative care skills. The EPEC™ curriculum was produced by the American Medical Association and The Robert Wood Johnson Foundation with support of the National Institutes of Health and published in 1999. It teaches the fundamental skills and philosophies of end-of-life care, centering on communication skills, interdisciplinary patient-centered team care, ethical decision-making and symptom management.

EPEC-O was adapted from the original curriculum by the National Cancer Institute (NCI), with supplemental funding from the Lance Armstrong Foundation, through the EPEC™ Project Team at the Northwestern University Feinberg School of Medicine. The orientation and intent was to improve palliative care in clinical oncology. The curriculum consists of highly adaptable training modules and is primarily a train-the-trainer seminar-based format. The EPEC™-O CD-ROM/DVD is available free from the NCI site[21] and curriculum modules are posted on the EPEC™ Web site.[22] The first EPEC™-O training conference was held in June 2005. One of the invited attendees was an IHS representative.

In October 2005 an interagency agreement was signed between the IHS and NCI to repurpose the EPEC™-O curriculum for use by the IHS. This came to fruition in January 2007 when the NCI and IHS jointly sponsored the first EPEC™-O /IHS training conference, held on the Navajo Reservation in Window Rock, Arizona. In preparation for that conference a new module entitled "Cultural Considerations in End-of-Life Care of American Indians/Alaska Natives" was developed.

Representative three-member teams from nearly all IHS areas attended. Twenty-nine pre-and post-conference questionnaires were completed. Knowledge of palliative and end-of-life care among attendees improved from 55 percent

rating their knowledge as fair or poor before the conference, to 100 percent rating good (35 percent), very good (55 percent) and excellent (10 percent) after the conference.

Because of the success of the conference and the strong recommendation from attendees that training be provided to a wider audience, the NCI has provided funding for two more train-the-trainer conferences.

Summary

Palliative care and end-of-life services are poorly available yet critically needed among AI/AN people. A number of formal programs are in place that can serve as models for future programs. Formal training in palliative care for IHS providers was started in 2001 and continues on an annual basis. The involvement of groups such as the NCI should help propel these efforts forward more quickly. It is essential that all of these efforts bring services that are both culturally relevant and sensitive to people who often face desperate situations with limited resources, options and hope.

To paraphrase Robert Frost, the journey has started but we have miles to go before we sleep.

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Issues in Bereavement: Preparatory Grief vs. Depression

By Joann Bennett, DO; Nancy Berndt, RN; Lynne Hunter, MSW

In end-of-life care, distinguishing grief associated with advanced illness from symptoms of clinical depression can be difficult. The complex physical and psychological symptoms seen at the end of life pose challenges to those caring for patients with severe, life-threatening illness. The distinction between preparatory grief and depression has been debated in the literature. Overlooking depression in the patient facing end of life can lead to absence of treatment. The task of differentiating depression from the normal grief associated with end of life is important. In this article, we identify the rationale for differentiating grief from depression and how to identify these two entities. The key differences will be identified and approaches to treatment will be discussed.

Preparatory (anticipatory) grief is a normal reaction experienced by patients who are dying. Usually, patients have a progression through the physical, psychological, emotional, spiritual, social, cognitive and behavioral changes necessary to move toward acceptance of their loss. At times, the patient can experience "waves of intense grief," requiring them to process their loss again.[1] It is common to go through this type of grief, and it frequently leads the patient toward acceptance of their situation. This acceptance prepares the patient for the final separation that death brings to them. Symptoms associated with grief can include somatic distress, loss of appetite and sleep disturbance. Emotional and spiritual distress may lead to social withdrawal.[1,3]

Depression is characterized by a negative self-image, lack of self-worth, anhedonia, persistent dysphoria and hopelessness. Thoughts of suicide and desire for early death can be an indicator of depression. Physicians caring for this group of patients should have a high index of suspicion for depression. Evidence of neurocognitive symptoms in the elderly can be an indication of depression. According to the DSM-IV-R, criteria for major depression include five of the above listed symptoms lasting for more than two weeks duration. In addition, at least one of the symptoms must be depressed mood or anhedonia. In palliative care, the use of somatic symptoms as an indicator of depression may result in misdiagnosis of the patient who is truly experiencing physical decline from his or her terminal disease. These patients should not be confused with patients who are depressed and exhibiting somatic symptoms. The distinction of somatic symptoms that are part of the patient's disease and its co-morbidities from those associated with depression can be difficult. Use of standardized tools such as the Edmondton Symptom Assessment Scale (ESAS) can be helpful in making this distinction. Uncontrolled symptoms can lead to depression, and this underscores the importance of palliative care for patients that have terminal disease.

Clinical depression is experienced by 22 to 75 percent of people who are dying. Depression is not an inevitable part of dying. Attention to the presence of depression and timely introduction of antidepressant therapy is the key to reducing the incidence of depression. The treatment of depression may also include non-pharmacologic approaches such as psychotherapy and psychosocial intervention.[3]

Clinically, depression and grief frequently coexist. Clinical assessment is essential. Approaching the patient and asking "are you depressed?" or "do you feel that you are better off than many other people in this situation?" has proved to be a valid method to obtain diagnostic information about the patient's frame of mind. Some patients and family members are readily able to identify depression, while others do not have this introspection. Validated depression screening tools are helpful in the diagnosis of depression.[7] In the patient with cancer, it has been shown that a single-question screen is more effective in identifying patients with depression in comparison to more complicated psychiatric screening tools. It is the responsibility of the physician or interdisciplinary team to distinguish clinical depression from grief in patients with life-threatening and chronic, progressive illnesses. Once identified, depression can be treated more quickly, allowing improved quality of life. Note Table 1, which compares and contrasts preparatory grief and depression.

Pharmacotherapy in association with psychosocial intervention can lead to significant improvement in depressed patients at end of life. A risk of undesirable side effects from antidepressants exists; therefore, careful identification of depression before initiating pharmacotherapy is prudent.[1] Lack of treatment of depression in this group of patients may lead to social withdrawal from friends and family leading to worsening of the depression as well as delaying

Table 1.
Comparison between preparatory grief and depression in end-of-life care

Preparatory Grief	Depression
• Normal Self-Image	• Negative Self-Image
• Absent anhedonia	• Anhedonia
• People process through grief and it diminishes in intensity over time	• Pathological Process, patient may become "stuck" without treatment
• Maintain sense of hope	• Loss of sense of hope
• Thrive with social interaction	• Withdrawal, isolation
• Brief period of agitation, then acceptance	• Agitation and sense of discomfort
• Patients frequently cope with grief on their own	• Treatment is necessary for patient to improve
• Improved with symptom control	• Active desire for early death
• Positive attitude toward the future	• No hope for future

adequate assessment and treatment of other physical symptoms.[3] Patients who have adequate support for their grief and treatment of depression, if present, are more able to do the emotional work of saying good-bye to family members. This is a source of improved quality of life for the patient as well as the family. Assisting the patient in dealing with grief includes taking the time to reflect, empathize, educate and validate the patient's experience.[6] Educating the family leads to improved coping with the stress of a family member's illness and subsequent death. These supportive interventions are key in the care of patients with life-threatening disease.

The approach to the terminally ill patient with psychological stress is well delineated by the ACP-ASIM End-of Life Care Consensus Panel,[4] which eloquently discusses the reasons for identifying and treating the patient with psychological stress. Psychological distress is common, and many patients and their families (as well as their caregivers) believe it is necessary at end of life. This represents a barrier to effective therapy of depression. Early diagnosis allows the introduction of pharmacologic agents in a timely manner, thus allowing them to have time to be effective. Diagnosis of depression later in the course of their disease requires a different pharmacologic approach.

The standard agents used for the treatment of depression in terminally ill patients are the selective serotonin reuptake inhibitors (SSRIs) or tricyclic antidepressants. Choosing paroxetin or sertraline in this patient population may decrease side effects because of fewer active metabolites. Tricyclic antidepressants have autonomic side effects and are sedating. The use of tricyclic antidepressants should be accompanied by judicious dosing and close observation. It is important to reassess and adjust medication to achieve the desired response. Referral to psychiatry should be considered if the patient is not responding to treatment. Other indications for referral to psychiatry include history of or active mental illness, requests for assisted suicide, or if the patient is suicidal.[4]

The patient in whom depression is noted at the very end of life may not have time to respond to the traditional approach of SSRIs. It is in this population that psychostimulants may be effective. Use of methylphenidate or dextroamphetamine in this group of patients may bring about improvement because they take effect quickly. These drugs are indicated in the patient with depression that has a relatively short life span.[4]

Caring for patients at the end of life requires the practitioner to have skill in diagnosis and treatment of physical and psychosocial issues. The absence of high-quality interdisciplinary care can lead to patient and family suffering due to lack of attention to issues in symptom management and emotional needs. Grief is a common occurrence and supportive care is helpful in teaching the patient and family to cope. Recognizing the presence of depression and treating it appropriately leads to improved quality of life and, therefore, improved quality of care.

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Pain Management and Assessment at the End of Life

By Michael Robinson, MD

There have been many articles and books written about pain management and assessment addressing chronic non-malignant pain, cancer pain, implanted devices to aid in pain management and others dealing with pain at the end of life. Most articles have dealt with assessment tools, primarily in patients who are cognitively unimpaired or who can speak English. This article will primarily focus on the following issues: pain assessment in those who are culturally diverse or cognitively impaired; and the ethics of end-of-life pain management.

It is estimated that the population of the United States is now one-third non-White. The Sioux Falls School District estimates that 19 percent of its enrolled students are non-White, illustrating cultural diversity even here in South Dakota. There is no doubt that other communities in South Dakota have or will have an equally diverse culture. To communicate with this culturally diverse population, we must have a plan in place to deal with pain assessment issues, especially at end of life. We know that those approaching the end of life with cancer or other chronic illnesses fear pain as a result of their illness.

Before we can adequately deal with diverse cultures, we need to reflect on our own attitudes, beliefs and prejudices. Mistrust in physicians may be an issue particularly in certain ethnic cultures. Physician perception of patients may be influenced by ethnicity. As a result of misperceptions, minority patients are less likely to receive adequate analgesics for cancer pain relief and less apt to have completed advance directives.[1] In one survey, physicians had a negative stereotype about black patients that included a perceived higher risk of noncompliance and substance abuse.

We also need to understand the particular cultural practices and beliefs regarding pain management and assessment. In some cultures, asking about pain may be disrespectful because admitting pain may be related to admitting weakness. Instead, we should ask about the patient's comfort. In certain cultures, referring to a patient by his or her first

name might also be disrespectful.

Symptom management in other cultures requires attention to differences in the meaning and expression of pain and suffering in addition to perceptions and customs related to touching or handling the human body. In certain cultures the concept of patient autonomy and informed consent is alien; often family members are the decision-makers instead of the patient. We want to specifically determine how decisions are to be made about the patient's medical care and ask whether the patient holds a belief that is prevalent within a culture. It may be worthwhile investigating folk remedies or cultural practices in dealing with or evaluating patients with pain.[2]

The American Academy of Family Physicians (AAFP) has published cultural proficiency guidelines on end-of-life care. Principle 5 states "Care at the end of life should recognize, assess and address the psychological, social, spiritual/religious issues and cultural taboos realizing that different cultures may require significantly different approaches."[2]

Pain assessment and communication may be difficult in this diverse population. Quite often there is a language barrier which may require the use of a translator, and published guidelines for the use of translators are as follows: the translator should not be a family member (family members may misinterpret, filter, summarize or censor sensitive subjects); a pre-visit discussion with the translator should outline what will be covered in the encounter; and there should be a literal word-for-word translation of any unfamiliar terms.

Prior to the encounter the spokesperson for the patient and family should be identified, since some cultures prefer information be given only to the caregiver or decision-maker, not the patient. During the interview the patient should be looked at while being addressed in the second person, written instructions given and confidentiality respected. Disclosing information to the wrong person (sometimes the patient) may be seen as disrespectful or impolite, provoke anxiety or depression, eliminate hope, and in some cultures the word may "come true" if spoken.[2]

Various sources including "Last Acts" indicate pain is frequently a problem in the nursing home population. Studies demonstrate that we don't adequately manage or assess pain in nursing homes.[3] Studies report as many as 40 to 80 percent of nursing home residents are in some type of pain, and South Dakota nursing homes are no different. In these patients with pain, only 50 percent have adequate relief of their symptoms. This reflects a problem in the recognition as well as treatment of pain in the nursing home setting.

What about pain assessment in those cognitively impaired? Here we are not dealing with another culture but an inability to effectively communicate. Patients with severe cognitive impairments tend to have fewer complaints and are less able to report pain. Therefore, to determine the presence of pain we often have to rely on pain behaviors such as facial grimacing, verbal reports or vocalizations, body movements, interpersonal interactions, mental status changes, or changes in appetite. In those who can somewhat communicate a typical number scale, a facial scale or a color scale can be used to determine the presence of pain (Figure 1).[4]

Figure 1.
Typical number and facial scale for determining

In those less able to communicate we need to rely on family or caregivers to report changes in behavior that may indicate pain. This observation of pain behaviors includes changes at rest and with activity, assuming that if it would cause us pain it is likely causing the patient pain. In these patients, changing behavior(s) may be due to pain or non-pain causes such as infection, constipation or a primary mood disorder. In some instances, if behavior is changing and pain is a possibility, consider an analgesic trial such as scheduled acetaminophen, if not contraindicated. Regular assessment and monitoring of response to interventions are paramount. Remember that physiologic parameters may be unreliable indicators of pain.

There are several tools for evaluating pain in the cognitively impaired: the Doloplus-2 scale which scores somatic, psychomotor and psychosocial reactions. Scores greater than five out of 30 suggest pain as a reason for various reactions.[5] Other scales used in the geriatric population includes the Non-communicative Patient's Pain Assessment Instrument (NOPPAIN) which assesses everyday activities (sitting, standing, walking, and transferring in and out of bed) and reports of pain by the patient or an observer.[6] Other pain assessment tools include the PAINAD scale (Pain Assessment in Advanced Dementia).[7]

In 2005 new guidelines were published by the American Pain Society (APS) regarding treatment of cancer pain in children and adults. These guidelines include less emphasis on the "ladder approach," regular screening and assessment, use of a pain diary and newer titration algorithms for pain, particularly for a pain emergency. Someone presenting with

a pain emergency (pain rated seven to 10 on a 10-point scale) should initially receive strong opioids (i.e., morphine, oxycodone, fentanyl) for primary treatment and not weak opioids or non-steroidal analgesics. There are published pain algorithms by the APS and the National Comprehensive Cancer Network (NCCN) regarding medication titration in a pain emergency that involve rapid titrations based on the peak effect of the analgesic and ongoing assessment. There are also published guidelines for patients who present with pain that is rated 4 to 6 or less.[8,9]

What about the ethics of pain management? Does effective pain management at the end of life hasten death or shorten life?

There are several published articles addressing this issue: Portenoy found no association with analgesic use and hastened death;[10] Walsh concluded that morphine does not cause chronic ventilatory impairment despite preexisting or concurrent respiratory disease in hospice patients;[11] Morita concluded that there was no association with patient survival and opioid/sedative use in terminally ill cancer patients;[12] and Good concluded there was no decrease in survival in patients receiving opioids or sedatives in the last 24 hours of life.[13] These articles suggest that the underlying disease causes death rather than the effective management of symptoms in the end-of-life setting.

Two professional societies have developed position statements regarding pain management at the end of life. The American Society of Pain Management Nurses (ASPMN) and the American Pain Society (APS). Their position statements follow:

ASPMN[14]

- Nurse uses personal/professional code of ethics characterized by respect for human dignity
- Do good and avoid harm
- Provide comprehensive and compassionate end-of-life care, including promotion of comfort, relief of pain, and at times, forgoing life-sustaining treatments
- Duty to benefit is adequate to support the use of increasing doses of opioids to alleviate pain, even if there may be life-shortening side effects
- Provide relief that is based on pain report and goals defined by patients and the health care team

APS[15]

- Terminal illness often accompanied by severe pain
- Pain and other symptoms can often be relieved, suicidal wishes are often linked to unrelieved pain
- Symptom control is often suboptimal because focus of care is on cure rather than palliation
- Policies to ensure adequate symptom management should take precedence over legalization of physician-assisted suicide (PAS) and euthanasia
- Health professionals must be protected to aggressively treat pain with drugs and terminal sedation when required

This article has dealt with different aspects of pain assessment at the end of life. Specifics regarding drug/opioid doses, implantable devices, and neurosurgical techniques are not addressed here but are adequately covered in a multitude of published materials.

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Management of Gastrointestinal and Respiratory Symptoms in Palliative Care

By Priscilla F. Bade, MD

Pain is distressing, but is not the only symptom that causes misery for patients with life-threatening illness. Constipation, nausea, vomiting, lack of appetite, dysphagia, shortness of breath, cough, fatigue, delirium, depression and anxiety are other symptoms that need palliation. This article will overview symptom assessment in palliative care, and then, in more detail, it will address specific gastrointestinal as well as respiratory symptoms. Psychological symptoms are discussed in another article in this issue.

Symptom Assessment in Palliative Care

To identify and treat symptoms effectively, assessment is important. History and physical examination are first steps. The history should include the nature and time course of the symptom, along with its severity and consequent effect on the patient's function and quality of life. Caregiver input is also helpful, particularly if the patient is suffering from dementia or delirium. Careful inquiry about medication use (prescription, over-the-counter and alternative/complementary medications) and comorbidities may affect the diagnostic process and choice of treatment. Physical examination should be directed at identifying the cause of the symptom. Further investigation, including laboratory tests and radiological studies, may be performed if the results will cause a significant change in management.

It is important to discuss goals of care with the patient and family. The question should be asked: "Is our main goal at this time to keep this person alive as long as possible and as functional as possible while maintaining comfort, or is the main goal to preserve comfort and to allow a natural death?" In the early stages of a life-threatening illness,

emergency room visits, invasive diagnostic testing and hospitalization may be very appropriate. In end-stage disease, these interventions may provide discomfort and expense without favorably influencing the outcome of the illness.

In the hospice setting, empiric symptom management may be accepted without knowing the exact cause if diagnostic testing is overly burdensome to the patient. Empiric therapy should be followed by continued assessment to determine if the treatment is effective.

When judging effectiveness of prescribed medications, check to confirm how often they are actually administered. Medications ordered on a "PRN basis" may not have been given. PRN stands for *pro re nata*, which literally means "at the birth," but is used to mean "as needed." Unfortunately, too often it ends up being "Patient Receives None." The patient may not report the symptom to caregivers and, therefore, not receive the medication. It may be useful to regularly schedule administration of the medication, at least for a trial period, to see if it is effective.

Palliative care is most effective when performed by a team. The physician may not always be available to assess the patient in a timely fashion. Nurses (in home health, hospice or long-term care facilities) may see the patient and report symptoms to the physician. Communication may be done via phone or fax and, if necessary, a home or office visit. Further questioning may be needed to obtain important history and results of physical examination.

Gastrointestinal Symptoms

Nausea and vomiting

Nausea has many potential causes and is mediated by neurotransmitters in the GI tract as well as in several areas of the central nervous system: the chemoreceptor trigger zone (CTZ), the vestibular apparatus and the cerebral cortex. These neurotransmitters are serotonin, acetylcholine, dopamine and histamine. Serotonin is an important neurotransmitter in the lining of the gut; acetylcholine and histamine in the vestibular system; and all four neurotransmitters are found in the CTZ. Knowledge of the etiology of symptoms should direct the choice of antiemetic measures, although empiric therapy may be necessary at times.

The history should focus on characterizing the nausea and vomiting in addition to any associated symptoms. Anorexia may represent a constant low-grade nausea. Constipation may also contribute to nausea, but may be underreported by patients who think it is normal to have infrequent bowel movements when oral intake is limited. Esophageal burning may be from gastroesophageal reflux or infectious esophagitis (candida, herpes). Discomfort associated with eating can be caused by esophagitis, gastritis, bowel obstruction, ileus or impaired mesenteric circulation.

A thorough medication history is essential and should include new and recently discontinued medications, counting prescription and over-the-counter drugs and supplements. Opioids, nonsteroidal anti-inflammatory drugs, antibiotics, antidepressants and chemotherapy drugs can all cause nausea. Diuretics and other medications can cause electrolyte disturbances, which can lead to nausea. Abrupt discontinuation of steroids can cause nausea due to adrenal insufficiency.

Past medical history can give insight into the cause of nausea and may include peptic ulcer disease or gastroesophageal reflux. Disorders causing autonomic neuropathy, including diabetes mellitus, advanced cancer, Parkinson's disease and others, can impair gastric emptying. Anxiety and depression can be associated with nausea. Anticipatory nausea and vomiting associated with chemotherapy are mediated by the cerebral cortex.

For cancer patients, the type of cancer and site of origin and location of metastatic disease are important to determine the cause of nausea. Bowel obstruction, liver metastases and peritoneal carcinomatosis can all cause nausea and vomiting. Malignant bowel obstruction can occur with almost any malignancy, but it is most common with advanced ovarian and colorectal cancer. Primary tumors or metastases in the brain can also cause nausea.

Physical examination, including rectal examination, may provide evidence of abdominal masses, bowel obstruction or fecal impaction. Papilledema or neurological signs may be evidence of central nervous system tumor. Orthostatic decreases in blood pressure without a corresponding increase in heart rate may be evidence of autonomic insufficiency.

Laboratory studies may be helpful to rule out renal or hepatic failure, electrolyte disturbance, pancreatitis or toxic medication levels. A supine abdominal film may help to identify constipation, particularly in cognitively impaired patients who are unable to give an accurate history. An upright abdominal film may identify bowel obstruction.

Therapy for nausea and vomiting is directed at removing the specific, underlying stimulus when feasible. Antiemetics

should be directed against the involved neurotransmitters for best response. Wood et al. recommend a mechanism-based management scheme, though they acknowledge that nausea may be multifactorial, requiring empiric treatment that addresses several mechanisms at once.[1] Medications that target the dopamine type 2 (D2) receptor, such as metoclopramide or haloperidol, are useful for first-line therapy of nausea and vomiting. However, sedation, stiffness and dysphagia are potential side effects. 5-hydroxytryptamine type 3 (5HT3) antagonists (e.g., ondansetron, granisetron) also target nausea mediated by the CTZ. Evidence supports the use of 5HT3 agents for nausea and vomiting induced by chemotherapy, radiation therapy and post-operative. The 5HT3 antagonists also may be helpful for opioid-induced nausea and vomiting, but they are expensive and may not be more effective than the less expensive D2 antagonists.

Gastroesophageal reflux and peptic ulcer disease can cause nausea and anorexia. Histamine type 2 (H2) receptor blockers (e.g., ranitidine, famotidine) are available over the counter and are inexpensive, but they might not be as effective as proton pump inhibitors (e.g., omeprazole, esomeprazole, lansoprazole) for these disorders.

Opioid-induced nausea occurs through several mechanisms, including stimulation of the CTZ, gastroparesis, constipation and vestibular sensitization. The effect on the CTZ is mostly through central D2 receptors, whereas the nausea caused by gastroparesis is mediated through peripheral D2 receptors.

Chemotherapy can cause nausea and vomiting through several mechanisms. Direct stimulation of the CTZ is thought to be mediated by 5HT3 receptors and neurokinin type 1 receptors. Chemotherapeutic agents also can damage the GI mucosa, causing release of neurotransmitters including 5HT3. Chemotherapy-induced nausea and vomiting may be mediated by anxiety as well. Anxiolytics prior to each dose may help to prevent anticipatory nausea and vomiting. Advanced cancer itself can cause autonomic dysfunction, leading to constipation and gastroparesis. Poor gut motility can lead to distension of the bowel wall, stimulating the splanchnic and vagus nerves.

Dexamethasone may reduce tumor-associated edema in the brain or gut, thereby reducing nausea. Malignant bowel obstruction-associated symptoms may also improve with octreotide to reduce secretions within the gut. Gastric suction may be necessary if medical interventions are unsuccessful.

Motion-associated nausea and vomiting may respond to agents that block stimulation via the vestibulocochlear nerve, such as scopolamine or diphenhydramine. However, these medications have anticholinergic properties which may cause delirium and sedation, particularly in elderly patients.

If first-line agents are not sufficient, adding a second agent directed at another neurotransmitter may be useful, because nausea and vomiting at the end of life are often multifactorial.

Constipation and Diarrhea

"Constipation" and "diarrhea" mean different things to different people, so it is important to find out what the patient means by these terms. The normal frequency of bowel movements ranges from three times a day to once every three days, so an individual's previous bowel pattern is important. The complaint of constipation may be more related to hard stools than to infrequent stools. Diarrhea may refer to increased stool frequency or decreased consistency. Inquiry should be made into the person's eating habits, including fiber and liquid intake, as well as the presence of associated symptoms such as abdominal pain, nausea and vomiting, bloody stools, or melena. A prolonged time without a full-sized defecation, accompanied by frequent passage of liquid stool, may reflect a fecal impaction with a stool mass having a ball-valve effect so that only liquid stool passes.

Many medications have constipating side effects. Frequent culprits in end-of-life care include opioids, agents with anticholinergic side effects and certain calcium channel blockers such as verapamil and diltiazem. Discontinuing or reducing the dose of these medications may be helpful, but if this is not possible, a bowel regimen should be initiated.

If the problem is infrequent stools, a stool softener will most likely not be helpful. If patients are able to eat an adequate diet, increased fiber and liquid intake may be the first step. Prune juice and bran help some patients. End-stage patients are often unable to maintain adequate fluid intake. A fiber supplement for these patients would only aggravate the constipation, since bulking agents require liquid to pass through the colon.

In end-of-life care a structured bowel program, including scheduled laxatives, is often necessary. Such a program starts with a regularly administered stimulant laxative such as sennosides, which may be combined with a stool softener such as docusate. The dose is increased as needed to the

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maximum prescribed amount. If this is not effective, it may be augmented with an osmotic laxative such as milk of magnesia (or in patients with renal insufficiency, sorbitol or lactulose). Suppositories such as bisacodyl or enemas and/or digital rectal stimulation are used as needed.

Opioid-induced constipation should not be treated with fiber, but with stimulant laxatives. A scheduled stimulant laxative should be started along with the first dose of opioid.

Diarrhea may be medication related; antibiotics, selective serotonin reuptake inhibitors (SSRIs) and acetylcholinesterase inhibitors may be culprits. A trial of stopping these medications is warranted. Patients who have recently been treated with antibiotics (especially fluoroquinolones or clindamycin) are at risk for *Clostridium difficile* enterocolitis. This is treated by discontinuation of the contributing antibiotic and initiating treatment with metronidazole or oral vancomycin. Patients suspected of having *Clostridium difficile* enterocolitis should not be treated with antimotility agents until this problem is excluded, because antidiarrheals can increase the risk of toxic megacolon in the setting of enterocolitis. Fecal impaction should also be ruled out. If no reversible underlying cause is found, antimotility agents such as loperamide are of use to reduce symptoms.

Anorexia

Loss of appetite is common at end of life, but reversible causes should be addressed. Anorexia may be the result of nausea, sore mouth, altered taste and smell, dyspepsia, polypharmacy, metabolic disturbances, infection, dysphagia, gastric stasis, anxiety, and depression.

In evaluating anorexia, a medication history is important because of potential effect on appetite. A number of medications are protein bound; as protein stores are depleted by illness or undernutrition, the amount of free drug may rise to toxic levels. Phenytoin, digoxin and other medications may require dose adjustment even if measured levels are in the "therapeutic" range. Medication interactions can also increase drug levels. Drug interactions are inevitable in patients taking eight or more medications; attempts at medication reduction are often helpful. Some medications, such as metronidazole and angiotensin converting enzyme inhibitors, can cause taste perversion.

Physical examination should include assessment of the oral mucosa, teeth, abdominal and rectal. Evaluate for thrush, oral mucosal irritation, dry mouth and dental caries. Attention should also be paid to the patient's ability to manipulate utensils and to hold a drinking glass. The one-liter bottles often provided at hospital bedsides may be too heavy for frail patients to lift. Patients should also be observed for evidence of oropharyngeal dysphagia, which will be discussed later in this article.

Anorexia may be more distressing for caregivers than for the patient. If anorexia is not reversible, the patient should be offered food as desired and tolerated. Caregivers should be counseled that it is all right for the patient to eat only a bite or two if he or she is not hungry for more. It may be helpful to present a small amount of food, and then offer more if the patient desires it.

A number of medications have been tried for anorexia. Corticosteroids such as dexamethasone may increase appetite in the short term, but do not increase lean body mass. Systemic side effects such as hyperglycemia, proximal myopathy and fluid retention may limit use. The benefit of corticosteroids may be limited to a few weeks. Megestrol acetate and other progestogens can improve appetite but do not increase lean body mass. Fluid retention may be a problem. Onset of benefit may take up to two weeks. Antidepressants may improve the appetite in depressed patients. The antidepressant mirtazepine has been used successfully for this purpose in elderly persons. Start with a low dose and increase gradually if needed, while monitoring the patient for excessive sedation or other side effects. Antidepressants often require three to four weeks to reach their full effect.

Artificial Feeding and Palliative Care

Families may ask if artificial feeding would be helpful for a patient who cannot eat. In this case, the goals of care should be considered carefully, as well as the burdens and benefits of artificial feeding. Artificial feeding may be appropriate for someone who is recovering from an acute stroke or from surgery for cancer of the throat or GI tract and is otherwise functional and desires artificial nutrition. However, in widely metastatic cancer or advanced dementia, there is little evidence that artificial feeding prolongs or enhances life. Cancer can cause cachexia through the production of cytokines which cause loss of lean body mass as well as anorexia. This cachexia is not reversible by feeding. Tube feedings have not been helpful in healing pressure sores, preventing aspiration pneumonia, or improving quality of life for patients with advanced dementia.[3,4] Hand feeding with an appropriately modified diet can sustain patients

with advanced dementia for months to years.

If artificial feeding is employed, the enteric route is preferred whenever possible. Intravenous nutrition is very expensive and does not provide as complete an assortment of nutrients as enteral feeding.

Tube feeding requires invasive measures for tube placement. Most demented or delirious patients will not leave a nasogastric tube in place for more than a few hours, even if their arms are restrained. This places them at high risk for aspiration of tube feedings and is highly frustrating for caregivers. Percutaneous feeding tubes are better tolerated, but do not prevent aspiration pneumonia. Insertion sites might become infected, or the tube may become plugged or dislodged (often at an hour when replacement is not readily available without going to the emergency room). Patients and families should be counseled about the risks versus the benefits of artificial feeding prior to placement of a feeding tube.

Dysphagia

Oropharyngeal dysphagia is a common problem at the end of life for patients with neurological disorders.[5] Patients with advanced dementia, certain strokes or Parkinson disease develop impaired neuromuscular control of swallowing. Delirium can also impair swallowing. Patients with neuromuscular dysphagia may cough and aspirate on thin liquids. Patients who lack the ability to chew due to dental problems or because of oropharyngeal dysphagia may benefit from altered diet textures. Dysphagia diet textures vary from Level I (puree), to Level II (soft and slippery), to Level III (ground or chopped meats and exclusion of crunchy foods such as raw vegetables), to Level IV (regular diet without crunchy foods). Oral dietary supplements may be useful; however, these should only be offered between meals to avoid interfering with meal intake.

Evaluation by a speech pathologist can be helpful to select the appropriate diet for a patient with dysphagia. Thickening the liquids to nectar, honey or pudding consistency may reduce the incidence of aspiration. Unfortunately, thickened liquids may be unpalatable to the patient, making it hard to provide adequate hydration. The diet level that produces the best intake by the patient should be the final choice. Insisting on a restrictive diet that the patient will not eat is counterproductive. If, after evaluation and correction of reversible factors, a patient is not able to consume enough calories and fluids to sustain life, hospice care may be the most appropriate choice. Recurrent aspiration pneumonias are also an indication for hospice care.

Respiratory Symptoms

Dyspnea is common at the end of life: it is experienced by 70 percent of cancer patients in the last six weeks of life; 50 percent to 70 percent of patients with other illnesses dying in a hospital; and more than 90 percent of those dying of chronic obstructive lung disease (COPD). Dyspnea can cause poor sleep, depression, anxiety, fatigue, social isolation and interfere with activities of daily living.

There are many potential causes of dyspnea. These include primary pulmonary problems such as COPD, asthma, pulmonary fibrosis, pneumonia, pulmonary embolus, cancer, pleural effusions and pneumothorax. Other diseases that can cause dyspnea include heart failure, coronary artery disease, anemia, anxiety, depression, cough, pain and vocal cord dysfunction. Diagnostic testing should be directed toward identifying treatable causes. Disease-specific treatment may be effective to reduce dyspnea.

History taking should be directed not only toward identifying potential reversible causes, but also toward learning the degree of impact on quality of life. Clinicians should inquire about anxiety, which can induce or worsen dyspnea.

Physical examination should include evaluation of intravascular volume status. Though elevation of jugular venous pressure (JVP) can result from severe chronic lung disease, in this case JVP will rise and fall in time with the patient's respirations. A persistent elevation of JVP during respiration suggests volume overload. Chest percussion can indicate the presence of pleural effusion while lung auscultation may demonstrate crackles from pulmonary fibrosis, heart failure or infectious infiltrates. Cardiac examination may disclose murmurs, rubs or gallops. Edema may indicate volume overload, but it is not specific for heart failure. Asymmetric edema may be caused by deep venous thrombosis, which is a risk factor for pulmonary embolus, but the edema may also be a result of previous leg injury or lymphedema.

Non-pharmacologic measures can be helpful for dyspnea.[6] Patients in the earlier stages of disease may benefit from rehabilitative exercises to improve breathing techniques, anxiety and endurance. Pursed-lip breathing and diaphragmatic breathing are more efficient than rapid breathing using upper airway muscles. Upright posture uses gravity to

assist in lung expansion (though patients who lean forward onto their elbows for extended periods of time should have padding under the elbows to reduce ulnar nerve compression and pressure sores of the elbow area). Energy conservation techniques, such as frequent rest breaks, can be useful. Using a fan or an open window to cause a breeze in the room can relieve feelings of shortness of breath for some patients.

Aerosolized bronchodilator therapy is often helpful for reactive airway disease. It may also be tried in the absence of wheezing to see if it is helpful. If the patient is able to use a metered-dose inhaler with a spacer chamber, this device may be just as effective as a nebulizer machine but is more economical. Long-acting inhaled medications such as salmeterol or tiotropium may reduce the need for shorter-acting beta-agonists or ipratropium. The short-acting preparations should be used for breakthrough symptoms. Levalbuterol may produce less anxiety and tachycardia compared to albuterol, though it is considerably more expensive. Levalbuterol can be considered if albuterol is not helpful or is producing unacceptable side effects.

Oxygen therapy can improve exercise tolerance in patients with chronic lung disease and hypoxia. Pulmonary rehabilitation can be beneficial for reducing dyspnea and improving exercise tolerance in COPD patients, though would not be tolerated by patients who are dying.[7] The benefit of oxygen therapy in nonhypoxemic cancer patients is less clear. Oxygen therapy may be of symptomatic benefit even with normal oxygen saturations, perhaps via stimulation of trigeminal nerve endings (similar to using a fan). Although oxygen therapy has few side effects, it is expensive and inconvenient for the patient. Patients and families should be counseled to turn the oxygen off if they choose to smoke, since facial burns, smoke inhalation and house fires are a real hazard.

Opioids are the primary non-specific treatment for dyspnea. Opioid therapy reduces the subjective sensation of breathlessness as well as responses to hypoxia and hypercapnea. Nearly all opioids tested have been shown to be effective for dyspnea related to COPD, although the mechanism is not well understood. Opioids may also be helpful for dyspnea related to cancer, although the evidence is not as strong.[8] Nearly all routes of administration appear to be effective, although the role of nebulized opiates remains controversial. The goal is comfort rather than a target respiratory rate. Opioid-naïve patients should start with 5 to 15 mg of morphine equivalent. The side effects of opioids are the same as when treating pain (nausea, constipation, drowsiness and confusion).

Benzodiazepines are useful if the patient is experiencing a significant amount of anxiety associated with breathlessness. Trials show mixed results in patients with chronic dyspnea who do not report anxiety. These agents can cause drowsiness, unsteady gait and dysphoria, and should only be used if the benefits outweigh the risks.[9]

Summary

Non-pain symptoms are common at the end of life and careful assessment as well as treatment can alleviate them. Reversible causes should be sought and corrected. Empiric treatment may be appropriate when diagnostic testing is burdensome. Treatments should be assessed to determine whether they are being used appropriately and are effective. Side effects such as constipation should be anticipated and treated as needed. An interdisciplinary team approach can be beneficial to assess outcomes of treatment.

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Artificial Hydration and Nutrition: A Practical Approach to Discussion and Decision-Making

By Joann Bennett, DO; LuAnn M. Eidsness, MD; Sandy Young, RN

It had been a difficult week. An 83-year-old long-term patient of mine had been admitted to the ICU with septic shock due to pneumonia. The prognosis looked grim. She had completed a living will and appointed a durable power of attorney for health care after many careful discussions in my office and at home. Despite her written wish not to be intubated or to be resuscitated in the event of a catastrophic illness, the family felt uncomfortable not "trying to do something." After all, she had been living at home independently and had been very active up until this hospitalization. The patient had been intubated two weeks ago over a weekend while another physician was covering in the hope that her condition could be stabilized. Indeed, the patient had agreed to intubation "if it will help me get better." It was now time to consider placement of a feeding tube and tracheotomy. But, given the patient's condition and lack of progress, I was going to have to face this family and discuss end of life. In particular, the issue of artificial hydration and nutrition was sure to come up.

This scenario is not uncommon in our current milieu of high technology in the hospital. Physicians frequently face complicated technological and ethical decisions that cannot be made in a vacuum – physicians need to be able to communicate this information to patients and their families in a time of crisis. It is important for each physician to understand the issues involved with life-threatening illness and end-of-life care because they are the trusted, physician-advisors to these patients and families. Ideally, an informed conversation regarding the types of decisions that may be faced in the hospital should take place prior to the time of hospitalization and crisis. Perhaps the most complex is that of artificial hydration and nutrition (AHN). In this article, a review of the pertinent issues regarding AHN in the literature will be presented and a framework for the physician to utilize in considering these issues which supports informed recommendations regarding the use of AHN in clinical practice will be provided.

When a patient is unable to maintain adequate nutrition due to illness, the medical caregivers will necessarily look to technological means to provide the equivalent food and fluid. Many times caregivers initiate IV hydration and tube feeding while patients are hospitalized. This, however, should not be an automatic shift; the decision to provide this medical technology should be accompanied by a clear plan of care, taking into consideration the particular patient's diagnosis, prognosis and realistic goals.

The assumption that all patients should have tube feeding has not been supported by scientific evidence.[1,2,3,4,5] Therefore, it is incumbent on the practitioner to determine whether the long-term provision of hydration and nutrition is not only supported by medical evidence but is also consistent with therapy goals. The prognosis for both survival and function associated with the patient's illness should be clarified in the mind of the caregiver and communicated to the patient and family clearly so that informed decision-making is possible.

Withdrawal of AHN is not uncommon, nor is it immoral or illegal. In their article "Seven Legal Barriers to End-of-Life Care," Meisel et al. discuss the facts regarding the legal issues surrounding end-of-life decisions. They point out that "many legal barriers to end-of-life care are more mythical than real."[6] The American Medical Association (AMA) has issued a statement acknowledging that a physician can ethically withdraw all means of life-prolonging medical treatment, including food and water, from a patient in an irreversible coma. An excellent discussion of decision-making in the terminal patient can be found in the UNIPAC series.[8] The courts in many states and the U.S. Supreme Court have upheld this view and allowed the withdrawal of feeding tubes. Additionally, the American Academy of Hospice and Palliative Medicine clarifies that AHN are life-sustaining medical therapies with risks and benefits. The interventions comprising AHN may be indicated in the course of a terminal disease as a therapeutic trial directed toward well-defined, realistically set goals. AHN

may be withdrawn if the burden of therapy outweighs any benefit, or when the therapeutic goal shifts.[7]

Even with guidance and support, the decision to withdraw or withhold AHN at end of life may be a difficult decision for patients, families and health care staff. The patient's physical status, emotional and spiritual concerns, and prognosis may play a role in the decision to withhold or withdraw AHN.[9,10] When a decision is being made to withhold or withdraw any life-sustaining treatment, it should be based on:

1. Medical indications
2. Analysis of benefits vs. burdens
3. Determination of goals of treatment and quality of life based on patient wishes

Research provides us with evidence that not only do patients want to participate in their end-of-life decision-making, but they also overwhelmingly believe that their primary care physician should be the one to initiate the discussion. In 2005, Life Circle of South Dakota facilitated a survey of attitudes and knowledge about dying and end-of-life care in South Dakota. For this survey, a modified instrument from Life's End Institute was used. The survey was sent randomly to 10,204 South Dakota households.[11] Roughly 2,500 surveys (24.8 percent) were returned. The survey results indicated that 75 percent of those responding did not want artificial nutrition if they were dying and unable to eat. The results also revealed that 64 percent rejected artificial hydration if they were dying and unable to drink. Interestingly, the survey indicated that 88.8 percent of respondents felt "very comfortable" or "somewhat comfortable" talking about death. In contrast, only 6 percent indicated that they had discussed end-of-life care with their physicians. Thirty-nine percent said their physician should be the one to initiate end-of-life conversations, and 95 percent wanted honest answers from their physicians. This data supports that of other national studies about patient's wishes regarding end-of-life decisions.[12,13]

Medical Indications for AHN

The decision to initiate AHN in patients with advanced cancer or severe, life-threatening disease should be preceded by careful consideration of the goals of the patient and the evidence supporting this therapy.[14] The fact that medical technology is available does not mean that it is appropriate in every patient. The availability of PEG tubes for enteral nutrition is an excellent example of how technology has been utilized without consideration of whether there is medical evidence that it is effective.[2] No studies demonstrate PEG tubes prevent aspiration, but PEG tubes are frequently placed with this reason as justification. Ethically and legally the decision to provide AHN is a medical decision. There is a tendency to allow cultural or emotional issues to influence the decision, leading to medically inappropriate actions.[15,16]

Burdens of AHN

1. Patient may require restraints to allow administration of AHN
2. Increased symptoms related to overhydration, or inability to tolerate feeding
3. Monitoring requirements, including laboratory draws
4. Increased caregiver responsibility, perhaps to the extent of changing the patient's location due to caregiver inability to perform necessary interventions
5. Risk of aspiration pneumonia, diabetes, diarrhea, gastrointestinal discomfort

Benefits of AHN

1. Dehydration-related delirium, myoclonus or seizures may respond to a trial of hydration[17]
2. A time trial may ease family anxiety and allow time to accept the ensuing loss of a loved one
3. Medically supplied nutrition may be indicated in specific situations:
   a. Nonfunctional GI tract where death will occur due to malnutrition prior to the effects of the disease
   b. Patients receiving curative therapy who temporarily are unable to maintain oral intake
   c. A trial of nutrition is desired by the patient in whom nutrition may delay the loss of strength; in order to reach a specific goal (i.e., a family event)

Lack of hydration does not impose increased symptom burden in patients with terminal illness. Simple interventions such as moistening the lips, mouth care, and allowing sips of fluid and/or food have been demonstrated to relieve the symptoms of thirst and hunger.[18] Family and physician lack of understanding of the medical evidence regarding the benefits and burdens of artificial feeding may lead to

uninformed decision-making about the initiation of AHN. Personal feelings about the patient's weight loss and inanition, as well as the denial of the upcoming loss of a loved one can overshadow evidence-based decision-making. In particular, the weight loss associated with advanced cancer is expected due to decreased caloric intake as well as cancer mediated hypercatabolism.[19]

Use of parenteral nutrition (TPN) should be limited to those situations where it is medically indicated. Parenteral nutrition is not indicated in advanced cancer because it has not been demonstrated to benefit the patient.[20] There are a few exceptions to this:

1. Head and neck cancer patients undergoing radiation, who have weight loss due to inability to eat during treatment
2. Patients who have nonfunctional GI tract who are losing weight due to inability to eat, such as patients with proximal obstruction of the bowel due to carcinoma
3. Patients with extremely short gut syndrome or ALS may have improved survival and quality of life with AHN if initiated in a timely way[14]

In patients with dementia, the lack of medical evidence and misunderstanding of the risks and benefits often leads to the initiation of AHN. Not only does the initiation of AHN fail to delay the progression of the disease, but it also adds burden to the patient at end of life.[1,2,3,4] Guidelines that may be used in the process of decision-making include the Karnofsky Performance Scale Score or ECOG Performance Scale.[19] James Hallenbeck, MD, encourages a review of benefits vs. burden. In this editorial he notes the trend of gastroenterologists to act as technicians and place feeding tubes without consideration of the medical indications, benefits and burdens.[15]

Medical decisions should be preceded by clear prognostication. The importance of the physician evaluating the patient and effectively communicating the prognosis to the patient or surrogate decision-maker cannot be over-stressed. There is evidence that accurate physician prognostication is sadly lacking in the current medical environment.

Nicholas Christakis, MD, demonstrated in a study of 504 patients in a hospice environment that "only 20 percent of the prognoses made by 365 physicians were correct" and that "63 percent were overestimates."[21]

Improved scientific tools for prognostication are becoming available as palliative care research has addressed the issue of improving communication in patients with severe, life-threatening disease. Prognostication will always be an inexact science. Physicians need to be more comfortable with assisting patients and families in the use of the information that is available to make informed decisions. The challenge is how to educate caregivers regarding the skills of prognostication and communication, particularly in our current medical culture where physician time is at a premium. Marks and Sachar illustrate the difficulty of achieving a change in physician behavior in their article in the *Annals of Internal Medicine*. An example of how difficult it is to disseminate new ideas about management of patients with common problems is illustrated by their evaluation of pain management. In this study, misinformation about the treatment of pain was frequent and led to the lack of adequate pain management in this population.[22,23] It has been demonstrated that understanding prognosis leads to the earlier application of symptom management, thereby decreasing suffering at the end of life.[24] Because patients and families have been shown to make decisions based on their survival probabilities, accurate prognostication could allow patients to make better decisions about treatment choices.[25] Rather than leading to loss of hope, truthful discussions about prognosis leads to improved patient and family communication. This allows the family to spend quality time with the patient and allows earlier application of palliative strategies. Palliative prognostic scoring can assist the physician in clarifying the survival of patients with life-threatening illness.[26,27] Physicians, therefore, should be aware of the prognostic features of a patient's illness and include this in the discussion of the plan of care early in the course of the disease.

Ethical Aspects of AHN

End-of-life care, in general, and decisions regarding artificial hydration and nutrition specifically, can be fraught with moral, cultural and spiritual issues. Sometimes the underlying concern is not readily evident. It is important to remember to evaluate each patient, treatment and goals on their own merit, according to that patient's particular set of circumstances, but against the backdrop of appropriate and effective medical care (casuistry). Robert Veatch, professor of medical ethics at the Kennedy Institute for Ethics at Georgetown University, points out that physicians should

not make value judgments about the validity of the decisions that patients and their surrogates make. In reference to the case of prolonging life in terminally ill or unconscious patients, he makes the point that although he and many clinicians would make the decision not to prolong the life of such a patient, approximately "10 percent of the U.S. public concludes that it is worth preserving life even when it is permanently unconscious or will be both inevitably short and burdensome." He further points out "health professionals and lay people who do see value in preserving such life are not objectively wrong. They are simply different."[28] He further points out, however, that "although some patients value life prolongation [this] does not lead to the conclusion that they automatically have a right to the interventions at stake." From a justice standpoint, some demanded treatments might be in the categories of treatments that health systems should not provide due to excessive cost and consumption of resources. Some might be demonstrated to be physiologically futile in producing the desired outcome, and beneficence would require physicians to unilaterally refuse to provide such treatments." This tension between respect for autonomy and the physician's call to prevent harm and promote good often lies at the crux of the ethical dilemmas health care providers struggle with when facing the question of whether to withhold or withdraw treatments. While we should be cautious about imposing our values on the patient or decision-maker, it is clearly our responsibility to offer care that is medically sound.

Surrogate decision-makers also have difficulty in separating their own interests from that of the patient. Veatch states that "No longer do we view with a degree of inevitability that we must all eventually die."[29] In his discussion of the ethics of nutritional support at the end of life, he points out that "for many caregivers, separating the patient's quality of life from their own interests can cause difficulties" in much the same way our beliefs as physicians can interfere with an honest conversation about end-of-life decisions. As a result of this muddling of interests, the patient may not receive adequate symptom control at the end of life or may have life-prolonging interventions that add to the burden of dying. For instance, many patients that are dying are encouraged to eat and drink by their family. It may become a point of contention, or even cause friction. In the natural course of the disease process, the patient is experiencing less desire to eat, yet the family equates the provision of sustenance as a required and familiar form of nurturing. Carefully explaining the dynamics of the body's natural rejection of food and redirecting families to mouth care, encouraging sips of water or ice chips can ease the tension and improve quality of life significantly.

The distraction of conflicts that occur can lead to a lack of attention to the patient's spiritual and existential needs. These issues cause distress not only to the patient, but the family unit as well. Because despair at the end of life is not uncommon, it is especially important that conflicts are mediated and that the patient and loved ones' psychosocial needs are attended to. "Awareness of events common to the dying process, the potential physical and psychosocial suffering … and the end-of-life care practices associated with reducing that suffering can lead to … being able to take a proactive rather than a reactive approach to end-of-life care."[30]

This review is not complete without a discussion of the influence of religious beliefs on decisions regarding AHN. Religious and cultural values do influence decision-making when patients and families are considering AHN. A physician who is guiding patients and families through the decision-making process should not impose their own belief system on their patient. The decisions regarding end-of-life care, including AHN, should be based on the medical indications, with concurrent respect for the patient and family's values and wishes. In advising families and patients it is important to consider their religious and cultural beliefs, possibly including their spiritual advisors in the conversation if desired. At the same time, assumptions about a particular religion or cultural background should be avoided. As previously discussed, any recommendation about treatment should be preceded with careful consideration of the medical indications and patient prognosis. Clear discussion of the goals of AHN and the expected outcome can lead to cohesive goals that everyone can accept and support. Many religions have guidance available for their congregants to use in negotiating these types of decisions. Physicians are encouraged to become familiar with the religious philosophies common to their locale. A palliative care team or hospital chaplaincy can frequently assist in these discussions to assure that valid information is available to everyone involved.[31]

The physician caring for a patient with a potentially life-limiting disease is faced with many difficult tasks. In the usual course of medicine, diagnosis, treatment planning, support for the patient and cure generally fall together. It can be challenging when "cure" is elusive. Our responsibility is to be aware of the patient's prognosis, ethical issues and wishes. We guide patients through difficult times and advise them during difficult decisions. In his book *The Nature of Suffering and the Goals of Medicine*, Eric Cassell states "It is the responsibility of physicians to care for the sick even with imperfect means in a sea of uncertainty. This is the source of their grace. Thus it has always been and thus it is now — the relief of suffering is the fundamental goal of medicine."[32]

We need not fear addressing the issue of AHN; working to choose appropriate interventions represents the core of why we are physicians – to care for patients.

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Photo by Senator Tom Dempster

Hospice Care at the End of Life (Beware the H-word)

By Michael Robinson, MD

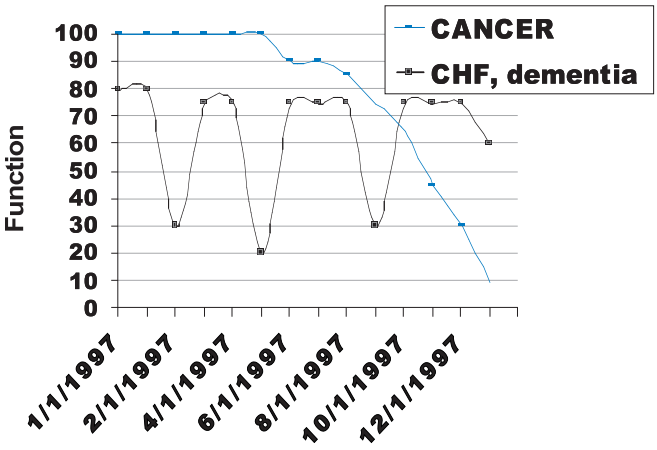
The word "hospice" has dissimilar meanings to different people, including physicians. To some it carries negative connotations: giving up life-prolonging options, pulling the plug, a place to die, a death sentence or added paperwork. Others look to hospice as a means of better symptom control, better quality of life, cost savings, and access to experts in end-of-life care such as physicians, social workers, nurses, volunteers and chaplaincy.

Surveys suggest that physicians see the benefit of hospice in terms of improved symptom management and quality of life. There are essentially three barriers that remain to hospice referrals: physician barriers, patient/family barriers and system barriers. This article will explore some of the barriers to hospice referral and look at potential solutions.

The National Hospice and Palliative Care Organization[1] (NHPCO) has information available about hospice care in the United States. The first hospice program in the country began in the early 1970s. Medicare started to fund hospice programs in 1983 (the Medicare Hospice Benefit), and initially this benefit was developed for end-stage cancer patients. This benefit covers hospice services for those with a terminal diagnosis (likely to take the patient's life within six months if the illness continues on trajectory). There are two 90-day benefit periods followed by unlimited 60-day extensions if the patient meets criteria (disease progression or continued decline in physical function) for continued hospice care. Eligibility for these benefits are certified by the patient's physician and the hospice medical director.

Currently (2005), there are over 4,100 hospice programs nationwide that cared for or are caring for over 1.2 million people (83 percent over age 64). Cancer was the No. 1 diagnosis (46 percent), followed by cardiac disease, dementia and chronic obstructive lung disease (12, 10 and 7.5 percent, respectively). Of these patients, 75 percent died in a

Figure 1.



"home-like setting" (home, nursing home or residential facility). The current median length of stay (MLOS) nationwide in hospice programs in 2005 was 26 days. In the Avera Mckennan Hospice program, the MLOS in 2004 was 13 days.[2] Yes, days. This most likely represents a nationwide lack of early referrals to effective palliative care programs, and instead, the common practice is to wait to delay referral until the patient is very ill.

If only one-third of terminally ill patients and half of end-stage cancer patients are referred, then why are there not more and earlier referrals to hospice? Physicians may be reluctant to refer to hospice programs for a number of reasons. Initially, hospice programs were designed for patients with end-stage malignancies and their prognosis was relatively easy to estimate. Once function of the end-stage cancer patient declined to less than 50 percent of time out of bed, there was a relatively predictable downhill decline and death, whereas patients with cardiac disease, dementia, chronic obstructive pulmonary disease (COPD), and general debility and decline had a gradual downhill course punctuated by periods of worsening and improvement (Figure 1).[3]

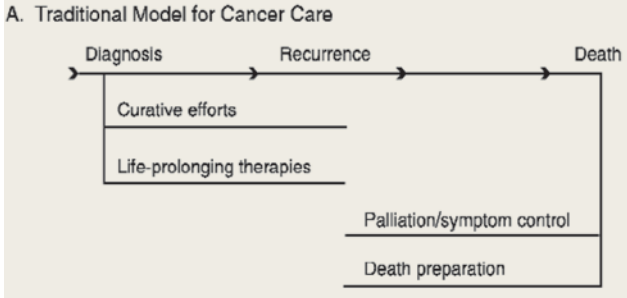
Since the Medicare Hospice benefit now includes over 50 percent of patients with non-cancer diagnoses, one can see the difficulty in estimating prognosis. Hence, the difficult decision as to when a patient may "be ready for hospice." Remember, "hospice" is a philosophy of care that can take place in many settings including the home, nursing homes, hospice residences and even in the hospital for acute symptom management. Hospice admission guidelines are available for non-cancer diagnoses such as cardiac disease, chronic lung disease, dementia, stroke, ALS, renal and hepatic disease, as well as debility and decline.

Physician-related difficulties in referring to hospice include concern that the patient may lose hope, a feeling that the patient or family may not accept the prognosis, inability to place the patient in a disease category, and that it may deny potential life-prolonging treatment. Other potential concerns of the physician include a fear of fraud, too much paperwork and worry about financial pressures of the practice (the patient may not come to the office as often). Physicians may also lack communication skills or time to discuss these difficult issues.

Patients and families may construct barriers to effective and timely hospice referral. They may feel abandonment as they transition to a new care team (who is their support now?) or that they are abandoning their physician. They may not understand hospice care can be given in their homes or a home-like setting (residential facility or nursing home), and they may have a concern that they would have to "give up or forgo certain treatments." The decision to offer more costly (potentially life-prolonging) treatments – radiation therapy, transfusions, antibiotics, hyper-alimentation and even "palliative" chemotherapy – is decided by the local hospice program. Ideally, there should be a transition to comfort-based care rather than an abrupt change in goals of care. Discussions regarding goals of care, advanced directives and options for managing the disease at different stages of illness should be discussed as a continuum rather than only during a crisis. This is where palliative care fits into the hospice continuum of care (Figures 2 and 3).[4]

The traditional model shows disconnect between curative

Figure 2. Traditional model for palliative or hospice care. Modified from the American Medical Association Institute for Medical Ethics (1999). EPEC: education for physicians on end-of-life care. Chicago, IL, The Robert Wood Johnson Foundation.



and life-prolonging treatment and planning for palliative or hospice care (Figure 2). The mixed management model incorporates an ongoing dialogue and plan of care throughout the illness that eventually incorporates hospice as a source of symptom management (Figure 3).

In addition to physician and patient/family barriers there are system barriers that can delay hospice referrals. Medicaid payments are often unreliable, private insurance plans often have poor and inconsistent hospice benefits, and it may be difficult to effectively work with nursing home (e.g., skilled nursing facility/SNF) payment systems. For example, patients on a skilled benefit in a nursing home may not receive hospice care until they're "off" their skilled Medicare benefit. SNFs may feel they can provide adequate symptom management and do not need hospice services. The magnitude of this potential problem will increase in the future, as it is estimated that 160 million of us will be residing in SNFs by 2040. Another system barrier in South Dakota is related to geography. Most of the large cities in the state have hospice programs, but they only cover a certain radius around that city. Because South Dakota is a rural state, there are many areas with no hospice coverage. These uncovered areas may have visiting nurses or county nurses, but this is not the same as an organized hospice program.

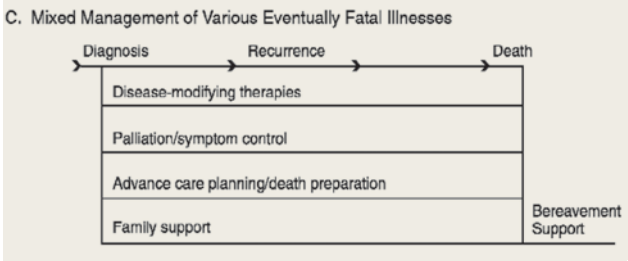
How do we achieve earlier referral and increased utilization of hospice services? For the physician we can improve his/her end-of-life skills (particularly with communication), support with palliative care teams, marketing at tumor conferences or discharge planning meetings, point out consequences of inaction, and support other non-physician links such as nursing and social workers.

For patients and their families we can educate the public as well as market palliative care at church groups, nursing homes and health fairs. During visits with their physicians, patients can be encouraged to ask about hospice and how it relates to their health and prognosis.

For the system, consider changing the six-month rule to perhaps a one-year rule for hospice coverage, allow palliative care teams to more aggressively identify hospice candidates, use telemedicine for geographically underserved areas, change how reimbursement is given to SNFs and promote earlier utilization of hospice services.

Hospice is an important piece of the end-of-life pie. The benefit of hospice include better control of symptoms, the Medicare system saves money compared to traditional care, physicians are "kept in the loop" and, above all, the patient and family benefits.

Figure 3. Mixed model for Fatal Illnesses. A continuum of care from early disease modifying therapies to end-of-life care. Modified from the American Medical Association Institute for Medical Ethics (1999). EPEC: education for physicians on end-of-life care. Chicago, IL, The Robert Wood Johnson Foundation.



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Quality Focus:

Guidelines for Quality Palliative Care

By Stephan D. Schroeder, MD
Medical Director, South Dakota Foundation for Medical Care

The increasing number of patients with chronic, debilitating, life-threatening illness has led providers to consider issues related to palliative and hospice care. Providing quality end-of-life care requires a patient-centered process that involves coordination within a multidisciplinary team.

The National Consensus Project for Quality Palliative Care, representing five major U.S. palliative care organizations, has established guidelines to promote consistent quality care within the structure of ongoing services. These guidelines should be considered to assist in assessment, information sharing, decision-making, planning and care delivery for patients facing end-of-life needs.

The structure should be interdisciplinary and include both the patient and the family. The team should include appropriately trained individuals and supervised volunteers. Support for education and training should be available for the provider team members. The physical environment in which care is provided should meet the preferences, needs and circumstances of the patient and family to the best extent possible. Clinical aspects of care involve pain control and comfort measures as well as other symptoms and side effects that need skillful application. Barriers to effective pain management and sedation (i.e., fear of side effects, addiction, respiratory depression) should be recognized and addressed. The psychological and psychiatric aspects as well as the social needs of the patient need constant assessment.

Also important are cultural, spiritual and religious concerns, including a grief and bereavement program that is available to patient and family. Signs of impending or imminent death should be noted and communicated. The patient's goals, preferences and choices should be respected within the limits of applicable state and federal laws.

The program should address the complex ethical issues arising in the care of persons with life-threatening, debilitating illness. Providers should be knowledgeable about legal and regulatory aspects of palliative care including wills and guardianship agreements. They should also be aware of the dilemmas related to specific interventions such as withholding or withdrawing nutrition or hydration. Self-determination choices and informed consent should be recognized and defined. All those involved in the care and decision-making process should understand the DNR/DNI status.

Palliative care is a growing practice specialty and providers need fundamental training across many treatment settings. The service should be easily accessible 24/7. Respite care should be encouraged to help support family members and those providing the care at home. The process should be constantly reassessed to ensure that appropriate care is being given.

Providers may often face family members and patients who have developed unrealistic goals due to misinformation perpetuated by multiple outside sources. Hopefully, guidelines will foster patient-centered quality care at the end of life and not futile efforts with inappropriate or unnecessary care.

The following three tables were taken from:

1. "Guidelines for Delivering Quality Palliative Care," American Family Physician, Vol. 73, No. 6, March 15, 2006
2. NCPQPC "Clinical Practice Guidelines for Quality Palliative Care"
3. http://www.nationalconcensusproject.org

TABLE 1. Models of Palliative Care

Model	Associated facilities
Combined consultative service team and inpatient unit	Hospital, nursing home
Combined hospice program and palliative care program	Hospital, nursing home, freestanding hospice inpatient facilities
Consultation service team (physician and nurse)	Usually in a hospital, office, nursing home, or home; may include social work evaluations
Dedicated inpatient unit	Acute and rehabilitation hospital, nursing home; sometimes combined with a freestanding inpatient hospice
Hospice-based consultation in outpatient settings	Outpatient settings
Hospice-based palliative care in the home	Home
Outpatient palliative care practice or clinic	Hospital or private practice

TABLE 2. Core Outcomes of Palliative Care

Care should be coordinated across settings through regular, high-quality communication during transitions or when needs change and through effective case management.
Control of pain and symptoms, psychosocial distress, spiritual issues, and practical need should be addressed with the patient and family throughout the care continuum.
Patients and families should be prepared for the process of dying and for death, if anticipated, with exploration of hospice options, enhancement of personal growth opportunities, and availability of bereavement support.
Patients and families should receive ongoing information that enables their full understanding of the condition and options; their values and goals should be elicited; the pros and cons of treatment should be reassessed on a regular basis; and decisions of care should be sensitive to changes in patients' conditions.

TABLE 3. Areas of Palliative Care Requiring Regular Assessment and Documentation

Area	Examples
Physical	Pain; nonpainful symptoms (e.g., shortness of breath, nausea, fatigue, weakness, anorexia, insomnia, anxiety, depression, confusion, constipation); treatment side effects; functional capacities; treatment efficacy and alternatives (and patient and family preferences)
Psychological	Understanding of the illness and its consequences; care giving needs or capacity; stress; grief and bereavement risks for the patient and family (i.e., depression and comorbid complications); coping strategies
Social	Family structure and geographic location; cultural concerns and needs; finances; sexuality; living arrangements; caregiver availability; access to transportation; access to prescription and over-the-counter medicines
Spiritual	Spiritual background, beliefs, and practices of the patient and family; hopes and fears; life completion tasks; wishes regarding care setting for death

DAKOTACARE Update:

Five Wishes

By E. Paul Amundson, MD
Medical Director, DAKOTACARE

As physicians (insurance companies like to refer to us as "providers;" however, I will use physicians) deal with death and/or dying patients, the biggest struggle may not always be the direct care decisions made, but the confusion on the part of patient's family and friends as to what the patient would want done. When patients have a durable power of attorney or other type of end-of-life care plan in place, it always makes the physician's job easier.

We have heard the national statistics of cost of care in the last few days, weeks and months of someone's life. A recent Dartmouth Atlas of Health Care study (May 2006) that evaluated the costs of providing care to 4.7 million Medicare recipients between 2000 and 2003 estimated medical expenses in the last two years of life at $29,199 per patient. This is the national average. There was wide variation among different states. New Jersey had the highest costs. South Dakota was in the bottom quartile of states for costs.

But does lower cost equal a lower quality of care? Other recent Dartmouth studies have shown that regions with the highest health care costs actually have lower-than-average outcomes and, in general, poorer quality of care. With about 75 percent of total U.S. health care costs resulting from treating the chronically ill, some may argue that we needlessly sacrifice resources on end-of-life cases that could be applied to those with the chance of brighter outcomes.

Health plans have been criticized for their willingness to pay for patients in the hospital as long as tests are being ordered. David E. Weissman, MD, FACP, Medical College of Wisconsin Professor of Medicine and Director of the Palliative Care Center of Froedtert, states "the moment I tell them (health plan) a patient is dying, they want the patient out. The incentive is for us to keep doing tests and procedures. It's not about providing the best level of care."

There may be something you and your patient(s) can do to combat this issue. Living wills and durable powers of attorney are crucial for proper communication between individuals, their family and confidants, and you, the physician. These are oftentimes confusing to the patient and do not provide the "health care decision-maker" or physician with an adequate description of the patient's true end-of-life wishes.

A program known as "Five Wishes" was developed several years ago and is considered by many to be the most "patient friendly" health care decision document of its kind. It was written with the help of the American Bar Association's Commission on the Legal Problems of the Elderly and many leading end-of-life experts. It meets the legal requirements in South Dakota, Minnesota and Iowa. It can replace existing documents, is written in lay terms so it is much easier for the patient to understand and is easily revocable. The term "Five Wishes" alludes to the five main topics included in the document. Each wish can be customized by the patient.

The document requires the patient to choose someone to serve as their "Health Care Agent." This agent can be given the authority to:

- Make choices about medical care and services, including the authority to withdraw life-supporting care
- Arrange for admission to a hospital, hospice or nursing home facility
- Make the decision to request or withhold artificial nutrition and hydration (AHN)
- Authorize or refuse to authorize medications or procedures to help with pain
- Donate organs

It requires two witnesses, neither of whom can be a provider or an employee of a provider. Others, such as life insurance agents or relatives are also excluded. Patients may come to your office with a copy for your files. It even comes with a wallet card that lists the Health Care Agent and the patient's primary care physician.

This document was developed by Aging with Dignity (www.agingwithdignity.org) in conjunction with The Robert Wood Johnson Foundation. If you are interested in seeing a copy of this document, please e-mail me (pamundson@dakotacare.com) or contact Aging with Dignity at 888.5.WISHES (888.594.7437).