

End-of-Life Care in Utah: The Report Card



*End-of-Life Care
Partnership*

How did we learn about the Utah experience at the end of life?

The End-of-Life Care Partnership conducted a telephone survey of 150 individuals who were agreeable to sharing their experience in the death of a significant other. The aim was to assess the current experiences with end-of-life care in Utah in order to identify areas for improvement. The questions focused on areas that have been identified nationally as important to the quality of a dying experience. These include whether people die where they want, whether they received services such as hospice care, whether they experienced unrelieved symptoms, and whether their wishes for end of life care were communicated and respected.

Details of the survey Method

We retrieved death certificates of Utah residents who were 18 years of age or older from the Utah Bureau of Vital Statistics. We used the records of patients who died between February and April of 2000, and we excluded deaths due to suicide. A potential sample of 540 was randomly selected from all deaths (n=2,840). Of these, telephone contact information for a survivor was located 69.9% of the time. We sent a letter about the study to identified informants six months following the date of death and offered an opportunity to decline participation. We then telephoned the informants. If contact was not made after at least three attempts on different days and at different times of the day (morning, afternoon and evening), informants were listed as "unavailable." When we reached an informant, we reminded them of our letter and asked if they wanted to participate in the study. If they agreed, we administered a structured interview by telephone. We interviewed only informants who said they were familiar with circumstances of the decedent's death. A structured interview guide included both closed and open-ended questions that addressed the place where the decedent received care, use of hospice and home health services, pain and other symptom management, advance directives and planning, emotional and spiritual concerns, and support for the family before and after the death. We also asked open-ended questions about what had been most helpful, what had been most difficult

The End-of-Life Care Partnership (formerly the Partnership to Improve End-of-Life Care in Utah), is a coalition of individuals and organizations who are combining their efforts and expertise to improve care for persons near the end of life and their families. Nearly 300 individuals representing more than 100 organizations throughout Utah are members.

The Partnership is sponsored by *HealthInsight*, and is funded by a grant from the Robert Wood Johnson Foundation. The grant that has supported the program for its first four years will end in 2003; we will rely on grants and donations to continue our efforts into the future.

The Partnership has met these major objectives in the past 4 years:

- Town meetings to publicly discuss end-of-life care in Utah;
- More than 25 "dialogue to action" focus group programs where families were brought together with healthcare providers to discuss end-of-life experiences and to encourage change in the way end-of-life care is provided;
- With KUED-7, publication and distribution of 25,000 "Living with Dying: End-of-Life Care in Utah" end-of-life care guides;
- Publication and distribution of more than 5000 "Tool Kit for Health Care Advance Planning" workbooks;
- Publication of the Deseret News "Final Acts" series on end-of-life care in Utah;
- Implementation of the Physician Order for Life-Sustaining Treatment ("POLST") Form; and
- Development and maintenance of a web site, www.carefordying.org, which currently receives nearly 10,000 visits per month.

and suggestions for changes that are needed in caring for dying patients and their families. For each decedent, we linked our questionnaire data with data available on the death certificate that included age, sex, race, years of education, marital status, county of residence and death, site or type of facility where death occurred and cause of death. The time to conduct the surveys ranged from 20 to 95 minutes, with an average of 40 minutes.

Who were the participants?

A total of 228 survivors were approached to participate in the study; 150 consented for a 65.8% response rate. The survey was conducted in two waves. In the first wave of interviews, 100 deaths due to any cause were included (31 of these were cancer deaths); the second wave included 50 cancer deaths. Thus of the 150 participants, 81 deaths were due to cancer and 69 were from another cause.

The age of decedents ranged from 23 to 100 with a mean of 74, nearly 75% percent were 65 or older. They were 99% Caucasian and 57% male. Nearly 75% were LDS and 71% lived on the more populated area of the Wasatch Front. When we compared findings based on whether the decedent was from a rural versus urban area and based on religion, no differences were found. When we compared the sample with the population based on death certificate data, there were no significant differences in age and place of death. The informants had varying relationships to the deceased. Over half (51%) were spouses, 29% were children, 4% were parents, 5% were siblings and 12% had some other relationship. Sixty-eight percent of the respondents were female.

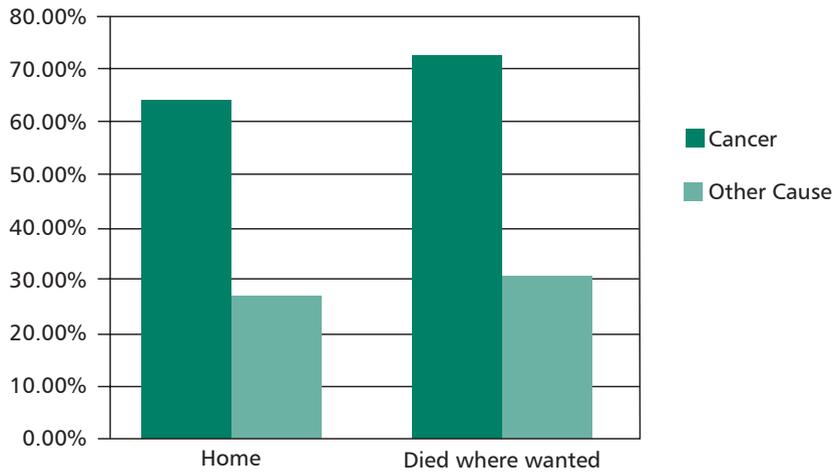
Where do people die?

Place of death is an important indicator of end-of-life care. Nationally, many people die in the hospital or intensive care unit when they preferred to die at home. We first evaluated the first wave of 100 randomly selected deaths to determine place of death (see Table 1) and then compared the place based on whether the death was due to cancer in the sample of 150. The place of death differed significantly between the cancer death and other cause of death groups (see Figure 1). Sixty-four percent of cancer deaths were at home as compared to 26% of deaths due to other causes. **Only 54% of the total sample died where they wanted.** More individuals with cancer died where they wanted. When people did not die in their preferred place it was usually due to a sudden change in condition or the need for more care.

Place of Death	Home	Nursing home	Hospital	Other
Percent	37%	33%	28%	2%

Table 1: Place of Death of 100 Randomly Selected Deaths in 2000

Figure 1: Where People Die:
cancer vs. other causes



Men (77%) were much more likely to die at home than women (40%); 35% of women died in a nursing home as compared to 18% of men. Those who were 65 or younger more often died at home (55%) and 97% in this group preferred their home as a place of death. Of those over 80, 38% died in a nursing home; 76% of those over 80 wanted to die at home. There is still room for improvement in providing services needed for people to die where they want to die.

The End-of-Life Care Partnership has worked to educate the public about hospice and other support services that increase the chance that people who want to can die in their homes. Information about end-of-life care options is available at www.carefordying.org.

Did hospice make a difference?

Hospice is a program of interdisciplinary care to support individuals and families at the end of life. Of cancer patients, 66% used hospice services as compared to 21% of those who died from another cause. Of those who used hospice services, 67% used hospice for less than one month with 28% using hospice for less than one week. Women were more likely to be aware of hospice services than men, and more men (65%) died with hospice care than women (34%). Thirty percent used home health services other than hospice. Of those who used hospice, 92% would recommend hospice for the care of a seriously ill family member.

Use of hospice was associated with improved care and outcomes in numerous areas including:

- Better pain relief from treatment or medicines
- How well spiritual needs were met
- Satisfaction with emotional support provided
- Having a living will
- Knowledge that illness would lead to death
- Information about what to expect at the time of death and after death

Many respondents described how hospice helped. For example, one said, “In the beginning I had zero understanding. Hospice answered questions and gave us information. They explained what to anticipate. Hospice stayed with us until the body was removed and they contacted the agencies that needed to be contacted. Give hospice all the support you can. I hope they are available when I need it.”

The findings demonstrated that hospice services were beneficial but there is a need to increase awareness of hospice and hospice referrals. It is particularly important for physicians to make referrals to hospice earlier so that help can be provided for a longer period of time.

The End-of-Life Care Partnership has provided public education about hospice, in addition to providing education to physicians and nurses in rural communities about hospice admission criteria. Further education about admission criteria is necessary so that physicians understand when referrals are appropriate.

What symptoms were experienced at the end of life?

Numerous physical and emotional symptoms can influence the quality of life during the final stage of life. We measured six types of symptoms. There were three symptoms that were experienced by 60% or more of the patients: confusion, pain, and shortness of breath. Only 60% of respondents believed that the pain could be controlled. About one third of patients or family members were reluctant to use pain medications. The group who died from cancer had significantly higher rates of nausea, anxiety and pain as compared to the other cause group. Pain severity without treatment was greater in the cancer group with nearly 60% experiencing pain that was “extremely severe” without treatment as compared to 41% in the other cause group. Almost half (48%) of the cancer patients were in pain all of the time. Nausea was significantly more prevalent in those 65 or younger (65%) as compared to 35% in those over 65. Table 2 reports the percentage of patients who experienced a symptom, were treated, and were treated effectively. For all symptoms, a certain percent were not treated but we don’t know why.

Type of Symptom	Percent with Symptom	Percent who were treated and treated effectively
Pain	63%	41%*
Shortness of Breath	61%	71%
Confusion	60%	11%
Nausea	43%	60%
Anxiety	40%	65%
Depression	37%	46%

Table 2: Symptom Experience of Utahns at the End of Life (n=150)

* Defined as number reporting relief ≥ 8 on a 0 (no relief) to 10 (complete relief) scale

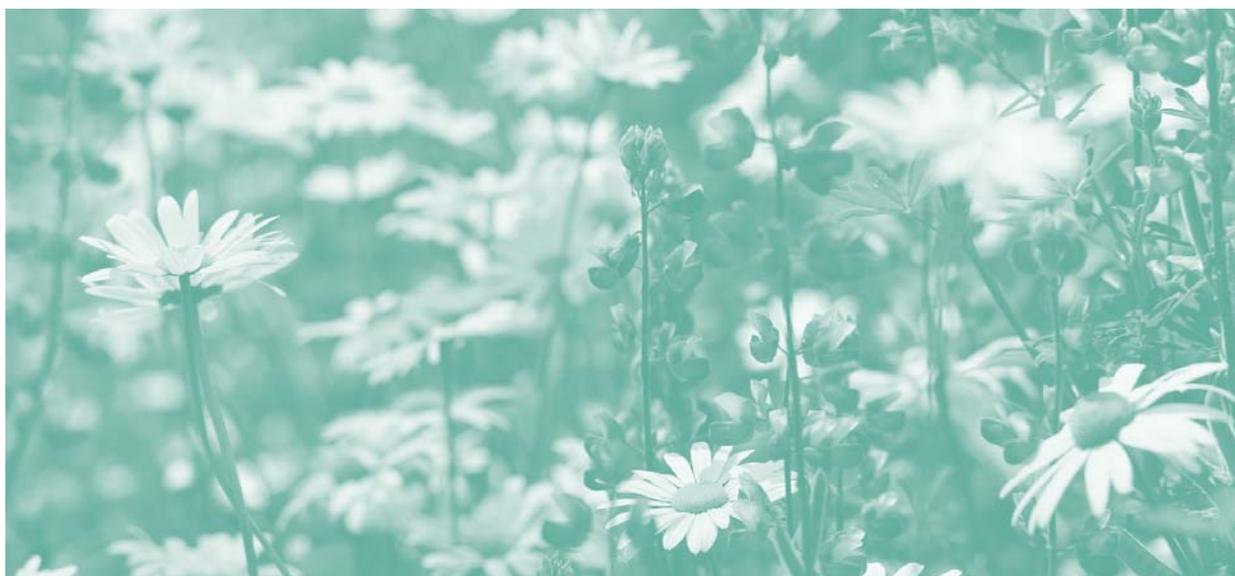
Similar to other studies, dying persons experienced many symptoms that perhaps could have been relieved by better treatment. Unrelieved pain, which can be successfully managed in most cases, remains problematic.

Because research has shown that those who demand quality pain management are the most likely to receive quality pain management, the Partnership has worked with other organizations such as Cancer Pain Relief-Utah to dispel myths about pain management and to educate the public about pain. Radio Public Service Announcements on pain management were broadcast throughout the state of Utah in 2000.

The Partnership has also educated physicians and nurses serving rural communities about quality, state-of-the-art pain management, with a focus on rural communities. Such efforts should continue.

Did Utahns have Advance Directives?

Advance directives provide written communication of an individual's wishes related to medical treatment and care at the end of life and designate a decision-maker to act in one's behalf. We asked about a durable power of attorney for healthcare and a living will. Sixty percent of all patients had a durable power of attorney for healthcare and 69% had a living will. Somewhat more cancer patients (74%) had a living will than those who died from other causes (62%). The percentage with advance directives increased with age ($p < .01$) and with use of hospice services. A high percentage of respondents (91%) knew that illness would lead to death, knew about wishes for life-sustaining treatment (85%), and felt that these wishes were met (91%). For example, one respondent reported, "It goes back to preplanning with the nursing home on how to handle my father's care. They gave me feedback. Periodically I had a meeting with a nurse, physical therapist, social worker and they had an open discussion and planned what to do in event of medical issues. My father's wishes were followed when it happened." Although not everyone had formal written documents, the results suggest that many individuals' wishes were communicated and that these wishes were met.



In an effort to assure that most people continue to have their end-of-life care wishes honored, the Partnership has made Utah's advance directive forms available on its web site, www.carefordying.org, since 1999. In 2002 and 2003, we published and distributed more than 5000 copies of the *Tool Kit for Health Care Advance Planning*, which helps individuals think about and record their end-of-life care preferences.

How was it for those who died in a nursing home?

Nursing homes have been identified nationally as institutions that provide critical care to many individuals at the end of life. Of all deaths in the sample of 150, 27% occurred in a nursing home. The frequency increased with age to 31% of those over 65 and 40% of those 80 and older. A little more than half (52%) of those over 65 died where they wanted to die; only 12% wished to die in a nursing home. Patients who died in the nursing home setting experienced multiple symptoms (see Table 3) with confusion, pain, and shortness of breath being most common. Of those who experienced pain, 75% experienced pain most or all of the time. The mean level of pain relief achieved on a 0 (no relief) to 10 (complete relief) scale was 6.9. Only 70% of respondents believed that their loved one's pain could be relieved. Individuals who die in a nursing home continue to have significant needs for more effective symptom management.

The Partnership's sponsoring organization, *HealthInsight*, has provided quality improvement training in nursing homes in an attempt to improve the quality of pain management among nursing home residents. The Partnership has worked with *HealthInsight* to train nursing home staff about effective pain and symptom management in the nursing home setting.

Type of Symptom	Percent Experiencing Symptom	Percent Reporting Symptom who were Treated and Treated Effectively
Confusion	70%	11%
Pain	60%	42%*
Shortness of Breath	60%	71%
Depression	43%	47%
Anxiety	38%	67%
Nausea	33%	85%

Table 3: Symptom experience of Utah patients who died in a nursing home (n=40)

* Defined as number reporting relief ≥ 8 on a 0 (no relief) to 10 (complete relief) scale

Did families have the information and resources they needed?

At the end of life, families and loved ones need information and support. Many expressed the need for more information. One respondent explained, "I understood very little. The doctors beat around the bush and leave you guessing and you have to figure it out for yourself." Another explained, "I would have liked to have known what options are there to take care of people at home. It would have been

easier if I didn't have to dig so hard for answers to questions, to know what is available - services, support groups. Information is key to all. Some doctors don't want to go over so many things with you and the insurance doesn't want to either. There should be information about how to care for home ridden people."

Only 64% of respondents were aware of grief support programs. More than half (55%) had heard from the health care team since the patient's death. Twenty-nine percent reported financial concerns during the illness. Only 10% had financial concerns about what to do with the body after death. These concerns were more common in those 65 and younger. Although many resources are available, there is still a need to reach people with the information they need when they need it.

From June 2002 through May 2003, the Partnership assisted the Deseret News in the publication of twelve monthly stories on end-of-life care in Utah in a series called "Final Acts." Topics ranged from dying children to pain, to signs and symptoms of impending death. These stories, in addition to the guide produced by KUED and the Partnership, *Living with Dying: End-of-Life Care in Utah*, and the Partnership's web site, www.carefordying.org, have helped to provide some of the information to Utahns that those surveyed said they need.

Were Utahns satisfied with end of life care?

Overall there was a high level of satisfaction with the care provided before death. The mean was 8.6 on a 0 (No) to 10 (High) scale. Satisfaction with emotional support provided by the health care team was somewhat lower (Mean 7.9). This decreased to 6.5 for satisfaction with support provided after death. When death was due to cancer, the satisfaction ratings were higher. There was a need to know more about what would happen at the time of death. For example, one respondent said, "I would have liked to have been told before the morphine drip that conversations with her would be nonexistent. I couldn't say to her that she would die in the next few days. I had only said that they would keep her comfortable. I feel bad about missing the last opportunity to talk to her." Communication from health-care providers to patients and families about what to expect remains an important aspect in promoting satisfaction with end-of-life care.



How does End-of-Life Care in Utah rate nationally?

Criteria	Utah	U.S.	Last Acts Standard for Excellence ⁵
Location of death			
Percent of deaths in a home ^{1,2}	35.5	22.3	>60
Percent of deaths in a nursing home ^{1,2}	23.4	22.0	-
Percent of deaths in a hospital ^{1,2}	37.3	50.9	-
	(2001)	(1999)	
Advanced Planning			
Quality of state advance directive laws, 2002 ⁵	2.5 on scale of 0-5	N/A	4.5 - 5
Percent of terminally ill patients in nursing homes with formal advance directives, 1999 ³	31.4	42.4	N/A
Percent of terminally ill patients in nursing homes with Do Not Resuscitate orders, 1999 ³	64.3	73.5	N/A
Percent of terminally ill nursing home patients with orders to forgo artificial hydration and nutrition, 1999 ³	12.5	11.7	N/A
Care in ICUs			
Percent of residents over 65 with 7 or more ICU days totaled across all admissions during last 6 months of life, 2000 ⁵	6.8	10.0	0-6
Hospice Use			
Percentage of people over 65 who used hospice in the last year of life, 2000 ⁵	24.9	21.5	>50
Median length of stay in hospice (days), 2001 ⁵	19.3	25.3	>60
Pain Management			
National rank based on amount of morphine prescribed per 100,000 people ⁴			
2001	38th		
2000	N/A		
1999	45th		
1998	48th		
1997	48th		
Percent of terminally ill nursing home residents in moderate or excruciating pain, 1999 ³	65.3	44.3	N/A
Palliative Care-Certified Physicians and Nurses			
Percentage of primary care physicians certified in palliative care, 2000 ⁵	0.41	.33	.50 - .97

Sources:

- Utah Vital Statistics
- US vital statistics from the CDC NCHS (National Center for Health Statistics) Data Warehouse, <http://www.cdc.gov/nchs/data/statab/V/S00199.TABLE309.pdf>
- Center for Gerontology and Health Care Research at the Brown Medical School, <http://as800.chcr.brown.edu/dying>
- DEA, <http://www.deadiversion.usdoj.gov/arcos/index.html>
- Last Acts, <http://www.lastaacts.org> This organization assigns a grade based on an ideal standard. In several categories, no state achieved an A.

Summary

In comparison with the nation, Utah residents are more likely to die in a home and to use hospice care. They are less likely to spend time in an ICU and to have formal advance directives and Do Not Resuscitate orders. Survivors generally report that medical care and emotional support meets their expectations. A national organization of expert end-of-life professionals judge the quality of end-of-life care in Utah as significantly less than it could be if higher expectations were established and met.

Steps to Take to Achieve Excellent End-of-Life Care

Patients

- Acquire accurate information about your diagnosis, treatment options and prognosis.
- Learn what to expect from end-of-life care and what services are available in Utah. Information is available at www.carefordying.org and in the Partnership/KUED guide, *Living with Dying: End-of-Life Care in Utah*
- Discuss your values, preferences and fears with family and physician.
- Designate someone to make decisions on your behalf if you cannot (a “healthcare proxy”).
- Communicate your preferences to your healthcare proxy and other loved ones through a living will, conversations, written directions, and/or the Partnership’s *Tool Kit for Health Care Advance Planning*.
- Ask your physician to complete a Physician Order for Life-Sustaining Treatment Form that will allow all healthcare facilities and Emergency Medical Services providers to honor your end-of-life care treatment wishes.
- Tell those you love that you love them.
- Say I’m sorry to those you’ve hurt.
- Forgive those who have hurt you.
- Say your goodbyes.

Families

- Acquire accurate information about your loved ones diagnosis, treatment options and prognosis.
- The Partnership’s *Tool Kit for Health Care Advance Planning* contains lists of questions to ask health care providers that will help you to assess treatment options.
- Learn what to expect from end-of-life care and what services are available in Utah. Information is available at www.carefordying.org and in the Partnership/KUED guide, *Living with Dying: End-of-Life Care in Utah*. Tap into these services early.
- Ask your loved one to share his/her values, preferences and fears. The Partnership’s *Tool Kit for Health Care Advance Planning* provides information on getting the conversation started.
- Know about your loved ones advance directives and orders to limit treatments.
- If you are acting on behalf of your loved one, ask his/her physician to complete a Physician Order for Life-Sustaining Treatment Form that will allow all healthcare facilities and Emergency Medical Services providers to honor your loved ones end-of-life care treatment wishes.
- Advocate for your loved one.

Providers

- Provide accurate information about the patient’s diagnosis, treatment options and prognosis.
- Recognize that some people with chronic progressive diseases are terminally ill. Offer them the

palliative care that many cancer patients now receive.

- Explain what to expect from end-of-life care and what services are available in Utah. Direct patients to resources such as www.carefordying.org or the Partnership/KUED guide, *Living with Dying: End-of-Life Care in Utah*.
- Ask your patients to share his/her values, preferences and fears.
- Know about the patient's advance directives and use the Department of Health's transferable Physician Order for Life Sustaining Treatment Form to limit unwanted treatment.
- Learn what constitutes excellent end-of-life care, including palliative care and pain management. If you do not have the expertise or desire to provide quality palliative care, involve experts.
- Follow up with families who have experienced a loss to answer remaining questions and assist with bereavement.

Institutions

- Ensure that the patient/family is asked whether they have or wish to have advance directives and if completed, make sure that preferences are followed. If patients wish to complete advance directives, provide competent assistance.
- Be certain that staff have the requisite knowledge and skill to provide competent and compassionate end-of-life care. Be certain that staff use the knowledge and skill to assure that all patients receive competent and compassionate end-of-life care
- Complete and send a Physician Order for Life Sustaining Treatment form with patients if they go to another site of care.
- Help patients/families understand and navigate the health care system.
- Provide a comfortable, private room where patients and their families can be together before death and say goodbye.
- Provide the environment and services that meet patient/family emotional and spiritual needs.
- Support the End-of-Life Care Partnership in its efforts to provide professional and public education about quality end-of-life care.

Report Card Team

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