

Death and End-of-Life Planning in One Midwestern Community

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Background: The major health care organizations in a geographically defined area implemented an extensive, collaborative advance directive education program approximately 2 years prior to this study.

Objectives: To determine for a geographically defined population the prevalence and type of end-of-life planning and the relationship between end-of-life plans and decisions in all local health care organizations, including hospitals, medical clinics, long-term care facilities, home health agencies, hospices, and the county health department.

Methods: For more than 11 months, end-of-life planning and decisions were retrospectively studied for all adult decedents residing in areas within 5 ZIP codes. These decedents were mentally capable in the 10 years prior to death and died while under the care of the participating health care organizations. Data were collected from medical records and death certificates. Treating physicians and decedent proxies were also contacted for interviews.

Results: A total of 540 decedents were included in this study. The prevalence of written advance directives was 85%. Almost all these documents (95%) were in the decedent's medical record. The median time between advance directive documentation and death was 1.2 years. Almost all advance directive documents requested that treatment be forgone as death neared. Treatment was forgone in 98% of the deaths. Treatment preferences expressed in advance directives seemed to be consistently followed while making end-of-life decisions.

Conclusions: This study provides a more complete picture of death, end-of-life planning, and decision making in a geographic area where an extensive advance directive education program exists. It indicates that advance planning can be prevalent and can effectively guide end-of-life decisions.

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DESPITE the great attention given to death and dying in the medical, ethical, and legal literature in the United States, an incomplete picture remains of end-of-life planning and decision making. It is reported that nearly 80% of deaths occur in health care organizations and more specifically that 60% of deaths occur in hospitals.¹ The findings of SUPPORT (Study to Understand Prognosis and Preference for Outcomes and Risks of Treatments) provide a picture of the treatment of critically ill patients with limited prognosis, but it does not provide a picture of end-of-life planning and decision making for the general population.² The findings of the La Crosse Advance Directive Study (LADS) reported herein provide a more comprehensive, detailed look at death, end-of-life planning, and forgoing medical treatment in a geographically defined population.

An advance directive profile of the La Crosse area population in Wisconsin that

is described in this study was first collected in March 1991 in a random telephone survey of 304 adults (B. J. Hammes, PhD, B. L. Rooney, PhD, MPH, B. A. Bendiksen, PhD, unpublished data, 1991). At that time it was found that 15% of this population reported to have some type of written advance directive. This finding was similar to that in published reports.³⁻⁸ Since 1991, the major health systems in La Crosse have implemented a collaborative, systematic, communitywide advance directive education program called "Respecting Your Choices." This program was fully implemented 2 years before LADS and approximately 2 years after the telephone survey described earlier. The Respecting Your Choices advance directive education program includes locally developed patient education materials; availability of these materials throughout the community; uniform training and continuing education of more than 120 local advance directive, nonphysician educators; access to advance directive educators at all health care organizations; com-

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SUBJECTS AND METHODS

STUDY DESIGN

The design of LADS was a retrospective review of end-of-life planning and end-of-life decisions in all health care organizations in a midwestern community. The study protocol and consent process had the approval of Gundersen Lutheran Medical Center's (La Crosse) institutional review board before the study began.

STUDY SUBJECTS

This study included all adults who had resided in an area within 5 ZIP codes for at least 6 months before their death, were thought to be mentally capable at some point in the 10 years before death, and died while under the care of the participating health care organizations between April 24, 1995, and March 31, 1996. Excluded from the study were the deaths of those younger than 18 years (since they could not create their own advance directive); individuals who never had been mentally competent in their last 10 years (since advance directive legislation was first passed in Wisconsin in 1986); and adults who died outside the care of the participating health care organizations (since patient preferences could not have influenced treatment decisions and treatment decision making was not possible). The researchers screened all emergency department deaths to determine if the treatment of the decedent in the emergency department was long enough to allow review of the person's preferences by medical staff or if the person was essentially dead on arrival.

Participating in the study were 2 nonuniversity, non-profit teaching hospitals that provide a full range of medical specialists except for in the areas of transplantation and a burn center; 3 medical clinic systems; 6 nonprofit, Medicare-approved, long-term care facilities; 3 nonprofit home health agencies with hospice programs; and a county health department with home care. The managed care penetration rate for the community during this study was approximately 20%. Two long-term care facilities and a retirement home for a religious order were excluded from the study because they were geographically remote. Deaths at these nonparticipating sites were reviewed by examining the hospital and clinic medical records of the decedents and by reviewing the death certificates. Information on the demographics and causes of death were gathered to make sure that deaths at these nonparticipating sites were not markedly different from those of the study population.

Occurrence of all deaths was verified by death certificates. All eligible decedents were entered into the study.

Through a medical record review the decedent's most involved proxy was identified as well as the physician(s) who was most involved in making end-of-life decisions (not necessarily the physician who signed the death certificate). A proxy typically was a person with power of attorney for health care, a legal guardian, a loved one and/or family member, or a close friend.

DATA COLLECTION

Data from the decedents' medical records and death certificates were collected by an accredited records technician who worked full-time on this research project and was trained in the study protocol. Requests for billing information were sent to the respective organizations and provided by a designated person from that billing department.

Any inconsistency in data identified during collection or entry into the database required a second review of the data sources. If questions about interpretation of data occurred, these questions were discussed and resolved in regular meetings with the data collector and the principal investigators.

Death Certificate Review

A review was done of all death certificates for the county during the time of the study. For adult decedents who resided in areas within 5 ZIP codes, information was collected about the date of death and birth, sex, location of death, immediate cause of death, and other significant medical conditions. For those who qualified for the study, marital status and highest educational level completed were also collected. For other deaths only age and sex were recorded.

To categorize the causes of death, the 3 main causes of death and up to 4 other significant conditions were abstracted from death certificates. These causes of death then were grouped into 4 categories: chronic, terminal, sudden, or no underlying disease. Terminal causes included cancers, infection with the human immunodeficiency virus, and the acquired immunodeficiency syndrome. Chronic causes were other progressive, incurable illnesses that lead to death over many months or years. Sudden causes were diseases in which no previous disease existed and that lead to death rapidly. No underlying cause existed when a trauma or self-inflicted injury was the cause of death.

Medical Record Review

The researchers had access to a decedent's medical records at all participating organizations. Medical records

mon policies and practices of maintaining and using advance directive documents; and the documentation of advance directive education in the patient's medical record when such documentation occurred in a health care organization.⁹

In this article, the demographics of the study population and prevalence of end-of-life planning and decision making for this population are reviewed. Also, the consistency between preferences stated in an advance directive and the decisions made at the end of life are reported.

RESULTS

DEMOGRAPHICS

The study was conducted in western Wisconsin (about 130 miles south of Minneapolis, Minn) in a mixed urban and rural population (**Figure**). The economy of the area consists of manufacturing, retail, education, health care, and farming. According to the 1990 census, there were 92 476 individuals residing in areas within the 5 ZIP

included all charts at hospitals, clinics, long-term care facilities, hospices, and home health agencies. Data were collected from a decedent's medical record approximately 1 week after death to determine eligibility for the study.

Data collected from the medical records included the decedent's exposure to advance directive education, dates of education, and who was present during the education. (These data were available in many records since an advance directive education record is used in many institutions as part of the communitywide advance directive education program described earlier.) The medical record was also reviewed for both oral and written advance directives. An oral directive was identified if a note or dictation by a health professional indicated that decisions were being made in accordance with remembered oral statements made by the decedent previous to the decision. Written advance directives included an instructive directive, such as a living will or treatment preference form, a power of attorney for health care, a note or dictation recorded by a physician during a clinic visit, or a letter from a decedent. A physician's do not resuscitate order or other physicians' orders did not count as an advance directive.

A distinction was made between the decedent's decision and the decedent's advance directive. When a decedent had faced a clear medical choice at a specific point and indicated that he or she wanted treatment stopped or continued, this action was considered a decision about treatment even though the treatment or the forgoing of treatment occurred in the next days or weeks. When a decedent faced more hypothetical scenarios and indicated a preference, that was coded as an advance directive.

Physician Survey

Physicians who were identified as being involved in a decedent's end-of-life decisions were sent a survey approximately 1 to 2 weeks after the death of the individual. The physicians were permitted to review the decedent's medical record when answering the self-administered survey if they desired. Nearly 90% of physicians completed and returned their surveys. A total of 135 different physicians responded to the surveys; many had cared for multiple decedents in the study. No significant difference could be found between responders and nonresponders when decedents' data were reviewed ($P > .05$).

Proxy Survey

The interviews of proxies were conducted by 2 registered nurses with master's degrees who were trained in the study protocol and had worked extensively in advance directive education.

The identified proxies were sent a letter approximately 3 weeks after the death of the decedent inviting them to participate in an interview. The delay in recruiting proxies to participate in the study was longer than for the physician survey because of concerns about issues of grief and the practical necessities that often follow the death of a loved one. The letter inviting the proxy to participate described the purpose of the study and the nature and length of the interview. If proxies wished to participate, they waited to be telephoned by the interviewer. If they wished not to be contacted or participate, they could indicate their choice by leaving a message at the research site. Those who left a message were sent a second letter recognizing their decision not to participate and indicating that if they changed their mind, they could call the interviewer at some future time.

Overall, 77% of proxies agreed to be interviewed. No significant difference ($P > .05$) between responders and nonresponders could be found when decedents' or proxies' data were reviewed.

The interviewers telephoned the proxy approximately 5 days after the letter was sent. Efforts were made to interview proxies in person if possible. For those proxies who lived too far from the study site or were unwilling to have a face-to-face interview, a telephone interview was offered. Oral informed consent was obtained before the interview started.

The survey took approximately 30 minutes. Interviewers were instructed to spend additional time to attend to the proxy's emotional needs. If the proxy indicated that he or she wanted additional help with issues of grief, a list of resources on bereavement was available for the interviewers to make referrals.

STATISTICAL ANALYSIS

The data were collected on standardized forms as described earlier. Responses to questions for which there may have been a variety of responses were left open ended. These items were coded after all the data were collected using a standardized coding scheme. Each data collection form for a single decedent was given a code number to protect confidentiality. All data were entered into a database and analyzed using SAS statistical software.¹⁰

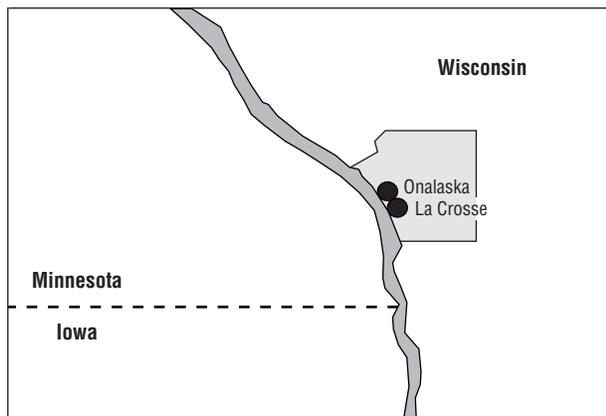
Univariate and multivariate analyses were performed using either parametric or nonparametric methods depending on the variables. Parametric methods included analysis of variance and analysis of covariance techniques. Nonparametric methods included χ^2 and Cochran-Mantel-Haenszel χ^2 analysis, along with nonparametric 1-way analysis of variance.

codes included in this study. This number represents 95% of the total population of La Crosse County.

During the study period 1123 deaths occurred in La Crosse County. Of this total, 416 were excluded because the decedents were not residents of the areas limited to the 5 ZIP codes or they were younger than 18 years. Of the remaining 707 deaths, 167 decedents were excluded because they did not die while under the care of a participating health care organization or they were never capable of expressing preferences in the 10 years before death.

After all exclusions, 540 decedents qualified for the study. The median age was 82 years and more than half were women (**Table 1**). Eighty-five percent of the study group died of chronic or terminal diseases while 14% died of sudden illnesses. Of those who died of sudden causes, 83% were 75 years of age or older. Slightly more than one third died in hospitals. Nearly 50% died in long-term care facilities and 14% died at home.

The characteristics of these 540 decedents were quite similar to the characteristics of the entire group of adult



The study was conducted in western Wisconsin (about 130 miles south of Minneapolis, Minn) in a mixed urban and rural population. The economy of the area consists of manufacturing, retail, education, health care, and farming. According to the 1990 census, there were 92 476 individuals residing in the areas within the 5 ZIP codes included in this study. This number represents 95% of the total population of La Crosse County.

decedents from the study area. Of this total group of 707 adults who resided in areas within the 5 ZIP codes and died in La Crosse County, the median age was 81 years and more than half were women (Table 1). Chronic and terminal causes accounted for 80% of deaths, while 20% died of sudden causes or no underlying disease. Less than one third of the entire group died in hospitals while 47% died in long-term care facilities and 21% died at home or elsewhere in the community. When the demographics of those included in the study were compared with characteristics of the 167 adult decedents from the areas within the 5 ZIP codes who were excluded, no unexpected differences were found (Table 1).

ADVANCE DIRECTIVES

Of the 540 decedents in the study population, 459 (85%) had advance directives.

Prevalence	No. (%)
Subjects with written advance directives	459 (85)
Written advance directives found in medical record	437 (81)
Type	
Power of attorney for health care	353 (77)
Instructive	46 (10)
Oral, recorded by physician	41 (9)
Unknown, report made by proxy	19 (4)

Almost all these documents (81%) were found in the decedents' medical records. The 22 documents not found in the medical records were identified through interviews with the proxy. Most of the written advance directives were legal or other types of forms. A power of attorney for health care was used by 353 decedents. Of this group, 61 appointed an agent but provided no additional written instructions in their documents. In the other 292 power of attorney for health care documents, written instructions regarding end-of-life treatment preferences were provided either in the document or by using a separate form, such as a living will. There were an additional 46 decedents who had only instructive documents. In 41 instances a physician recorded the decedents' preferences in a note or dictation, but no signed form existed.

Those who had formulated their own written advance directives were different from those who did not in several respects (Table 2). Those decedents who had no written advance directive were younger, more likely to die of sudden causes, and more likely to die in a hospital. Those decedents whose preferences were documented by their physician were older and more likely to die in a long-term care facility.

The decedents with advance directives had typically recorded their preferences a year or more before their death. The median time between advance directive documentation and death was 1.2 years. While 20% of documents were created within 60 days of death, 40% were created 2 or more years before death.

In decedents' written advance directives, the most common rationale to forgo life-sustaining treatment was a permanent change in quality of life (35%). The next most common reasons were limited survival (17%), death expected soon despite treatment (12%), persistent vegetative state (9%), and if the burdens outweighed the benefits (9%). Other reasons included consideration of the cost of treatment, the amount of suffering, the incurability of the disease, the loss of mental faculties, treatments being inconsistent with stated values, and honoring the legal right to refuse medical treatment.

The request not to attempt cardiopulmonary resuscitation (CPR) was the most common preference. A total of 271 documents indicated that CPR should not be attempted at some point. Of these requests, 90% stated that CPR should never be attempted. Other treatments listed as not desired were the use of feeding tubes, mechanical ventilation, antibiotics, hospitalization, and intravenous infusion. In a large percentage of cases these treatments were listed as not desired under any circumstance (Table 3).

In 209 documents, comfort care was requested and in 185 documents, pain management was desired. Feeding tubes were listed as always desired in 10 documents. In 8 instances CPR was listed as always wanted and in 12 documents, intravenous infusion was always wanted. These preferences about feeding tubes, CPR, and intravenous infusion were found in 24 different advance directives.

More than half (53%) of the decedents were determined to be exposed to advance directive education. In 23% of cases, information on exposure to education was not obtainable since the proxy was not interviewed and no education record was found in the medical record. Of those who received education, 77% received help in a health care organization. While a hospital was the health facility where education occurred most frequently, proxies named nonhospital sources for advance directive education 60% of the time.

Treatment was forgone near the time of death in 528 (98%) of the 540 decedents. In these deaths the incidence of forgoing specific treatments was CPR, 100%; hospitalization, 32%; feeding tube, 18%; ventilation, 17%; and antibiotics, 7%.

When specific treatment preferences were compared with decisions made at or near the time of death, the decisions were generally consistent with preferences stated in the advance directives (Table 4). Decedents

Table 1. Demographics of Adult Deaths From LADS*

Characteristics	Deaths Included in LADS (n=540)	Excluded From Study			Total (N=707)
		Deaths From Nonparticipating LTC (n=48)	Deaths Outside Health Care Organizations (n=100)	Deaths of Adults Not Mentally Capable in Last 10 y (n=19)	
Age, y					
Mean	79.95	83.5	69.9	86.6	78.95
Median	82.21	83.43	73.3	86.0	81.40
Range	20-103	65-103	21-102	71-97	20-103
Sex, % M	46.3	35.4	56	15.8	46.1
Cause of death, %					
Late chronic	58	65	46	84	58
Terminal	27	19	6	11	23
Sudden	14	17	35	5	17
No underlying disease	1	0	13	0	2
Location of death, %					
Home	14	0	73	5	21
LTC	49	100	0	90	47
Hospital	36	0	27	5	32

*LADS indicates La Crosse Advance Directive Study; LTC, long-term care facility.

Table 2. Demographic Data of LADS Study Population*

Characteristics	Patient Documented Advance Directive (n=418)	Physician Documented Advance Directive (n=41)	Patients With No Written Advance Directive (n=81)	P
Median age, y (range)	82.3 (30.9-103.2)	88.0 (69.3-102.2)	74.2 (20.4-101.4)	.001
Sex, %				
M	46	34	53	.14
F	54	66	47	
Marital status, %				
Married	39	32	43	.45
Widowed	50	56	41	
Divorced	6	2	6	
Single	6	10	11	
Median education, y	12	12	12	.93
Cause of death, %				
Chronic	58	63	54	.17
Terminal	28	22	22	
Sudden				
≥75 y	10	15	18	
<75 y	2	0	6	
No underlying disease	1	0	2	
Location of death, %				
Home	16	7	10	.001
LTC	53	68	22	
Hospital	32	24	68	

*LADS indicates La Crosse Advance Directive Study; LTC, long-term care facility.

dents who did not have a written advance directive were more likely to receive CPR and feeding tubes.

Eighty-three decedents had preferences about limiting hospitalization. These preferences were not followed as closely (Table 4). Thirty-seven decedents had indicated that they no longer wanted to be hospitalized. In 21 instances there were no hospitalizations following this documentation. In 16 instances there was 1 additional hospitalization. Forty-six other decedents said they would not want hospitalization under certain circumstances. In 22 instances no further hospitalizations occurred and in 24 instances hospitalization did occur. Preferences about hospitalization were not indicated in 357 documents. Of these there were 92 instances in which

no hospitalization occurred and 265 instances in which hospitalization did occur. Of those 100 individuals who had no documentation in their medical records, 21 were not hospitalized in the last 6 months of life, and 79 were hospitalized.

Based on notes in the medical record, patients were considered by the attending physician to be capable of making their own end-of-life decisions in 43% of the cases (Table 5). Persons who died of sudden and chronic causes were more likely to be mentally incapable when end-of-life decisions were made. In comparison, persons who died of terminal causes were most likely to be mentally capable when end-of-life decisions were made ($P<.001$).

Table 3. Relationship Between Specific Treatment Preferences in the Health Record and End-of-Life Decisions*

Instructions in Advance Directive	No. of Subjects (N=540)			
	Prevalence	Treatment Forgone	Treatment Provided	No Decision Needed
CPR				
No CPR	243	242	1	...
No CPR and/or conditional	28	26	2	...
CPR	8	7	1	...
CPR and/or conditional	59	59	1	...
Not mentioned	101	100	1	...
No directive in record	100	95	5	...
Ventilatory support				
No ventilatory support	58	17	0	41
No ventilatory support and/or conditional	45	5	4	36
No preference indicated	337	40	0	297
No directive in record	100	28	0	72
Feeding tube				
No feeding tube	57	22	0	35
No feeding tube and/or conditional	71	16	2	53
Use of feeding tube	10	1	0	9
Use of feeding tube and/or conditional	73	10	2	61
No preference indicated	230	33	8	189
No directive in record	100	14	9	77
Antibiotics				
No antibiotics	12	6	1	5
No antibiotics and/or conditional	99	7	2	92
No preference indicated	392	19	11	310
No directive in record	100	4	2	96

*CPR indicates cardiopulmonary resuscitation; conditional, the patient's advance directive instructions stated that this medical treatment should be forgone under some specific situations; and ellipses, data not available.

Table 4. Relationship Between Preferences About No Hospitalization and Admission to Hospital*

Instruction in Record	Prevalence	No Hospitalization After Preference	Hospitalization
No hospitalization	37	21	16
No hospitalization and/or conditional	46	22	24
Last 6 mo			
No preference indicated	357	92	265
No directive in record	100	21	79

*Data presented as number of subjects (N=540).

COMMENT

These results from LADS do provide a more complete picture of death, end-of-life planning, and decision making in a community where an extensive advance directive program exists. Previous studies have been limited by focusing on populations with specific disease processes, by being conducted in single types of health care organizations, or by being conducted in populations in which dedicated advance directive efforts were not in place.

Perhaps the most notable finding in LADS is the large percentage of individuals who had documented preferences before death. This figure is much higher than one expert estimated as likely. Emanuel¹¹ states that it is doubtful that the percentage of those with written advance directives will exceed those with financial wills. She estimates that about 50% of individuals have such financial wills.¹¹ Some studies at single organizations report a simi-

lar prevalence as that of LADS after a planned intervention,¹² but most reports indicate a significantly smaller prevalence of written advance directives at the time of death.¹³⁻¹⁷

Also of note from LADS is the number of documents found in the decedents' medical records. In SUPPORT² at baseline, 20.2% of subjects had a written advance directive, but only 2 documents were found in the patients' medical records.¹⁸ In a government study of health facilities' compliance with the Patient Self-Determination Act, the data showed that of those patients who had advance directives, 60% had a copy in their medical records.¹⁹ In LADS, 95% of those with advance directives had their document in their medical records at the time of death.

While this study was not designed to determine the effectiveness of the Respecting Your Choices advance directive education program implemented in La Crosse, the program seems to have been an important factor in the

Table 5. Mental Capability of Individuals When End-of-Life Decisions Were Made*

Subjects	Capable	Not Capable
All individuals	43	57
By cause of death		
Chronic	33	67
Terminal	75	25
Sudden	25	75

P = .001

*All data presented as percentage of subjects.

increased prevalence of advance planning and the number of documents in medical records. The evidence for this claim is indirect but other factors, such as culture, other demographic factors, or the legal climate, seem less important when other data are considered. For example, in 1991, when a random telephone survey of the LADS population was conducted, there was no difference in the prevalence of advance directive documents than that found in other studies at that time. So the LADS population looked no different from other populations before the education program was implemented. Moreover, the importance of other factors seems undermined when the SUPPORT data are considered. One of the participating sites in SUPPORT is also in Wisconsin and its county has nearly identical demographics as the population of LADS. If cultural, demographic, or legal factors were of great importance to explain the findings of LADS, then these influences should have been reflected in the SUPPORT findings too.

In LADS the vast number of individuals who had documented preferences had power of attorney for health care documents. Like other studies,²⁰ instructions in advance directives from LADS indicate that most individuals (81%) believe that there are limits to using medical intervention to prolong their life. In contrast, only 4% of decedents in LADS had indicated they always wanted some form of medical treatment, such as CPR, feeding tubes, or intravenous hydration.

This study also provides a clearer picture of the prevalence of forgoing treatment. When patients neared their death, treatment was typically forgone. Only in 2% of cases was there no decision to withhold treatment. In these cases treatment was stopped, typically CPR, because it simply failed to restore breathing and heartbeat. These deaths typically followed sudden, acute illnesses striking relatively healthy individuals in whom treatment failed. It is doubtful that given the prior health status of the decedent and the suddenness of the illness that advanced planning would ever make much of a difference in these situations.

Since LADS looked at decisions at or near death, it was not clear how often CPR may have been attempted in the 6 months before death for the 540 included decedents. In a review of 1 of the participating hospital's resuscitation records during the study period (that included reports of in-hospital, emergency department, and out-of-hospital resuscitation attempts), it was determined that 14 decedents in the study population had undergone CPR in the 6 months prior to, but not at, death. In these instances CPR succeeded to provide enough time

ahead of the next cardiac collapse (hours to months) for assessment of the patient's medical status and preferences. Decisions were made not to attempt CPR again for all 14 decedents. Based on this review, it appears that approximately 3% to 4% of decedents in LADS had undergone resuscitation that provided enough time for the decedent's preferences to direct the decision that CPR should not be attempted a second time.

For decedents in LADS who had planning in place, instructions seemed to be followed. In nearly 45% of all deaths, written preferences stated that CPR should not be attempted. In only 1 of these cases was CPR initiated. This action was prompted by a family member who called "911." Patients who did not want mechanical ventilation or feeding tubes did not receive them either.

There are 2 areas in which there is some unsettling inconsistency between the patient's documented preferences and treatment decisions. In 16 cases documentation existed that the patient was not to be hospitalized but was. In a review of these records, it was found that in 6 cases the patient was considered capable of making the decision and chose to receive care at a hospital. In 2 other cases the patient was hospitalized for management of pain. In the remaining 8 cases the family requested hospitalization. It was not determined if the family had made the initial decision not to hospitalize and then changed their minds, or if the family's decision overruled the patient's preference. In each of the cases, the patient was not sent to a hospital a second time.

The other cases of inconsistency that seemed troubling were the 7 instances in which decedents' preferences stated that CPR should be attempted but was not. A review of these cases revealed that good decision making seemed to have been followed. In 1 case CPR was initially tried and the heartbeat was restored, but the outcome was not good. A no CPR order was then written for this individual. In another instance an individual revised the preference orally, but the written advance directive was not changed. In 3 situations the decedent's appointed agent revised the CPR status in the final stages of an incurable illness. Two patients were found dead and CPR was not attempted. In none of these cases did there appear to be a careless disregard of formerly stated preferences.

Given the retrospective collection of data, it is difficult to determine the exact fit between patient preferences and actual decisions made during the last days of life. It appears, however, that on the whole these preferences were honored. There does not appear to be a blatant disregard or a systematic lack of awareness of patient preferences in these end-of-life decisions.

These findings of LADS are limited by its retrospective design and by the relatively small and homogeneous population studied. These factors make generalization a bit difficult. The findings also do not directly support the question of whether deaths were made better by advance planning. It would be helpful to repeat similar studies in other populations to determine the prevalence and type of end-of-life planning and decision making that exist in other geographic areas.

There are a number of questions that are difficult to sort out in these findings. One is that the prevalence of forgoing treatment is generally so high in the whole popula-

tion that it is not clear to what extent a shift in social and medical expectations is determining behavior rather than specific, individual preferences. The second question is how decisions in the weeks or months before death are altered by advance planning. Perhaps at these earlier points advance planning has little or no effect on treatment decisions, and it is only when a person's course toward death is clear and the instructions then clearly apply that planning does make a measurable difference.

CONCLUSIONS

The prevalence and demographic information from LADS provides a more complete view of end-of-life planning and decision making than previous studies. It indicates the level of advance planning that can be realized in a community. It emphasizes that end-of-life decision making will be needed in most deaths, but death usually occurs in identifiable groups. Such information might not only clarify who should be engaged in end-of-life planning, but also might help focus discussions on specific types of decisions. It also suggests that end-of-life planning occurs over time and is an ongoing discussion. Finally, given the consistency between end-of-life decisions and preferences stated in advance directives, it appears that it can be possible to respect patients' choices as death approaches.

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