

# End-of-Life Decisions: Family Views on Advance Directives

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A cross-sectional survey was administered to family members of patients who died at 1 of the 5 Catholic institutions comprising Mercy Health Partners, a health care system in Ohio, to determine their opinions about patient and family participation in decisions about end-of-life care. Among 165 respondents, 118 (86%) of 138 agreed that the family was encouraged to join in decisions and 133 (91%) of 146 that their family member's health care choices were followed. Most agreed that nurses answered their questions (93%, 141/151) and that the doctor communicated well with family members

(83%, 128/155). Seventy percent (107/152) indicated that their family member had at least 1 advance directive. There were no differences in whether health care choices were followed when patients with formal advance directives (92%, 92/100) were compared with patients without formal advance directives (88%, 35/40). A unique survey instrument can be used to measure family perceptions and opinions of participation in decisions about end-of-life care.

**Keywords:** decisions; end of life; advance directives

The view that the adult, informed patient with decisional capacity may decline medical treatment, even if the choice may lead to death, is widely accepted today among health care professionals and society as a whole.<sup>1-3</sup> This broad consensus developed through the 1970s and 1980s when a series of well-known ethical and legal cases challenged the assumption that professionals are obligated to provide, and patients are obligated to accept, every available means of technologic treatment.<sup>4</sup> It was recognized that the patient's own wishes are essential in treatment decisions, whether expressed concurrently or through an advance directive<sup>5-7</sup>

Formal advance directives, which include the living will, health care power of attorney, and the do-not-resuscitate (DNR) order, were primarily developed

to communicate the patient's wishes to family members and health care providers. Advance directives may also relieve the burden that many caregivers feel when they make end-of-life decisions for loved ones. In addition, advance directives may create a stronger sense of shared values and community among the family.<sup>8</sup>

Hospitals are required to provide information about advance directives at the time of patient admission, and many community agencies also provide this information.<sup>9-11</sup> Because of these initiatives, the number of individuals with advance directives is increasing, but they are still believed to be in the minority.<sup>12,13</sup> Further, it is not known whether advance directives actually help facilitate end-of-life decisions.<sup>14-17</sup> Limitations cited include vague or confusing instructions, cultural bias, and a narrow focus on the legal right to refuse instead of communication between doctors, patients, and loved ones. It may be that other factors, such as the doctor's availability and communication skills during the course of the hospitalization are more important than formal advance directives in making end-of-life decisions.<sup>18-20</sup>

Ohio's advance directive law (Durable Power of Attorney for Health Care and Living Will) came into

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effect in 1991 and has been described as one of the more complex among state advance directive laws.<sup>21</sup> The Ohio Do-Not-Resuscitate Comfort Care (DNRCC) law, effective in 1999, may also result in confusion among patients, families, and health care professionals because of its 2 designations. According to Ohio law, the comfort care protocol is either effective immediately DNRCC or at the time of arrest (DNRCC-A.)

This study was undertaken to measure family perceptions regarding end-of-life care for deceased family members, advance directives, and participation in end-of-life decisions.

## Methods

A previous publication demonstrated that family members' perspectives regarding end-of-life care could be measured by using a unique survey instrument.<sup>22</sup> A similar instrument, with several new questions added, was used in this prospective, multisite, cross-sectional survey. The survey was mailed to families of patients who had died in 1 of the 5 Catholic institutions within Mercy Health Partners of Northwest Ohio (MHP), a division of Catholic Health Partners. The 5 institutions were St. Vincent Mercy Medical Center (573 total beds, 101 intensive care beds), St. Charles Mercy Medical Center (390 total beds, 20 intensive care beds), St. Anne Mercy Medical Center (136 total beds, 8 intensive care beds), Tiffin Mercy Medical Center (128 total beds, 5 intensive care beds), and Willard Mercy Medical Center (34 total beds, 2 intensive care beds). Consistent with the recommendation of a focus group, surveys were mailed 13 months after the patient's death. Anonymous responses were returned by business reply mail. No incentives were offered to participants.

The survey's cover letter expressed sympathy to the family for the loss of the person who died in the MHP facility and explained that the purpose of the survey was to help the MHP hospitals improve patient care at the end of life. Family members were asked questions about their general satisfaction with the care and information provided by nurses, doctors, and chaplains; the adequacy of the hospital facilities; and appropriate use of advance directives. Demographic information was also requested.

Most questions measured responses on a 5-point Likert scale of agreement. The survey took approximately

15 to 20 minutes to complete. No identifying health information was used in this research project. Eligible participants included family members of patients who died in one of the MHP hospitals in 2004. This study was reviewed and approved by the Sisters of Mercy Northwest Regional Institutional Review Board.

Primary outcome measures for the survey included opinions about communication, respect for health care choices, participation in health care decisions, and whether advance directives were respected and followed. Descriptive statistics were used to summarize the responses for each question. The mean, standard deviation, and 95% confidence intervals (CI) were derived from the response scores. Percentages of respondents were identified who agreed (strongly agree + agree) and who disagreed (disagree + strongly disagree) for each question.

## Results

### Demographic Information for Patients and Respondents

Within the MHP regional health system, there were 935 eligible families. Addresses for mailing the survey were available for 605, and 165 family members participated in the study, for a 27% response rate. Demographic information of patients and respondents is described in Tables 1 and 2, respectively. Most patients (72%) were aged 65 or older at the time of death. The relationship of the respondents to the deceased included spouse (53%), adult child (27%), parent (9%), and sibling (7%). Most respondents (80%) indicated that they were Christians, with 17% indicating "other," and 3% "none."

Most respondents were women (77%) and white (88%), with smaller percentages of African American (10%), Hispanic (1%), and other (1%). Compared with 2004 ethnicity data for all patients who died in MHP hospitals, whites were overrepresented in the study at 88% of respondents versus 77% of all patients who expired, and African Americans (10% of respondents versus 15% of those who expired) and Hispanics (1% of respondents versus 2% of those who expired) were underrepresented.<sup>23</sup> Half of respondents had a high school education or less (47%), and half had some college education or more (50%).

**Table 1.** Demographic Information of Patients

Patient Characteristic	Patients, n (%)
Age (years)	
<1	4 (2)
1-5	0 (0)
6-12	2 (1)
13-17	2 (1)
18-39	7 (4)
40-64	31 (19)
>65	118 (72)
Missing	1
Sex	
Male	102 (62)
Female	63 (38)
Unit died in	
Critical care	55 (37)
Emergency department	10 (7)
General nursing	21 (14)
Operating room	1 (1)
Other	6 (4)
Intensive care unit	9 (6)
Palliative care	48 (32)
Missing data	15
Had advance directives of some sort <sup>a</sup>	107 (70)
Living will	86 (80)
Durable power of attorney	74 (69)
DNRCC	58 (54)
DNRCC-A	29 (27)
Other	5 (5)

NOTE: DNRCC = Do-Not-Resuscitate Comfort Care; DNRCC-A = Do-Not-Resuscitate Comfort Care-Arrest

a. Up to 5 responses allowed.

### Location of Death

In 2004, the most common hospital location of death was critical care (37%), followed closely by palliative care (32%). Other locations of death included the general nursing unit (14%), the intensive care unit (ICU; 6%), and the emergency department (7%). Over time, there has been a gradual shift in the location of deaths. For the years 1997-2001 combined, the percentage of deaths taking place in critical care (44% compared with 37% in 2004) and general nursing units (23% compared with 14% in 2004) has decreased, whereas the percentage of deaths taking place in palliative care (5% compared with 32% in 2004) has increased. An MHP Quality Improvement study confirms increased usage of palliative care services at the end of life. "Palliative care attended deaths" increased from 29% in 2003 and 46% in 2004 to 58% in 2005.<sup>24</sup>

**Table 2.** Demographic Information of Respondents

Respondent Characteristic	Respondents, n (%)
Sex	
Male	33 (23)
Female	113 (77)
Missing	19
Age (years)	
18-24	3 (2)
25-34	3 (2)
35-44	8 (5)
45-54	25 (17)
55-64	33 (22)
≥65	75 (51)
Missing	18
Race	
White	130 (88)
African American	14 (10)
Hispanic	2 (1)
Other	1 (1)
Missing	18
Religion	
Baptist	14 (10)
Catholic	48 (33)
Lutheran	21 (14)
Methodist	24 (17)
Pentecostal	5 (3)
None	4 (3)
Other	24 (17)
Christian	5 (3)
Missing	20
Education	
≤High school	69 (47)
Some college	33 (22)
Graduated college	27 (18)
Post-grad	15 (10)
Other	4 (3)
Missing	17
Relationship to Deceased	
Spouse	79 (53)
Parent	14 (9)
Child	40 (27)
Niece/nephew	1 (1)
Sibling	10 (7)
Son/daughter in law	1 (1)
Friend	2 (1)
Other	1 (1)
Missing	16

### Advance Directives

A high percentage of family members (70%) indicated that the patients had at least 1 type of advance directive. The most included Ohio state DNR orders at 81%, including DNRCC (54%) and/or DNRCC-A

**Table 3.** Primary Research Question Results

Survey Statement	Responses (n) <sup>a</sup>	% Agreed <sup>b</sup> (n)	95% CI
We got all the information we needed to make informed choices.	157	91 (143) <sup>b</sup>	87-96
By unit they died in			
Critical care	51	94 (48)	88-100
Emergency department	10	80 (8)	55-100
General nursing	21	86 (18)	71-100
Operating room	0	—	—
Other	6	100 (6)	100-100
Intensive care unit	9	89 (8)	68-100
Palliative care unit	47	91 (43)	84-99
The nurses answered our questions.	151	93 (141)	89-97
I was able to get all my questions answered by the doctor.	160	88 (140)	82-93
Hospital staff encouraged me to join in making decisions about my family member.	138	86 (118)	80-91
The doctor communicated well with family members.	155	83 (128)	77-89
My family member's healthcare choices were followed.	146	91 (133)	86-96
Patients with advance directives	100	92 (92)	87-97
Patients without advance directives	40	88 (35)	77-98
The living will and durable power of attorney for healthcare, and/or DNRCC, DNRCC-arrest, were respected and followed. (among those patient with advance directives)	100	89 (89)	83-95

NOTE: CI = 95% confidence interval for % Agreed; upper bound of CI truncated at 100%.

a. Includes those who responded to the question, excluding those who responded "not applicable" and those who did not answer the question.

b. The percentage of respondents who either strongly or somewhat agreed with the survey statement.

order (27%), living will (80%), and durable power of attorney for health care (69%).

Table 3 summarizes the primary survey questions. Nearly all family members (91%, 95% CI, 87%-96%) agreed that they received enough information to make informed decisions. Different nursing units were compared with respect to adequacy of information received. The percentage of respondents who agreed was highest in the critical care unit at 94% (95% CI, 88%-100%), followed by palliative care, 91% (95% CI, 84%-99%); ICU, 89% (95% CI, 68%-100%); general nursing unit, 86% (95% CI, 71%-100%), and emergency department, 80% (95% CI, 55%-100%). However, no statistically significant differences between the units were found when 95% CIs were compared.

Respondents agreed that nurses answered their questions (93%; 95% CI, 89%-97%), that they were able to get all their questions answered by the doctor (88%; 95% CI, 82%-93%), and that doctors communicated well with family members (83%; 95% CI, 77%-89%). There was general agreement that hospital staff encouraged them to join in making decisions for their family member (86%; 95% CI, 80%-91%).

## Discussion

### Location of Death

The implementation of excellent end-of-life care depends on the ready accessibility of resources and processes for health care professionals to follow.<sup>25</sup> In 1997, MHP began several initiatives to identify needs and develop resources in end-of-life care. The Pastoral Care End of Life Survey was one of these efforts. In addition, an interdisciplinary group recognized that establishing palliative care services, whether provided as a service in existing hospital units or in a dedicated Palliative Care Unit, would greatly assist in this effort.<sup>26</sup> A palliative care unit opened in 2000, and during the same year, a regional Palliative Care Coordinator position was established. Palliative Care Coordinators are presently in place at all 5 MHP hospitals.

### Adequacy of Information

Nearly all respondents (91%, 143/157) indicated that they received enough information to make informed choices, with only minor differences between various

hospital units. One factor contributing to the adequacy of information could be that the loved one's death was anticipated because of ongoing experience with the disease or because of a deliberate decision to withhold or withdraw life-sustaining treatment. In contrast to earlier this century, most deaths occur today because of progression of chronic diseases punctuated by acute exacerbations.<sup>27</sup> Over time, doctors, patients, and families learn about these chronic diseases and the probability of death with any given acute exacerbation. During hospitalization, doctors gather significant information about whether the patient is likely to return to the usual baseline. Although predictions are not completely accurate, given careful observation and diagnostic studies, it is often possible to anticipate when the patient's death may occur. Further, many deaths in hospitals today occur after a deliberate decision to withhold or withdraw life-sustaining treatments that no longer promise sufficient benefit to the patient.<sup>28-30</sup>

### Communication

Sharing of information, sensitive communication, and being with patients and families at the end of life are essential features of high-quality medical and nursing care.<sup>15,28,31-33</sup> When respondents had questions, they viewed nurses (93%; 95% CI, 89%-97%) and doctors (88%; 95% CI, 82%-93%) as good sources of information. Most (83%; 95% CI, 77%-89%) agreed that doctors communicated well with family members.

### Advance Directives and Participation in Decisions

The Federal Patient Self-Determination Act of 1990, patient rights standards set by regulatory agencies such as the Joint Commission on Accreditation of Healthcare Organizations,<sup>34</sup> individual states' advance directive laws, and portable DNR orders, were all developed to clarify patients' wishes when they are unable to decide for themselves. It was hoped that these various forms of advance directives would be a major factor in improving decision-making and reducing some of the burdens on family members at the end of a patient's life. This hope has been tempered recently by some studies showing lack of applicability to specific situations, misunderstandings on the part

of family members and health care professionals, and doctors' reluctance to follow advance directives when family members disagree.<sup>35-37</sup> Among patients with DNR orders who are cared for at home, families may experience uncertainty or uneasiness at the time of an arrest and summon emergency medical services. Hospice and palliative care education and support have helped reduce this circumstance. A recent study indicates that 78% of emergency physicians withhold resuscitation attempts for patients with a legal advance directive, indicating a willingness to honor patients' wishes regarding their own medical care.<sup>38</sup>

One of the most interesting results of the present survey is that 70% of respondents indicated the patient had some form of advance directive (see Table 1.) Among those indicating an advance directive, an Ohio state DNR order was the most frequent type (81%), including DNRCC (54%) and DNRCC-A (27%), followed by the living will (80%), health care power of attorney (69%), and other (5%).

The high percentage of those with advance directives in the present survey is confirmed by a recent chart review that sampled 32% of patients who died at the largest MHP hospital. Of the 171 surveyed, 130 (76%) had some form of advance directive, whether living will, health care power of attorney, DNR order, or other written order on the medical record at the time of death.<sup>39</sup> A recent study of Lucas County residents found that 41% of those surveyed had an advance directive, and of these, 80% had both a living will and durable power of attorney for health care.<sup>40</sup> In addition, historic data from one study demonstrated an increase of advance directive use among elderly patients after an intervention that consisted of printed materials and an educational meeting. Before the intervention, 31% of participants had completed a living will, and 46% did so after the interventions. Before the intervention, 11% had designated a health care surrogate, which rose to 20% after the interventions. Our study confirmed this common distribution of types of advance directives, with state DNR orders and the living will being the most commonly used advance directives, followed by durable power of attorney for health care.<sup>41</sup>

Other local and national studies estimate the percentage of individuals with advance directives is less than 25%, however.<sup>9,42,43</sup> Data for all regional MHP hospitals for the year 2005 demonstrate that at the time of admission, only 20% of in-patients indicated that they had a living will or a health care

power of attorney, or both, whereas among patients who eventually died during the hospitalization, the percentages were 26% for a living will and 29% for a health care power of attorney.<sup>44</sup> The data recorded advance directives only at the time of admission. It may be that those patients who eventually died did complete an advance directive during the course of their hospitalization. Among all emergency department patients, only 6% had either a living will or health care power of attorney, but for emergency department patients who died, 19% had a living will and 17% had a health care power of attorney.<sup>44</sup>

It is possible that those responding to the End of Life Survey are as a group more attuned to end-of-life issues and the importance of advance care planning, or simply that advance directives are more frequent among patients at the end of life than among the general patient population. It should be noted that these results are dependent on the recollection of the respondent and may not accurately reflect the existence of a valid advance directive.

Ohio's DNR law became effective in 1999. The law permits a choice of when the comfort care protocol will begin. Under a DNRCC order, the comfort care protocol is effective immediately. In contrast, a DNRCC-A order allows attempts to prevent an arrest from occurring. If the patient does proceed to an arrest despite these efforts, the comfort care protocol is initiated at that time. Some bioethicists predicted that patients and families would prefer the DNRCC-A designation because it allows resuscitative measures before an actual arrest and perhaps appears less final to those who still hold out hope for recovery. In the present survey, however, DNRCC was chosen twice as often as the DNRCC-A designation (54% versus 27%). Again, the explanation may be because the survey relates to families of patients who have died. Those who have decided on a DNRCC-A designation receive additional resuscitative measures and may survive a prearrest situation, whereas patients with a DNRCC have decided on comfort measures only.

Most respondents (86%) agreed that hospital staff encouraged them to join in making end-of-life decisions about their family member. Having an advance directive did not affect the family's agreement that the patient's health care choices were followed. Among all respondents, 91% agreed that their family members' health care choices were followed, compared with 92% when the patient had an advance directive and 88% when the patient did not. The average agreement

score (4.6) was the same for patients with advance directives as for patients without advance directives.

### Limitations and Future Directions

As with any survey, the validity of the responses depends on the veracity of the participants' responses. With a response rate of less than 50%, it is possible that the respondents' opinions were not typical of the entire group of eligible participants. In particular, the respondents may have been more attuned to or comfortable with end-of-life decisions; or as a group, they may have been more satisfied with end-of-life care than the non-responders. However, the written comments that some respondents chose to make contained both positive and negative perspectives.

The underrepresentation of African Americans (10% of respondents compared with 15% of all those who expired) raises concern about representation of minorities in this sample.<sup>23</sup> We are seeking to understand why we received fewer responses from minority individuals and plan to implement methods to improve representation.

Consistent with the patient population served by MHP, most respondents (80%) were Christian. The survey results may or may not be applicable to other faith traditions in Ohio.

The survey did not measure facts regarding end-of-life care but only the perceptions of family members 13 months after the patient's death. The respondents' recollections may have changed with the passage of time to either a more positive or more negative view of the care provided.

Future research may focus on larger and more representative samples of family members' opinions of end-of-life care and on the completion of advance directives during hospitalization. Qualitative research may also provide additional insights into these issues.

### Conclusion

In this regional survey, family members of deceased patients agreed that they received enough information to make informed choices, that doctors and nurses answered their questions, and that doctors' communication was generally good. A very high percentage of respondents indicated the patient had an advance directive, and living wills and Ohio DNR orders were the most common types. Family members' agreement

that they participated in decisions was the same whether or not the patient had an advance directive.

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