

# The Do-Not-Resuscitate Order: Outpatient Experience and Decision-making Preferences

Mark H. Ebell, MD, Mindy A. Smith, MD, K. George Seifert, MD, and Kenneth Polsinelli  
Ann Arbor, Michigan

*Do-not-resuscitate (DNR) orders have become a widespread part of modern medical practice. This study examined patient experience and decision-making preferences regarding cardiopulmonary resuscitation. A random sample of 800 outpatients (one half aged over 70 years) was surveyed by questionnaire, with a 51% response rate.*

*While only 11% of patients had ever discussed resuscitation with a physician, 67% had thought about the issue, and 44% had discussed it with someone other than a physician. Patients overwhelmingly preferred to preserve a good quality of life, even if it meant not living longer (93.9%). When asked who they would have help them with DNR decisions, physicians were most often selected, while spouses were the most valued advisors. In a series of scenarios such factors as dementia, drug or alcohol use, age, and pain had a significant effect on a patient's decision about resuscitation.*

*Discussions about DNR issues in the outpatient setting should be encouraged, as patient interest is strong, and greater physician awareness of patients' values and preferences can prevent unwanted resuscitation in the acute setting.*

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The do-not-resuscitate (DNR) order has become well accepted and widely used in American hospitals.<sup>1-3</sup> Studies have shown that as many as 68% of patients dying in a hospital setting have had a DNR order written.<sup>4</sup> In general, the decision to establish a DNR order is made late in the patient's illness, often in consultation with the family after the patient is no longer competent. In one study, 86% of families, but only 22% of patients, were involved in the decision to assign DNR status to a patient.<sup>5</sup> Another study of hospitalized patients found that whereas 47% wanted to discuss resuscitation with their physician, only 16% actually did so.<sup>6</sup>

Much research has focused on determining which patients benefit from resuscitation and which do not. According to various reports, approximately 10% to 12% of patients receiving cardiopulmonary resuscitation live to discharge.<sup>7,8</sup> Factors associated with poor survival following resuscitation include age over 70 years, unwitnessed

cardiopulmonary arrest, increased number of medications given during resuscitation, and increased duration of resuscitative efforts. In fact, a recent study documented a 0.0% survival-to-discharge rate for patients aged over 70 years.<sup>9</sup> A second report showed a 3.8% survival-to-discharge rate for a similarly aged group of inpatients, but of those 19 surviving patients, 10 required transfer to a nursing home or rehabilitation facility. Of the 9 intact survivors, most had suffered a witnessed arrest caused by ventricular arrhythmia of less than 5 minutes' duration.<sup>10</sup>

Other work has explored physician attitudes regarding DNR orders. A study by Farber et al<sup>11</sup> found that non-medical factors such as mental retardation, dementia, age, institutionalization, or a history of violent crime and drug abuse can affect the physician's decision to resuscitate, despite equivalent medical prognoses. Lawrence and Clark<sup>12</sup> found that physicians were less likely to advise resuscitation for patients with a diagnosis of cancer, even when compared with seriously ill noncancer patients with equivalent medical prognoses.

Very little work has been done to investigate the preferences and decision-making process of patients and their families regarding the DNR order. Since the legal right to terminate care belongs primarily to the patient and only secondarily to physicians and families, it is important to

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From the Department of Family Practice, the University of Michigan, Ann Arbor. Requests for reprints should be addressed to Mark H. Ebell, MD, Rt 2, Box 91A, Colbert, GA 30628.

understand how patients make this difficult decision. Components of this process include a determination of whom the patient would like to have involved in making DNR decisions, and exploration of the effect of experience, education, and other nonmedical factors. Schmerling et al<sup>13</sup> found that 87% of a group of elderly outpatients felt that discussions about DNR orders should take place routinely and were able to provide a clear opinion of their preferences. The purpose of this study was to explore how patients arrive at decisions regarding DNR orders.

## METHODS

A self-administered questionnaire was developed to obtain information from 800 outpatients from the University of Michigan Family Practice Center in Chelsea, Michigan (population 3800). Patients were randomly selected from the group of all outpatients seen from March 1, 1988, to March 1, 1989. The group was evenly divided between patients aged under 70 years and those 70 years old or older. A stamped return envelope was included with each questionnaire in the first mailing; nonrespondents received a second questionnaire without a return envelope 1 month later. The questionnaire was 8 pages long and took approximately 20 to 30 minutes to complete.

The questionnaire consisted of six parts. Part 1 obtained general demographic information about the patient and his or her family. Part 2 investigated past experience with DNR orders and the patient's preference for or against resuscitation. Part 3 asked the patient whom they would want to have involved in the DNR decision-making process. Part 4 investigated the relative value of factors such as safety, dependence, and pain to the patient. The questions were adapted from a recently published book containing a worksheet for making living wills.<sup>14</sup> Part 5 presented a number of scenarios matched for medical prognosis but differing in nonmedical factors. The matched pairs were separated and listed in random order. Part 6 consisted of 20 questions about general health and function adapted from a physical health scale developed by Prehn.<sup>15</sup> Answers indicating good health and a high level of function received 1 point, thus generating a health score ranging from 1 to 20. Severe impairment was defined as a health score  $\leq 8$ .

Before mailing the questionnaires, the primary family physician for each outpatient was contacted. Physicians were asked to select patients who they felt were not competent to respond to the questionnaire. These patients ( $n = 45$ ), as well as any patients whose questionnaire was returned because of no forwarding address ( $n = 14$ ) or who were known to have died during the study period ( $n = 15$ ), were excluded. Thus, the final study population consisted of 726 patients.

Patients were given the option of not completing any part of the questionnaire that they found upsetting; questionnaires were reviewed for completeness during data entry. If more than two questions in parts 1, 2, 4, or 5, or three questions in part 6 were not answered, that part was considered incomplete and was not included in the analysis. If more than 2 parts were incomplete, the entire questionnaire was considered incomplete and was discarded. Of the 726 patients in the final study population, 372 (51%) returned questionnaires, of which 34 (9%) were incomplete, leaving 338 (47%) of the 726 patients for data analysis.

Data were entered in a database using DBase III Plus,<sup>16</sup> and subsequent analysis utilized the Systat<sup>17</sup> statistics program. The following two-way variables were generated: college-educated (education—college or graduate school), married (marital status—married), widowed (marital status—widowed), older (age  $\geq 70$  years), severely impaired (health score  $\leq 8$ ), chronic illness (diagnosis of congestive heart failure or chronic obstructive pulmonary disease), and personal experience (patient was resuscitated or discussed DNR status of a relative with a physician). Information about the nonresponding patients, including age, sex, and ZIP code, was obtained from the medical record.

Differences between groups measured by continuous variables were evaluated by analysis of variance, and pairwise comparison was done by independent Student's *t* tests using separate variances. Differences in categorical variables were analyzed by the Pearson chi-square test.

## RESULTS

The characteristics of the respondents and nonrespondents were determined. Respondents tended to be somewhat older than nonrespondents (63.8 vs 60.7 years). There was no significant difference in male-to-female ratio, presence of chronic illness, or distribution of ZIP codes between the two groups. Of the respondents, 63% were female, and the most common ZIP code (34%) was for Chelsea.

Demographic information about the respondents is summarized in Table 1. Most patients were married, lived in their own home, and had at least a high school education. The mean health score was 14.4 for all respondents; 5% (17) had a score  $\leq 8$ , indicating severe impairment.

Respondents' experiences with DNR orders are found in Table 2. Only 8.7% of patients younger than 70 years and 14.3% of patients aged over 69 years had ever discussed resuscitation with a physician, usually their family physician (77%). The most common location for discussion (59%) was the physician's office. Patients who them-

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

	Age <70 yr No. (%)	Age ≥70 yr No. (%)	Total No. (%)
<b>Marital status</b>			
Married	132 (77)	98 (58)	230 (68)
Widowed	5 (3)	54 (32)	59 (17)
Divorced	23 (13)	6 (4)	29 (9)
Single	11 (7)	8 (5)	19 (5)
NS*	0 (0)	2 (1)	2 (1)
<b>Education</b>			
Elementary	6 (3)	29 (17)	35 (10)
High school	75 (44)	86 (51)	161 (48)
College	62 (36)	38 (23)	100 (29)
Graduate	27 (16)	13 (8)	40 (12)
NS	1 (1)	2 (1)	3 (1)
<b>Residence</b>			
House	158 (93)	138 (82)	296 (87)
Apartment	11 (6)	25 (15)	36 (11)
Nursing home	2 (1)	4 (2)	6 (2)
NS	0 (0)	1 (1)	0 (0)
<b>Lives (with)</b>			
Alone	26 (15)	59 (35)	85 (25)
Wife	76 (44)	85 (51)	161 (48)
Children	8 (5)	10 (6)	18 (5)
Siblings	2 (1)	3 (2)	5 (1)
Wife and children	55 (32)	9 (5)	64 (19)
NS	4 (2)	2 (1)	6 (2)

\*Not specified.

selves had been resuscitated were older (70 vs 63 years,  $P < .05$ ), were more likely to have discussed resuscitation with their physician (19.2% vs 3.6%,  $P < .001$ ), and had a lower health score (12.3 vs 14.8,  $P < .001$ ). Also, patients with one of two chronic illnesses (congestive heart failure or chronic obstructive pulmonary disease) were more likely to have discussed resuscitation with their physician (34.7% vs 10.2%,  $P < .001$ ).

Respondents ranked the relative importance of persons who they felt would be helpful in making a decision about a DNR order for themselves (Table 3). Physicians were the persons most often chosen as advisors, while spouses were the most valued. Overall, physicians, spouses, and children were the most valued advisors. Patients who were severely impaired based on their health score were more likely to value input from clergy (4.2 vs 3.1,  $P = .02$ ) and friends (3.5 vs 2.8,  $P = .03$ ). College education, age, marital status, chronic illness, personal experience with resuscitation, and preferring to live as long as possible regardless of quality of life did not significantly affect the choice of persons selected for help in making DNR decisions.

Patients overwhelmingly preferred to preserve a good

TABLE 2. RESPONDENT EXPERIENCE WITH DO-NOT-RESUSCITATE ORDERS

Experience	Percent Affirmative		
	Age <70 yr (n = 171)	Age ≥ 70 yr (n = 168)	Total (n = 339)
<b>Personal experience with resuscitation</b>			
Have thought about it	75	58	67
Have been resuscitated	3	6	5
Have discussed it with a physician	9	14	11
<b>Discussed your own resuscitation with anyone other than a physician</b>			
Spouse	72	43	60
Children	27	41	33
Parents	19	2	12
Friends	19	2	12
Siblings	10	13	11
Other	19	15	17
<b>Discussed resuscitation of a family member with someone other than a physician</b>			
Spouse	51	44	48
Children	15	46	25
Parents	29	5	21
Siblings	15	15	15
Other	39	31	36

quality of life over a life extended with no regard for quality of life (93.9%). Only 6.1% of the respondents preferred to live as long as possible, regardless of the quality of life. College education, marital status, physical

TABLE 3. RESPONDENTS' PREFERENCE OF PERSONS WITH WHOM THEY WOULD LIKE TO DISCUSS DO-NOT-RESUSCITATE (DNR) DECISIONS

	Average Rank	Rank for Severely Impaired Patients	Number of Respondents Selecting This Person (n = 339)
Spouse	4.8	5.0	248
Physician	4.6	4.7	310
Children	4.5	4.2	272
Nurse	3.5	3.3	251
Clergy	3.2	4.2*	252
Friend	2.8	3.5*	239
Social worker	2.1	2.9	227

NOTE: The relative importance of the person in helping to make DNR decisions was evaluated by a Likert scale in which 1 = not important, 3 = somewhat important, and 5 = very important.

\*Significant at  $P < .05$ .

TABLE 4. RANKING OF VALUES IMPORTANT IN MAKING DO-NOT-RESUSCITATE DECISIONS

Values	Age $\geq$ 70 yr/ Age < 70 yr	All Respondents
I want to maintain my capacity to think clearly	6.7/6.5	6.6
I want to be treated with dignity when I can no longer speak for myself	6.7/6.6	6.6
I want to leave good memories of my last days to my loved ones	6.6/6.5	6.6
I do not want to be a burden on my family	6.2/6.5	6.4
I want to experience a comfortable dying process	6.5/6.2	6.4
I want to be with my loved ones before I die	6.3/6.5	6.4
I want to feel safe and secure	6.4/5.9*	6.2
I want to be able to make my own decisions	6.2/6.3	6.2
I want to avoid pain and suffering	6.2/5.6*	5.9
I want to be treated in accordance with my religious beliefs	6.2/5.3*	5.7

NOTE: Values ranked on a Likert scale in which 1 = not important, 4 = somewhat important, and 7 = very important.  
\*Significant at  $P < .001$ .

impairment, chronic illness, or personal experience with resuscitation did not significantly affect this preference.

In Table 4 the relative importance of different values is summarized. College-educated respondents placed significantly less value ( $P < .001$ ) on avoiding pain and suffering than non-college-educated respondents. Older respondents placed significantly more value ( $P < .001$ ) on feeling safe and secure, avoiding pain and suffering, and being treated in accordance with their religious beliefs.

Brief scenarios, matched for medical prognosis but differing in social factors, are shown in Table 5. In the questionnaire the 17 scenarios were in random order, but are grouped in Table 5 by eight social factors. The presence of increasing age, dementia, drug use, severe pain, alcoholism, and wheelchair use all reduced the likelihood that respondents would recommend resuscitation for the patients described ( $P < .001$ ). Place of residence (home vs nursing home) was the only social factor that did not alter the recommendation to resuscitate.

The average ranking for all 17 scenarios was calculated (2.6 for all respondents). This ranking was compared with the average ranking for the following two-way variables: college educated, older, severely physically impaired, and married. None achieved statistical significance at  $P < .05$ . Patients who had expressed a desire to live as long as

TABLE 5. IMPACT OF NONMEDICAL FACTORS ON DO-NOT-RESUSCITATE DECISION MAKING

Social Factor	Scenario	Average Ranking
Age*	A 90-year-old man with a heart attack	3.6
	A 70-year-old man with a heart attack	2.2
	A 50-year-old man with a heart attack	1.4
Drug use*	A 24-year-old man with an infected heart valve due to heroin abuse	2.4
	A 30-year-old woman with heart disease due to rheumatic fever	1.8
Alzheimer's disease*	A 72-year-old woman with severe Alzheimer's disease and pneumonia	4.1
	A 73-year-old man who is otherwise well, but has a pneumonia	1.5
Pain*	A 64-year-old woman with severe pain due to bone cancer	3.9
	A 64-year-old woman with terminal breast cancer, but minimal pain	2.9
Alcoholism*	A 57-year-old man with end-stage liver disease due to alcohol abuse	3.7
	A 52-year-old man who had hepatitis, and now suffers from liver failure	2.9
Wheelchair*	A 78-year-old woman who is confined to a wheelchair and has a pneumonia	2.7
	A 73-year-old man who is otherwise well, but has a pneumonia	1.5
Cancer as diagnosis*	A 64-year-old woman with terminal breast cancer, but minimal pain	2.9
	A 68-year-old woman with severe, end-stage congestive heart failure	3.7
Nursing home	An 80-year-old man in a nursing home	3.2
	An 82-year-old man cared for by his wife in their home	3.1

NOTE: Scenarios were matched for medical prognosis, but differed in social factors (exact wording shown). A Likert scale was used in which 1 = definitely should resuscitate and 5 = definitely should not resuscitate.  
\*Significant at  $P < .001$ .

possible, regardless of the quality of life, had a significantly lower average ranking for the scenarios (1.9,  $P = .002$ ). Thus they were more likely to recommend resuscitation for any given patient.

## DISCUSSION

When basic demographic data were examined, the respondents were similar to the nonrespondents with the exception that they were slightly younger. That the average health score was 14/20, and that very few patients lived in nursing homes or were severely impaired, would

indicate that the study population represented a sample of well outpatients.

Only 39 of 339 patients (11.5%) had ever actually discussed resuscitation with their physicians, while 44% had discussed their wishes for DNR status with family or friends. While patients expressed a strong desire to consult with physicians about DNR decisions and valued their physicians' input highly, in practice such consultation is accomplished only rarely. This finding underscores the need for greater effort by primary care physicians to raise the issue of resuscitation in the outpatient setting, as they generally control the patient-physician interview. Patients with a chronic illness were more likely to have been resuscitated or to have discussed resuscitation with their physician; they are an especially appropriate group for discussions about DNR status in the outpatient setting. Such discussions can help prevent confusion, family stress, and unnecessary suffering because of unwanted resuscitation in the acute setting.

Patients indicated that their physician, their spouse, and their children were the persons whom they most wanted to include in discussions about resuscitation. Family physicians, who provide family-oriented care, are in the ideal position to suggest family meetings when appropriate. The greater value placed on input from clergy and friends by patients with a low health score may represent loss of other family members and increased dependence on other members of the community. Such information should be considered when planning a family meeting for severely impaired patients.

Older patients placed more value on avoiding pain and suffering, feeling safe and secure, and being treated in accordance with their religious beliefs. These issues should be given appropriate weight by physicians when discussing resuscitation with elderly patients and their families. Interestingly, patients with higher education placed relatively less importance on avoiding pain and suffering. Perhaps they have a greater faith in technologic advances in pain control as well as a greater sense of their own ability to control events, including illness and suffering.

Social factors clearly play an important role in the DNR decision-making process for most patients. Age, dementia, wheelchair use, pain, drug use, and alcoholism were all associated with a decreased tendency to choose resuscitation. These data are similar to those obtained by Farber and coworkers<sup>11</sup> in studies of physician decision making. Most ethicists, however, would probably agree that drug use, alcoholism, and wheelchair use are not appropriate reasons for denying resuscitation. This finding emphasizes the physician's role in guiding discussions about

DNR status. While somewhat controversial to some, consideration of a patient's age is important because of the significantly reduced survival to discharge and quality of life of older patients who have been resuscitated.

These data suggest a strong interest in issues surrounding resuscitation and an expectation for physicians to play an active role in DNR decision making. Future work will compare physician decision making with that of this group of outpatients. Any discussion of preferences regarding DNR decisions in the outpatient setting should involve family, friends, and clergy as appropriate. Nonmedical factors, although important to patients, must be balanced by accurate prognostic information from the physician. With help from their primary care physician, patients can make important choices about their health care and thus prevent unnecessary suffering.

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