

TRIAD I—The Realistic Interpretation of Advanced Directives

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Rationale: Living wills often accompany patients who present for emergent care. Despite evidence suggesting that misunderstanding could lead to inappropriate care, few studies have assessed underlying assumptions about these instructions and how care may be affected.

Objectives: To determine if the living will implies a code status before clinical interaction and to assess how the term “do-not-resuscitate” is defined in terms of patient care.

Methods: An intranet survey was administered to clinical departments at a 350-bed acute care and level II trauma center. There were 585 potential respondents including physicians, nurses, and first-responders. No age or experience restrictions or exclusions were applied, given that emergent care presumes neither minimum age nor previous experience. The survey presented a fictitious living will refusing lifesaving interventions and prompted respondents to assign a code status (do-not-resuscitate or full code) and define the level of care associated with the former. Clinical information was withheld to isolate responses to the advance directive.

Results: Between 440 and 452 responses were made. Most were female (64%) and nurses (62%) with an average age of 38.2 years (range 18–68) and an average duration of employment of 13.3 years (range 0.3–40.9). Seventy-nine percent (347/440) indicated do-not-resuscitate and 70% (317/452) construed do-not-resuscitate with “comfort care/end-of-life care.” Occupation hierarchy (pre-hospital, nurse, physician) was related to the likelihood of choosing full code or full care ($P \leq 0.001$, odds ratios: 4.03 [95% bounds 1.70, 9.55]; 2.19 [95% bounds: 1.04, 4.65], respectively).

Conclusions: A majority of caregivers at a level II trauma center construed a living will with a do-not-resuscitate order which, in turn, was equated with end-of-life care. Such understandings may unnecessarily put patients at risk when presenting for emergent care.

Key Words: living wills, do-not-resuscitate orders

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Living wills (LWs) are thought to protect a patient’s right to decide, a term also known as autonomy. Despite opinions that advance directives (the LW) are underutilized, they have become commonplace. Of the estimated 290 million people in the United States,¹ 20% have a LW.² With 60 million LWs in

existence, it becomes imperative that they are correctly interpreted to ensure patient safety and standards of care.

Controversy surrounds LWs. Language is often vague or poorly defined. Terms such as “terminal condition,” “incurable illness,” and “seriously incapacitating” rely on the interpretation by the treating physician. As discussed by Crippen et al,³ such terminology is situationally dependent and can vary during the course of intervention. Further, physician practices may vary and conceivably are influenced by both personal belief and sub-specialty practice. An aggressive physician or subspecialist may recognize nothing short of death as a terminal illness, whereas another may deem a condition incurable and elect to withdraw care and support.⁴ To better clarify intent, discussions between patient, family and treating physician have been recommended.⁵ Such discussion can still be nebulous.⁶ Furthermore, emergent treatment often makes this advice impractical as decisions often are made without a comprehensive knowledge of the patient’s history.

Living wills are not and should not be considered synonymous with do-not-resuscitate orders (DNR). Do-not-resuscitate order represents a designation not to intervene if a patient is found pulseless or apneic.^{7–12} Currently, state law governs the implementation for advance directives. In Pennsylvania, state statute stipulates and defines that life support be provided to a person with a LW unless the patient is terminal or in a state of permanent unconsciousness.¹³ Furthermore, there is a significant difference between an “effective” and an “enacted” LW. An “effective” LW is one that is valid legally binding but is not activated. An enacted LW is one that has become activated by the triggers in the document, most commonly a terminal condition or a persistent vegetative state.

Given little published data with respect to how LWs are interpreted, this study surveyed medical personnel and prompted their responses to a LW. We hypothesized that: (1) caregivers construe a LW to mean DNR and that DNR is assumed to define comfort care/end-of-life care; (2) respondent background (eg, training, years of experience) and occupation affects responses; and (3) attitudes toward death influence decision-making. The goal of the study was to provide insight as to how a LW is interpreted and whether it is or is not interpreted according to governing state statutes. Secondly, to determine whether experience or training affect this interpretation.

METHODS

The study population consisted of a convenience sample of physicians, nurses and first responders at a 350-bed acute

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Survey of Living Wills Physicians Survey – Initial Entry

Please complete the following questions and when finished, click the "Submit" button to record your answers and continue on with the survey process. If desired, you may click the "EXIT Survey" button to return to main page without taking the survey.

How long have you been in practice? _____ Years _____ Months

Have you had any training or instruction regarding advance directives or living wills? Yes No

Age: _____

Gender: Female Male

(1) A patient's living will is listed below. What is the patient's code status?

DNR Full Code

Living Will

(My specific direction to my family and health care providers)

I, , being of sound mind, willfully and voluntarily make this declaration to be followed if I become incompetent. This declaration reflects my firm and settled commitment to refuse life-sustaining treatment under the circumstances indicated below.

I direct my attending physician to withhold or withdraw life-sustaining treatment that serves only to prolong the process of my dying, if I should be in a terminal condition or in a state of persistent unconsciousness.

I direct that treatment to be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing life-sustaining treatment.

In addition, if I am in the condition described above, I feel especially strong about the following forms of treatment:

I do do not want cardio-pulmonary resuscitation.

I do do not want electrocardioversion.

I do do not want mechanical respiration.

I do do not want tube feeding or any other artificial or invasive form or nutrition (food) or hydration (water).

I do do not want blood or blood products.

I do do not want any form of surgery or invasive diagnostic tests.

I do do not want kidney dialysis.

I do do not want antibiotics.

(2) Do you feel it is your responsibility to discuss advance directives and end of life care?

Yes No

What is your specialty? _____

(3) Do you feel you are financially compensated to discuss advance directives and end of life issues?

Yes No

(4) What is your understanding of the code status designation DNR?

Comfort Care / End of Life Care Full Care

FIGURE 1. Living Will Survey.

TABLE 1. Respondent Demographics

Demographic	Summary Value
Mean age, yrs	38.2 (range: 18–68)
Tenure, yrs	13.3 (range: 0.3–40.9)
Gender	
Female (n)	62% (287)
Male (n)	33% (152)
Unknown/missing	5% (24)
Occupation	
Physician (n)	16% (73)
Nurse (n)	64% (295)
EMT and paramedic (n)	20% (91)
Unknown/missing	1% (4)

care, major referral center and teaching facility in Pennsylvania. The physicians and nurses hold licensure by the State of Pennsylvania to practice throughout the state, and many are licensed to practice in multiple states.

Study recruitment consisted of a notice that was sent to clinical departments. The notice introduced staff to the study and advised them of a password-restricted site within the institution's intranet system for accessing the survey and making responses. A reminder notice was sent 6 weeks later. Participants were also advised that the responses were recorded anonymously in a secured, electronic database. Anonymity obviated signing a consent form, guarded confidentiality, and allayed concerns about reprisal. Given respondent anonymity, only an estimate of 585 potential respondents can be provided. The study methods were approved by the institutional review board.

The survey asked participants to respond to an advance directive in the form of a valid yet fictitious LW. Its content conformed to Pennsylvania State statutes with content validity certified by legal review. This directive declined life-saving measures for a “terminal condition” or “persistent unconsciousness” (Fig. 1). It then prompted respondents to select a dichotomous response about the appropriate code status (DNR or full code) and their understanding of level of

TABLE 2. Responses to Code Status

Factor	DNR	Full Code	P value
Overall	79% (347)	21% (93)	<0.001*
Gender			0.234†
Females	78% (218)	22% (61)	
Males	81% (117)	19% (28)	
Prior training			0.052†,‡
Yes	78% (205)	22% (57)	
No	80% (123)	20% (30)	
Occupation			0.001†
Physician	64% (44)	36% (25)	
Nurse	79% (227)	21% (59)	
EMT and paramedic	89% (76)	11% (9)	
Professional Experience, yrs (SD)	12.9 (11.2)	14.8 (9.4)	0.552†
Age, yrs (SD)	37.5 (11.2)	40.2 (10.1)	0.309†

*Binomial test.
 †Logistic regression.
 ‡Interaction with occupation; see text.

TABLE 3. Responses to Patient Care

Factor	Comfort Care	Full Care	P value
Overall	70% (317)	30% (135)	<0.001*
Gender			>0.892**
Females	71% (202)	29% (84)	
Males	71% (105)	29% (43)	
Prior training			0.072**
Yes	69% (185)	31% (83)	
No	73% (115)	27% (43)	
Occupation			0.001***
Physician	50% (35)	50% (35)	
Nurse	68% (197)	32% (95)	
EMT and paramedic	94% (85)	6% (5)	
Tenure/experience	14.0 (11.5)	12.0 (9.6)	0.758**
Age, yrs (SD)	38.5 (11.4)	37.1 (10.0)	0.048**

*Binomial test.
 **Fisher's Exact Test
 ***Pearson Chi-Square

patient care associated with the term DNR (comfort care or full care).

Clinical information about the patient was not provided in this scenario to mimic an emergent condition. In addition, the survey Web site provided a set of instructions about completing the survey, and collected demographic and background information. It also assigned a survey number to each set of responses. This number was required for retest entries. The advantages to this mode of administration were ease of data collection, respondent anonymity, and widespread access throughout the institution.

Two versions of this survey were used, one for physicians (Fig. 1), the other for nonphysicians. The physician survey included 2 additional questions not addressed herein. Survey selection was accomplished electronically, based on the response to the occupation demographic.

Attitude and perception help govern behavior¹⁴ and influence physician decisions.¹⁵ Thus, a metric of attitudes toward death and dying would serve as a potential explanatory variable for LW survey responses. To measure attitudes toward death and dying, the death attitude indicator (DAI) was administered on the intranet site.¹⁶ It was originally developed to assess changes in student nursing attitudes following course work in death and dying. It was used herein because of content relevance, availability, and documented reliability. The DAI consists of 24 questions that use a Lickert scale to measure responses. Four questions directly relevant to caring for a

TABLE 4. Responses by Medical Discipline

Discipline	Patient Code Status Query		Patient Care Query	
	DNR (n)	Full Code (n)	Comfort Care (n)	Full Care (n)
Surgery	55% (6)	45% (5)	36% (4)	64% (7)
Emergency	76% (16)	24% (5)	71% (15)	29% (6)
Family practice	71% (10)	29% (4)	50% (7)	50% (7)
Internal medicine	67% (8)	23% (4)	14% (2)	86% (12)
Other	57% (4)	43% (3)	71% (5)	29% (2)

TABLE 5. Test-Retest Data

Retest Responses				
Initial Responses	DNR	Full Code	Comfort Care	Full Care
DNR	89% (64/72)	11% (8/72)	–	–
Full code	29% (5/17)	71% (12/17)	–	–
Comfort care	–	–	88% (64/73)	12% (9/73)
Full care	–	–	13% (3/23)	87% (20/23)

terminally ill patient, as well as the overall DAI score were used to show the impact of attitude on responses, as well as establish construct validity of the LW survey.

In addition to validating this survey, test-retest reliability was assessed. Volunteers were prompted to retest no sooner than 2 weeks and a maximum of 6 weeks after their initial responses. To maintain anonymity but allow a link between survey responses, subjects were instructed to record the survey number of their first test and supply it upon retest. Failure to supply a valid number nullified any retest data.

Data were summarized as either percentages or associated 95% confidence intervals (CI) for categorical responses or means and SDs for scale and ordinal (Lickert) variables. For the latter, data normality were confirmed via normality plots. The primary outcomes of responses for code status designation and understanding of the level of care associated with the term DNR were assessed with a binomial test. The relationship between code status designation responses and those for level of patient care associated with the term DNR were analyzed via χ^2 test using the Pearson-derived *P* value. Effects of background and training on responses were assessed with forward conditional logistic regression using threshold probabilities of 0.05 for entry into the model and 0.10 for rejection. Odds ratios (OR), 95% CI, and accompanying *P* values are listed for significant factors in the RESULTS section. A subset of physician responses were also compiled but not subjected to statistical analysis because of limited sample size. The influence of attitude toward death (DAI score) on survey responses was assessed in a separate logistic model. This assessment included responses to 4 questions related to patient care of the terminally ill, as well as the overall average response. Results of this analysis were also used to demonstrate the presence of construct validity of the survey. Finally, agreement between test-retest responses was measured with a kappa statistic.¹⁷ By convention, 0.05 was used as the threshold for statistical significance. SPSS v. 12.0 (Chicago, IL) statistical software was used for all analyses.

RESULTS

There were 440 responses to the code status query (Q1, Fig. 1) and 452 responses about the level of patient care associated with the term DNR (Q4, Fig. 1), yielding an estimated response rate of 75% (440/585) to 77% (425/585). For the retest, 89 valid responses were obtained for Q1 and 96 for Q4. Finally, 280 responses were made to the DAI. Most of the respondents were females (62%) and nurses (64%) with a mean age of 38.2 ± 11.0 years (range 18–68) and 13.3 ± 10.8 years (range 0.3–40.9) of professional experience (Table 1).

With respect to Q1, 79% (347/440) of respondents selected DNR for code status (95% CI, 75.2%–82.8%; $P < 0.001$) (Table 2). Occupation (in the order Emergency Medical Technicians [EMTs] and paramedics, nurse, physician) was a significant predictor of responses (OR, 4.03; 95% bounds, 1.70, 9.55; $P < 0.001$). At the extremes, 89% (76/85; 95% CI, 82.3%–95.7%) of EMTs and paramedics chose DNR versus 64% (44/69; 95% CI, 52.7%–75.3%) of physicians. In the context of occupation, prior training in advance directives showed a modest inverse relationship to the likelihood of selecting full code (OR, 0.478; 95% bounds, 0.227, 1.006; $P = 0.052$). This was most pronounced in EMTs and paramedics. Eighty-two percent (56/68) who had training interpreted the LW as a DNR whereas 75% (6/8) who did not selected full code. Neither gender, years of experience, nor age affected these responses ($P \geq 0.159$).

With respect to Q4, (understanding of DNR), 70% (317/452; 95% CI, 65.8%–74.2%) of respondents selected “Comfort Care/End of Life Care” ($P < 0.001$, Table 3). Although neither gender, prior training in advance directives, nor experience had a significant influence on these responses ($P \geq 0.072$), occupation and age exerted effects ($P \leq 0.048$). Ninety-four percent (84/90; 95% CI, 89.1%–98.9%) of EMTs and paramedics selected comfort care/end of life care compared with 50% (35/70; 95% CI, 38.3%–61.7%) of physicians. Occupational hierarchy (in the order EMTs and paramedics, nurse, physician) was predictive of the likelihood of choosing the response “full care” (OR, 3.11; 95% bounds, 1.66, 5.82; $P < 0.001$). Age demonstrated a modest interaction with occupation (OR, 0.97; 95% bounds, 0.95, 1.00). The largest age effect was observed for nurses. The mean age of those who selected comfort care/end of life care was 41.2 ± 11.2 years compared with 35.9 ± 9.7 years for those who selected full care.

Patient code status response was strongly associated with the level of care response. Seventy-six percent (262/345) of those who interpreted the LW as “DNR” chose “comfort care/end of life care” whereas 52% (47/91) who interpreted the LW as “full code” also selected ‘full care’ ($P < 0.001$).

Grouping the data by physician specialty (Table 4) demonstrated variations in responses. A 21% divergence in assigning code status was observed. Responses to patient care status for a DNR designation varied by up to 57%. At the extremes, 55% (6/11; 95% CI, 25.6%–84.4%) of the surgery specialty and 76% (16/21; 95% CI, 57.7%–94.3%) of emergency department physicians chose DNR as the appropriate code status designation. Interestingly, 71% (15/21; 95% CI, 51.6%–90.4%) of emergency department physicians chose comfort care/end of life care as their understanding of DNR.

The average DAI score was 3.0 ± 0.4 (range 1.7–3.9). Using a response cut-off of ‘3,’ 67% (188/280; 95% CI: 61.4%–72.5%) of respondents had a positive attitude toward death. Death attitude indicator scores were not predictive of responses to code status ($P \geq 0.086$). For level of patient care responses associated with the term DNR, the average DAI score was related to the overall likelihood of selecting ‘full care’ (OR, 3.04; 95% CI, 1.40–6.63; $P = 0.005$). However, responses to one of the DAI questions specifically pertaining to care (“What efforts should be made to keep an imminently

terminal patient alive?" Scale response: "All Possible" to "None") was inversely correlated to the likelihood of selecting full care (OR, 0.61; 95% CI, 0.44–0.84; $P = 0.002$). These correlations suggest some measure of construct validity of the LW survey, as well as demonstrate the effect that death attitude exerts on patient care responses.

Retest data demonstrated a response concordance between 71% and 89% (Table 5). This corresponded to κ values of 0.557 for code status and 0.685 for care status.

DISCUSSION

The data show that most respondents equated a LW with DNR and DNR with end-of-life care. There were few factors that exerted an effect on these responses. Overall, DAI scores were positive for the majority of respondents. Their effect was significant only for responses to patient care. Of the demographic and background data collected, only the profession was associated with substantial differences in survey responses; training in advance directive and age exerted modest effects on either code status or patient care, respectively. Neither prior training in advance directives, job tenure, nor gender had an effect.

Sufficient survey internal validity and reliability and minimal selection bias render the data credible. Test-retest reliability evidenced moderate-to-substantial agreement according to the criteria of Landis and Koch.¹⁷ Speculatively, we suspect that some of the discordance in responses associated with the retest reflects profound uncertainty in light of a significant issue. If true, the measured survey reliability noted herein is likely conservative and would probably be much higher if it were possible to adjust for the confounder of postsurvey discussions/information gathering. Content validity was established via legal review with material specifically adopted from Pennsylvania State statutes. Construct validity was conclusively demonstrated only for the level of care associated with DNR responses. This may reflect the emphasis of the DAI on nursing care and treatment of the terminally ill. Finally, selection bias is low as we estimated a response rate of more than 75%.

Study limitations include the purposeful omission of clinical information and limited sampling. Clinical information was specifically excluded from the survey to ascertain if the content or structure of the LW, in isolation, is problematic and misleading. With respect to sampling, the responses were limited to a single institution. However, many participants were trained in different regions of the country, obtain national licensure, and have privileges to practice in several states and facilities. We therefore submit that the sample has a substantial level of generalizability. Finally, an anonymity in a survey precludes follow-up. In particular, the retest rate was somewhat low but sufficient to provide credible reliability data.

The results corroborate our hypothesis that LWs are equated with do-not-resuscitate orders and that DNR orders are equated with comfort care/end of life care. This interpretation stands in conflict with Pennsylvania statute in terms of the conditions for enacting a DNR (eg, a patient who presents pulseless or apneic). This misinterpretation is not a provincial phenomenon. It has been a contention for 2 decades, starting with Eisendrath and Jonsen.¹⁸ Ultimately, a

Cleveland University Hospital system required the submission of a separate "STOP" order to clarify the role of life support in patients with a LW.¹⁹ Clarity in instructions and intent is why several authors have argued that communication with the patient is needed to ensure understanding and promote autonomy.^{6,20} However, patient dialogue cannot always be achieved in emergent conditions, and there is a heavy reliance on directives (the LW) or health care proxy. Recently, there have been several recommendations for the complete abandonment of LWs because of problems in their implementation.^{21–24} This discontent is pervasive as witnessed by a recent physician survey in Ireland.²⁵

Why problems exist in interpreting LWs undoubtedly reflects a multitude of factors. We addressed attitudes toward death, training, and demographics. Attitudes toward death influenced decisions about the level of patient care associated with the term DNR. With respect to demographics, women have been reported to harbor greater death anxiety than men²⁶ and conceivably may have a different interpretation of a patient's LW. Our data were not influenced by gender. Prior training in advance directives and age produced significant though modest effects on responses. Of all the factors examined, respondent profession was responsible for the largest disparity in responses. In particular, the rate of interpreting the LW as a DNR was between 15% and 25% greater in EMT/paramedics and nurses than in physicians. This "occupation" effect was observed by Eliasson et al,²⁷ who found that nurses were *less* likely than physicians to assign a DNR to ICU patients without an advance directive. The disparity between our study and theirs may reflect available information: the latter was based on presenting cases with adequate history; our scenario provided limited information. Concern about potential litigation also can affect decisions.^{27,28} Finally, differences in code status designations and level of care responses were apparent within physician specialties, ranging from 21% to 57%. Similarly, Kelly et al²⁹ found differences in assignment of DNR orders within specialties.

On the basis of the present data and recent report,³⁰ patient safety and care becomes a concern. Reports of patient incidents have been equivocal. In some cases, care provided to DNR patients is not compromised.³¹ Other studies have shown that both a DNR designation and prognosis affect physician behaviors, resulting in less aggressive critical care procedures,³² fewer interventions and less documentation,³³ and withholding treatment in nonterminal patients.³⁴ Physicians have also assigned a DNR designation without discussions with the patient or health care surrogate even when the patient or surrogate was competent to partake in such discussions.^{30,34} The intensity of nursing care efforts may also be affected should patients be classified DNR.^{7,30,35,36} Case scenarios have shown that increasing age as well as a DNR order significantly decreased the aggressiveness of nursing care.³⁷ Lastly, nurses have delayed notifying a physician of a change in clinical status of a patient who is DNR.⁷

This misunderstanding of DNR is not a result of unclear definitions. DNR represents a designation not to intervene if a patient is found pulseless or apneic.^{7–12} Furthermore, in 1983, a presidential directive was issued stating: "any DNR policy

should ensure that the order not to resuscitate has no implications on any other treatment decision."³⁸

The current state of dilemma regarding LWs and DNR orders likely arises from a fundamental lack of understanding about the conditions that set an advance directive in motion. Further, these conditions can be transitory and must be re-evaluated in the context of the patient's medical status.^{3,39} Presumably, education would help to remediate some of the misunderstanding.

CONCLUSIONS

Our results support our contention that both the LW and do-not-resuscitate orders are misunderstood. The LW is being perceived to define a DNR order before clinical interaction because of its presence rather than enactment. Do-not-resuscitate order is being construed to define comfort care/end of life care, which violates its published definition. There is much confusion on the topic of LWs and DNR. It is this confusion that could conceivably lead to compromises in patient care and safety.

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