



## Influence of an Educational Manual “Code Status” Choice Among Hospitalized Patients

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### Abstract

**Purpose:** This prospective study aimed to evaluate the impact of an informational manual on patient choice of code status when presented with a hypothetical imminent death scenario.

**Methods:** One hundred adult patients completed a survey to assess their general familiarity with end-of-life and code status issues. Then, they read a manual designed to deliver information about end of life issues. A post-reading survey assessed pre and post-reading “code status” choice in a hypothetical scenario involving the participants’ own imminent deaths.

**Results:** Twenty participants indicated that they would change their choice of code status after reading the manual. Twelve thought that the change would be from “full code” to “do not resuscitate.” Change of code choice was associated with having participated in Spanish.

**Conclusion:** After reading a study manual focused on end of life issues, twenty percent of participants indicated that they would change their code status choice in a hypothetical advanced-disease scenario. The manual may represent a useful complementary tool to educate patients about end-of-life options and to support their choice regarding code status.

**Keywords:** Code status; End-of-life; Code choice

### Introduction

Cardiopulmonary resuscitation (CPR) was developed to sustain cardiac and pulmonary function in patients on whom those organs arrest resulting from reversible conditions [1]. Consent to administer CPR is presumed, unless patients expressed in advance their preference for CPR to be withheld [2]. Patients should understand their prognosis and goals of care, as well as the benefits and risks that may arise from CPR. Since the hardest message to convey is the one of futility owing to the irreversibility of the underlying disease [3] physicians should make recommendations consistent with patient’s prognosis and goals of care [4]. The content of adequate discussions about code status has been outlined at large [2,5]. Yet, the outcomes of these discussions depend on multiple factors related to patients [6,7] and doctors [8-11].

We developed a written manual to educate patients about end-of-life (EOL) options. The objective of this study is to evaluate the impact of this manual on patients’ decision-making regarding their code status. Our hypothesis is that most patients would opt for a full code status, and that the manual will change the choice to do not resuscitate/ do not intubate, when faced with a hypothetical scenario of imminent death.

### Methods

The study was undertaken at Lyndon B. Johnson Hospital (LBJH), a tertiary care center in Houston, Texas, after obtaining Institutional Review Board approval (HSC-MS-12-0393); appropriate patient consent was obtained. The hospital has five medical-surgical units, each with seven four-bed rooms and three to five individual rooms. The study recruiter randomly selected patients admitted to the hospital. Patients were invited to participate only once. The main question addressed by this study was whether the patients would change their own code status under an imminent death scenario comparing their opinions before and after reading an instructive manual. We predicted a change rate of

20%. The sample size needed to obtain adequate power allowing a 5% chance of a type 1 error was calculated at 11 people.

### The patient encounter

Each patient encounter was divided into five steps: baseline survey, baseline knowledge test, reading of an informational manual, exit survey, and exit test, as described in the next paragraphs.

In the first step, we gave patients a *baseline survey*, on which the main questions were whether they have ever discussed end-of-life issues and Advanced Directives with their doctors and were they familiar with the concepts of full code and do-not-resuscitate.

The second step was knowledge assessment through a true/false/ don’t know-don’t understand *ten-item questionnaire*.

The third step was to *read a four-page manual* named “Discussing end-of-life issues”. This manual is available as an appendix to this article. The authors wrote the manual in English and in Spanish. The manual had three sections. Section 1 was the introduction in which was discussed: the life cycle; what dying means; whether death is irreversible;

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and the treatments for the cardiac and respiratory arrest. Section 2 was a discussion of decisions at the end-of-life: who gets cardiopulmonary resuscitation (CPR); the decisions that can be made; what the decision to have a code status of do-not-resuscitate/do-not-intubate (DNR/DNI) implies; who makes decisions regarding code status; whether the decision can be changed; and what other decisions matter at the end-of-life. Section 3 was the conclusion. The manual included the answers to the ten-item questionnaire of the second step.

We gave the patients about forty minutes to read the manual making sure that they completed it. Immediately after reading the manual (fourth step) we gave the patients a *post reading survey*, on which the questions were whether they would know what to ask their doctors if they knew they were dying; if they thought they had learned from the manual; and if the manual content was clearly presented. They were finally asked; in a hypothetical scenario that involved the possibility of their imminent death, whether their choice regarding accepting the application of Advanced cardiac life support(ACLS) resuscitation protocols (meaning being full code) or declining that option (meaning being DNR/DNI) would be changed after reading the manual.

Finally, in a fifth step, patients took a *post-reading test*, which was the same *ten-item questionnaire* as the pre-test taken before reading the manual. Changes in the score before and after reading were calculated. The following demographics were also collected: age, ethnicity, highest educational level, religion, surgical versus medical disease, and patient's perception on severity and acuity of their disease. Karnofsky functional score [12] was calculated for each patient.

### The imminent death scenario

Upon questioning about code choice, the following scenario was described to each participant:

"It is a fact that every living person will eventually die. However, there are some people that will die unexpectedly and some expectedly. Among the former, some deaths result from a sudden stop of the heart activity called arrhythmia that can be treated with an electric shock, restoring function if that happens fast enough, with good chances of a full recovery. On the other hand, some patients die from an advanced and progressive disease that either have no treatment, or failed too many treatment options. That is the case of certain forms of cancer, terminal liver, kidney, lung or heart disease"

Since the question is asked at the end of the patient encounter, we posted it as follows:

"Having just read about the issues expressed in the comment above, if you belonged in the group of patients whose disease have no hope of getting better, and your heart and lungs went into arrest, do you know which option you would choose? Asking doctors to make efforts resuscitating you, or letting the natural course of the arrest go, letting you die?"

The final question was "being that the case –for whichever choice– would you say your choice would have been different shouldn't you have read the manual you just read?"

### Statistical analysis

MedCalc® version 12.3.0 (MedCalc Software; Mariakerke, Belgium) was used in the statistical analysis. Categorical variables were analyzed by means of the Fisher exact test, and discrete variables were analyzed with use of the Student t test for unpaired samples. A 2-sided P value <0.05 was considered statistically significant.

## Results

The study was offered to 121 patients between August 2<sup>nd</sup> 2012 and October 26<sup>th</sup> 2012. One hundred patients (83%) agreed to participate.

Table 1 shows the baseline characteristics of the 100 patients enrolled.

### Code change

After reading the manual the election to undergo or decline ACLS protocols ("full code" versus "DNR/DNI") in the hypothetical advanced-disease scenario changed for 20 patients. Twelve patients changed from full code to DNR/DNI while the opposite was found in eight patients. Table 2 compares the characteristics of those who, when exposed to a hypothetical scenario of their imminent death, would change and those who would not change their own code status before and after reading the manual. The only variable significantly associated with a higher chance of changing the code status after reading the manual was having read the manual in Spanish, as opposed to having read it in English.

The 10-item questionnaire score increased by at least 1 point in 73 patients. Increment of score by any level was not associated with a higher likelihood of a code change. However, when analyzing those cases in which the case went from full code to DNR-DNI, incrementing a score by 6 points, or having a post-manual score of 7 or above was associated with a higher chance of code status change in the above direction ( $P=0.02$ ).

## Discussion

In this study we demonstrated that the study manual influenced participants' choice regarding the application of ACLS protocols in a

Patients' characteristics	n=100
Age in years (median and SD)	45 ± 14
Ethnicity	
Hispanic	54
Black	33
White	13
Educational level	
Elementary	7
Middle school	13
High school	55
College	23
Graduate school	2
Practices any religion	
Yes	78
No	22
Surgical admission (versus non surgical)	13
Perceived disease severity	
Mild	31
Moderate	34
Severe	34
Terminal	1
Perceived disease acuity (versus chronicity)	51
Karnofsky score (mean and SD)	85 ± 19
Ever discussed "end-of-life" issues with doctors	11
Ever discussed Advance directives with doctors	6
Familiar with "full code" or "DNR/DNI" concepts	29
Full code prior to reading the manual	57
Manual, survey and tests in English (versus Spanish)	64

**Table 1:** Baseline patient characteristics.  
SD: Standard Deviation

Patient characteristics	Code changed (n=20)	Code did not change (n=80)	P value
Age (median and SD)	41 ± 14	47 ± 14	0.05
Older than 45	8 (40%)	44 (55%)	0.32
Older than 65	0 (0%)	8 (10%)	0.35
Ethnicity			
Hispanic	14 (70%)	40 (50%)	0.14
Black	4 (20%)	29 (36%)	0.20
White	1 (5%)	11 (14%)	0.45
Not religious	4 (20%)	18 (22%)	1.00
Study in English	8 (40%)	56 (70%)	<b>0.02</b>
Educational level			
Elementary	1 (5%)	6 (7%)	1.00
Middle	2 (10%)	11 (14%)	1.00
High School	14 (70%)	41 (51%)	0.84
College	3 (15%)	20 (25%)	0.55
Graduate School	0 (0%)	2 (3%)	1.00
Surgical status	5 (25%)	8 (10%)	0.13
Subjective chronicity	11 (55%)	38 (47%)	0.62
Subjective severity			
Mild	4 (20%)	27 (35%)	0.29
Moderate	7 (35%)	27 (35%)	1.00
Severe	8 (40%)	26 (33%)	0.60
Terminal	1 (5%)	0 (0%)	0.20
Karnofsky less than 50	6 (30%)	10 (12%)	0.08
Baseline "full code"	12 (60%)	45 (56%)	0.81
Learned from manual	4 (20%)	27 (35%)	0.29
Score change after reading	1.45 ± 1.7	1.68 ± 2.0	0.65
Ever discussed EOL with doctor	2 (10%)	9 (11%)	1.00
Familiar with code concepts	3 (15%)	26 (32%)	0.17

**Table 2:** Characteristics of patients whose code status would and would not change after reading the manual. EOL: End-Of-Life; SD: Standard Deviation

hypothetical scenario of their own terminal disease. Change from full code to DNR-DNI was significantly more likely among those who – judged by their test score- acquired more knowledge from the manual. Change in any direction happened more among those who participated in Spanish, but this difference faded when analyzing the subgroup that would have changed from full code to DNR/DNI.

Different factors influence patients' choices regarding end-of-life issues. For instance, two independent studies showed that doctors that believe that prolongation of life is an adequate goal of care were less likely to offer comfort-care as an option [8,13]. Moreover, non-medical sources of information (such as TV portrayal of code survival) [14,15] contribute to patients' unrealistic expectations regarding chances of surviving a cardiopulmonary arrest.

The establishment of effective, informed and ethically sound guidelines for teaching doctors to overcome their lack of comfort discussing these matters should be guided by experts on end-of-life and communication [16,17]. However, these guidelines are aimed to teach the doctors, rather than the patients. In a study, cancer patients were more likely to choose comfort-care over CPR after seeing an educational video on EOL issues [18]. To our knowledge, ours is the first study that addresses the impact of a written manual on "code status" options.

The impact was statistically more significant among Spanish speakers; however, this difference disappeared when considering only the 12 patients whose status went from full code to DNR/DNI (6

Spanish speakers, P=0.34). We found no studies that reported language-based differences. However we did find studies where race [19,20] and socioeconomic status [21] made a difference. Non-white patients in the above studies were found more likely to choose full code, and to have documented discord among family members and with their physicians. On the contrary, another study addressing ethnicity influence on EOL issues found white patients less likely than Pacific islanders and Asian to request hospice, but there were no differences regarding code choice after Palliative care consultations [22].

We found the following limitations in our study:

First, the manual and tests were developed at a 9<sup>th</sup> grade level (as detected by Microsoft Word® readability tools); the recommended level for educational manuals is from 5<sup>th</sup> to 6<sup>th</sup> grade [23-25].

Second, we only tested knowledge within 30 minutes after reading, making unclear whether the acquired knowledge would last. On the other hand, we didn't leave the manual with the patient. If they had kept it, it could have reinforced knowledge further, and perhaps served as a reference for the patient.

Third, our interviewees weren't necessarily facing their approaching death. We need to test the benefit of our manual among patients who are actually suffering from advanced or terminal diseases.

Fourth, some responders decided to change their selected code status to *full code* when facing the imminent death scenario. We can't assess the relationship of this change with the intervention but in a randomized trial. Until then, the question of potential harm owing to the manual will remain open.

A new version of the manual, emphasizing the messages that we believe important for the patients' decision-making, may be used to complement, never to replace, the necessary patient-doctor encounters for end-of-life related discussions. The manual may represent a useful complementary tool to educate patients about end-of-life options and to support their choice regarding code status (Supplementary File).

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