# The Language of Data

# Workbook

### **Overview**

This workbook is designed to help you learn the language of data (LOD). The workbook is an electronic document with links to specific electronic resources. The LOD workbook has been designed such that each study task can be completed in about 5-10 minutes. You are encouraged to progress through this workbook at your own pace. You may wish to complete several tasks in a row or only complete one task at a time. The LOD materials will be available until the end of September 2014

The table below may be helpful to plan and track your progress through the workbook.

Task	Module	Activity	<b>Estimated Time</b>
Baseline	Paper	Read Manuscript	10 min
Assessment	Assessment	Online Baseline Assessment	20 min
	1	Quizlet - Flashcards	5 min
Phase One	2	Quizlet - Learn	5 min
Symbol	3	Quizlet –Test Format 1	5 min
Recognition	4	Quizlet –Test Format 2	5 min
	5	Quizlet - Scatter	5 min
Dhasa Tuus	1	Quizlet – Flashcards	5 min
Phase Two	2	Quizlet –Test Format 1	5 min
Symbol	3	Quizlet –Test Format 2	5 min
Vocabulary	4	Quizlet - Scatter	5 min
	1	Quizlet – Flashcards	5 min
Phase Three-A	2	Quizlet –Learn	5 min
Symbol	3	Quizlet –Test Format 1	5 min
Comprehension	4	Quizlet – Scatter	5 min
	1	Quizlet – Flashcards	5 min
Phase Three-B	2	Quizlet –Test Format 1	5 min
Symbol	3	Quizlet –Test Format 2	5 min
Comprehension	4	Quizlet – Scatter	5 min
	Case 1	Case Study 1	20 min
	Case 2	Case Study 2	20 min
Phase Four	Case 3		20 min
Case Study		Case Study 3	
	Case 4	Case Study 4	20 min
	Case 5	Case Study 5	20 min
Follow-up	Paper	Read Manuscript	10 min
Assessment	Assessment	Online Follow-up Assessment	20 min
		Total <b>estimated</b> time	< 4.5 hours

### **Baseline Assessment**

Before you begin this course, we will ask you to complete the Baseline Assessment.

### Please read all of the instructions before you begin the baseline assessment.

#### Instructions:

Before you take the Baseline Assessment, please print out and read the article by Annette M. Browning entitled: "Moral distress and psychological empowerment in critical care nurses caring for adults at end of life." SELECT THE LINK BELOW - - to go to this article (page 58)

Browning, A. M. (2013). CNE Article: Moral Distress and Psychological Empowerment in Critical Care Nurses Caring for Adults at End of Life. Am J Crit Care, 22(2), 143-151. doi: 10.4037/ajcc2013437

You will need a copy of the Browning article with you when you take the pre-test.

Take the Baseline Assessment only once.

- The Quiz is time limited and will turn off after 20 minutes.
- You should plan to spend no more than 20 minutes on the pre-test.
- You are not required to answer every question, but <u>there is no mechanism to go back and answer or change the</u> <u>answer</u> to a question you have skipped.

After you have read the article, please locate your unique username on page 5 of this workbook. You will need to enter your username to access the assessement.

> Please complete the baseline assessment by clicking on the link below. <u>http://www.proprofs.com/quiz-school/story.php?title=Njk0MTYwYK6X</u>



Be sure you have completed the Baseline Assessment before you continue to the next page!

### **Introduction to Quizlet**

Quizlet is a free website that can be used to teach and learn a wide variety of topics. For this course, we have created three learning phases.

> Phase One – Symbol Recognition Phase Two – Symbol Vocabulary Phase Three – Symbol Comprehension

In a moment, you will be directed to the quizlet.com website. If you have any difficulty navigating the website please access the Quizlet.com Help Center.

The HELP CENTER for quizlet can be found at http://quizlet.com/help

#### Flashcards Scatter Test Learn Help ( Center Q Search Q zleťs FAQs Everything ou need to know about Quizlet Quizlet basi Quizlet's study tools eating a study set С How Quizlet w Using Flashcards ating a new set C Sign up for Quizlet Using Speller ling symbols or accen Using Learn mode Upgrading to Quizlet Plus ling images to a set Creating a new set Using Test mode ying another user's s Finding a set Playing Scatter a set Studying a set Playing Space Race How auto-save works Sharing your sets Converting a MSWord document Printing on Quizlet

### This course will only use 4 of the Quizlet study tools

# Quizlet Log In Instructions

Each participant in the Language of Data survey has been assigned a unique username and password.

Username: Password:

Please use only this username and password. **Do not change the password or share accounts with others.** If you lose or forget your username or password, please contact Jennifer Rogers at <u>Jennifer@engagebydesign.com</u>.

Changing your username, password, or the email address you provided upon enrollment in the study will be detrimental to the study outcomes. If you need to make ANY changes, please contact Jennifer Rogers at <u>Jennifer@engagebydesign.com</u>.

Individual scores and performance will NOT be shared with the investigators. To maintain confidentiality, only the Language of Data Quizlet course designer (Jennifer Rogers) will have access that links participants, email addresses, and Quizlet registration information.

### Welcome to Quizlet

### Logging in to Quizlet is a 3-step process:

- 1. Go to <u>www.quizlet.com</u>
- 2. Enter and submit your unique username and password (see above).
- 3. On your Quizlet homepage, click on "Language of Data Site #1"

(Since multiple sites are involved in this study, specific site numbers will vary).

Instructions for the activity in each phase appear on the following pages.

To navigate between phases or to return to the class home page, click the Quizlet logo on the top left corner of your screen. Then repeat step 3.

# **Phase One – Symbol Recognition**

Phase I will help you learn to recognize different symbols that are common to the language of data. You will complete **FIVE excercises in Phase 1** and each exercise can be completed in under 5 minutes. Please complete each exercise at your own pace. You are welcome to repeat modules as often as you wish.

### Instructions:

### Log in to <u>www.Quizlet.com</u>

• On your Quizlet homepage under "Your Classes" click on "Language of Data Site #1" (Since multiple sites are involved in this study, specific site numbers will vary).

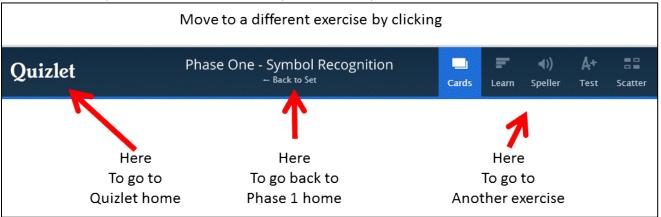
Click on  $\rightarrow$  Phase One – Symbol Recognition

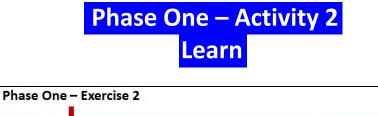
	Select This Option
Ċ	Phase One – Symbol Recognition 17 terms
	This week
	Phase Two - Symbol Vocabulary 17 terms
	Last week
	Phase Three (A) – Symbol Comprehension 16 terms



Start HERE										
Quizlet		Sea	ch Quizlet	Q	<b>F</b> Create a Set					
Phase C	)ne - Sy	mł	ol Recog	nition	🛞 Created by Langi					
Your Progress	Study S	cores	Teacher NEW	Info						
Fla			E Learn		(1) Speller					

- 1. **Flashcards:** Use navigation bar on the right side of the screen to customize your review of symbols and terms. You can view by photo first, English term first, or both sides at once, and with or without audio support.
- 2. Repeat this exercise as often as you want until you feel comfortable.







1. Select "See Math/Symbols first" (left hand side of screen)

	Select Math / Symbols
Remaining 17 Incorrect 0 Correct 0 Start Over Options See Math / Symbols first	r
🔲 Speak text	

- Speak text
- 2. Learn: Quizlet will prompt you with the symbol. You will type the English term represented by the symbol.
- 3. You may repeat this exercise as often as you want until you feel comfortable

# Phase One – Activity 3 Test Format 1

	Phase One – Exercise 3										
Quizlet		Search	n Quizlet	Q	🔫 Create a Set						
Phase On	e - Sy	mbol	Recogni	ion	Created by Langua	geofdata TEACHER 🔵					
Your Progress	Study	Scores	Teacher NEW!	Info							
	RT HERE Ishcards		E Learn		Speller	<b>→</b> &	Test				

### Before you begin

- 1. **TEST**: Quizlet provides multiple test configurations.
- 2. You will start with TEST FORMAT 1 Math / Symbols. Before you begin, select:
  - ✓ Written
  - ✓ Matching
  - ✓ Multiple Choice
  - ✓ True/False
  - ✓ Start with Photos

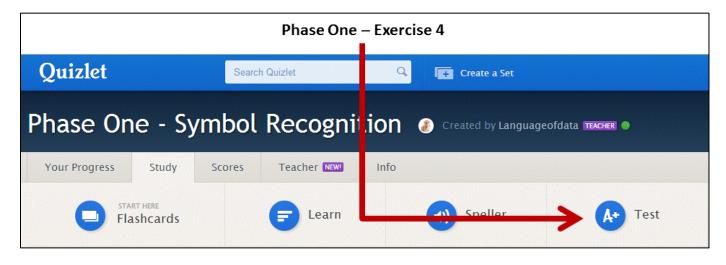
Question Types Written Matching Multiple Choice True/False

### Start With

- English
- Photos
- O Both

- 3. Select the CREGENERATE Test button
- 4. Answer all the questions
- 5. You will see your score after you complete the test
- 6. You may repeat the test as often as you want until you feel comfortable

# Phase One – Activity 4 Test Format 2



### Before you begin

- 1. TEST: Quizlet provides multiple test configurations.
- 2. Next you will complete **TEST FORMAT 2 English.** Before you begin, select:
  - ✓ Matching
  - ✓ Multiple Choice
  - ✓ True/False
  - ✓ Start with English

# Question Types

- Matching
- Multiple Choice
- . ✓ True/False

### Start With

- English
- Photos
- Both

- 3. Select the CREGENERATE Test button
- 4. You will see your score after you complete the test
- 5. You may repeat the test as often as you want until you feel comfortable



Phase One – Exercise 5									
Quizlet	Search Quizlet	۹ 🖬	Create a Set						
Phase One - Sy	/mbol Recogni	tion 🧔 🛛	ated by Languageofdata 🚥 📾						
Your Progress Study	Scores Teacher NEW	Info	Add to Folder						
Flashcards	<sub>,</sub> Learn		spatier Scatter						

- 1. In order to access appropriate format, RETURN TO PHASE ONE HOME PAGE BEFORE SELECTING SCATTER.
- 2. Scatter: Match the symbols and terms by clicking and dragging. Work as quickly as possible to beat record time.

### CONGRATULATIONS !!!

# You have completed Phase One !!!

You may repeat any portion of Phase I as often as you wish.

Please proceed to Phase Two when you are ready

# **Phase Two – Symbol Vocabulary**

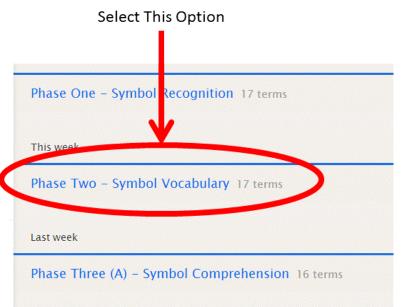
Phase Two will help you learn to recognize the vocabulary that is used when referring to the language of data. There are **FOUR exercises in Phase Two** and each one can be completed in under 5 minutes. Please complete each module at your own pace. You are welcome to repeat modules as often as you wish.

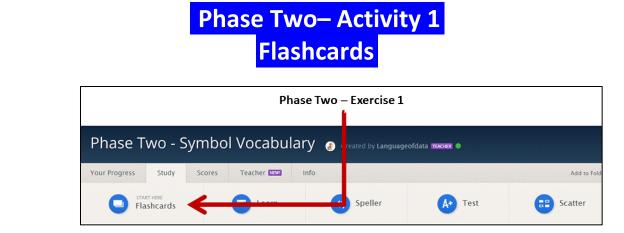
#### Instructions:

- 1. Log in to www.Quizlet.com
  - a. On your Quizlet homepage under "Your Classes" click on "Language of Data Site #1" (Since multiple sites are involved in this study, specific site numbers will vary).
- 2. Just as you did in Phase 1, you will see four SETS

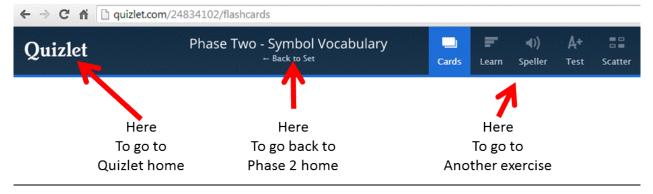


3. Click on Phase Two – Symbol Vocabulary

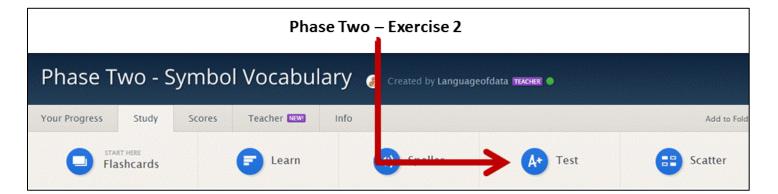




- 1. **Flashcards:** Use navigation bar on the right side of the screen customize your review of symbols and terms. You can view by photo first, English term first, or both sides at once, and with or without audio support.
- 2. Repeat this exercise as often as you want until you feel comfortable. Move to a different exercise by clicking







- 1. From the right hand side of the page, select "Question types
  - ✓ Matching
  - ✓ Multiple Choice
  - ✓ True/False
  - ✓ Start with Photos

#### Question Types

- Written
- Matching
- Multiple Choice
- True/False

#### Start With

- English
- Photos
- Both

- 2. Select the **Regenerate Test** button
- 3. You will see your score after you complete the test
- 4. You may repeat the test as often as you want until you feel comfortable

# Phase Two – Activity 3 Test Format 2

Phase Two – Exercise 3								
Phase Two - Symbol Vocabulary 🧃					Created by Languageofdata TEACHER			
Your Progress	Study	Scores	Teacher NEW	Info	Add to Fold			
	T HERE shcards		E Learn		Scatter			

### Before you begin

- 1. From the right hand side of the page, select "Question types"
  - ✓ Matching
  - ✓ Multiple Choice
  - ✓ True/False
  - ✓ Start with English

### Question Types

- Written
- Matching
- Multiple Choice
- True/False

### Start With

- English
- Photos
- Both

- 2. Select the **C** Regenerate Test button
- 3. You will see your score after you complete the test
- 4. You may repeat the test as often as you want until you feel comfortable





- 1. In order to access appropriate format, RETURN TO PHASE TWO HOME PAGE BEFORE SELECTING SCATTER.
- 2. Scatter: Match the symbols and terms by clicking and dragging. Work as quickly as possible to beat record time.

### CONGRATULATIONS !!!

## You have completed Phase Two !!!

Please proceed to Phase III-A when you are ready

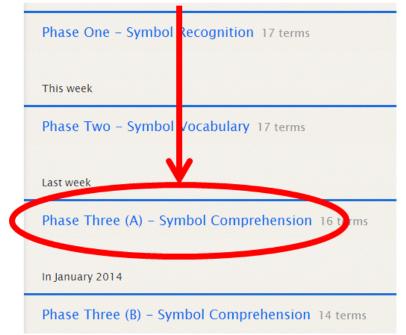
# **Phase Three (A) – Symbol Comprehension**

An important part of symbol/word comprehension is making sure a learner understands how to use that symbol/word and how that symbol/word functions in the language of data

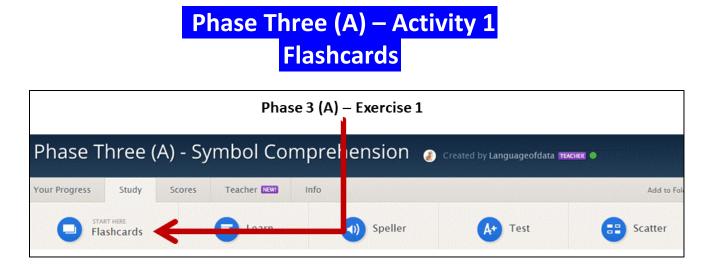
Phase 3(A) will increase your familiarity with the functions of commonly used symbols for the language of data. There are **FOUR exercises in Phase 3 (A)** and each one is designed to be completed in under 5 minutes. Please complete each module at your own pace. You are welcome to repeat modules as often as you wish.

Instructions:

- 1. Log in to <u>www.Quizlet.com</u>
  - On your Quizlet homepage under "Your Classes" click on "Language of Data Site #1" (Since multiple sites are involved study, specific site numbers will vary).
- 2. Just as you did in Phase I and Phase II, you will see four SETS



Select This Option



1. **Flashcards:** Each symbol/term in this study of the language of data describes either **a concept** or a **relationship between variables**. For instance, *n* describes a concept (i.e., a number of members) while a *standard deviation* describes the relationship between a set of data and its average value.



- 2. Select Start with Photos
- 3. Use the cards to review the function of each symbol/term. If you believe the symbol/term describes a relationship, try to identify the relationship in your head.
- 4. Repeat this exercise as often as you want until you feel comfortable.

# **Phase Three (A) – Symbol Comprehension**

An important part of symbol/word comprehension is making sure a learner understands how to use that symbol/word and how that symbol/word functions in the language of data

Phase 3(A) will increase your familiarity with the functions of commonly used symbols for the language of data. There are **FOUR exercises in Phase 3 (A)** and each one is designed to be completed in under 5 minutes. Please complete each module at your own pace. You are welcome to repeat modules as often as you wish.

Instructions:

- 1. Log in to <u>www.Quizlet.com</u>
  - On your Quizlet homepage, click on "Language of Data Site #1" (Since multiple sites are involved in this study, specific site numbers will vary).
- 2. Just as you did in Phase I and Phase II, you will see four SETS



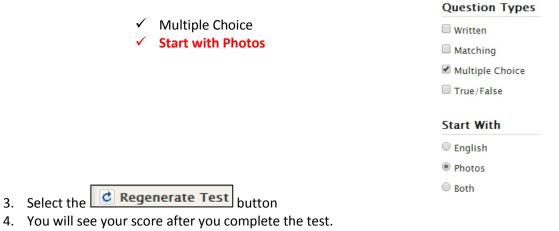
### Select This Option

# Phase Three (A) – Activity 3 Test Format 1

			Pha	se 3 (A)	– Exercise	3		
Phase T	hree (	(A) - Sy	mbol Co	mprel	ension	💰 Creat	ed by Languageofdata	ITEACHER .
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### Before you begin

- 1. **TEST**: Quizlet provides multiple test configurations.
- 2. You will start with TEST FORMAT 1 Math / Symbols. Before you begin, select:



5. You may repeat the test as often as you want until you feel comfortable



	Phase 3 (A) – Exercise 4										
Phase T	hree (	(A) - Sy	mbol Co	mprel	ension	Cre	ated by Languageofd	ata TEACHER			
Your Progress	Study	Scores	Teacher NEW	Info					Add to Fol		
	at HERE shcards		F Learn		Spaller		Tort	<b>→</b>	Scatter		

- 1. In order to access appropriate format, RETURN TO PHASE THREE (A) HOME PAGE BEFORE SELECTING SCATTER.
- 2. Scatter: Match the symbols and terms by clicking and dragging. Work as quickly as possible to beat record time.

### CONGRATULATIONS !!!

# You have completed Phase 3(A) !!!

Please proceed to Phase 3(B) when you are ready

# **Phase 3(B) – Symbol Comprehension**

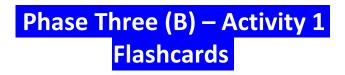
Phase 3(B) will increase you familiarity with the usage of commonly used symbols for the language of data. There are **FOUR exercises in Phase 3(B).** Each module is designed to be completed in under 10 minutes. Please complete each module at your own pace. You are welcome to repeat modules as often as you wish.

### Instructions:

- 1. Log in to <u>www.Quizlet.com</u>
  - On your Quizlet homepage, click on "Language of Data Site #1" (Since multiple sites are involved in this study, specific site numbers will vary).
- 2. Just as you did in Phase I and Phase II, you will see four SETS

i nuse on	ic symbol	Recognition 17 terms
This week		
Phase Tw	o – Symbol	ocabulary 17 terms
Last week		
Phase Th	ree (A) – Syı	bol Comprehension 16 terms
In January 2		
In January 2		

### Select This Option



Phase 3 (B) – Exercise 1									
Phase Three (B) - Symbol Compre tension 👩 Created by Languageofdata TRARER •									
Your Progress	Study	Scores	Teacher NEW	Info			Add to I		
E Fla	ashcards	←	<b>B</b> Learn		<ol> <li>Speller</li> </ol>	A* Test	Scatter		

- 1. **Flashcards:** Use navigation bar on the right side of the screen customize your review of symbols/terms and descriptions of use. You can view by symbol/term first, English description first, or both sides at once, and with or without audio support.
- 2. Repeat as desired. Repeat this exercise as often as you want until you feel comfortable.

# Phase Three (B) – Activity 2 Test Format 1

Phase 3 (B) – Exercise 2										
Phase T	hree (	(B) - Sy	mbol Co	mpre	nension	& Created by Languageofdata	1 TEACHER			
Your Progress	Study	Scores	Teacher NEW	Info			Add to I			
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### Before you begin

- 1. From the right hand side of the page, select "Question types"
  - ✓ Matching
  - ✓ Multiple Choice
  - ✓ True/False
    - ✓ Start with Photos

	Written
1	Matching

Question Types

- Multiple Choice
- True/False

Start With

- English
- Photos
- Both
- 2. Select the CREGENERATE Test button
- 3. You will see your score after you complete the test.
- 4. You may repeat the test as often as you want until you feel comfortable

# Phase Three (B) – Activity 3 Test Format 2

Phase 3 (B) – Exercise 3							
Phase T	hree (	(B) - Sy	mbol Co	mpre	nension	👔 Created by Languageofdata 🎞 🗮	
Your Progress	Study	Scores	Teacher NEW	Info			Add to I
	RT HERE Ashcards		E Learn				Scatter

### Before you begin

- 1. From the right hand side of the page, select "Question types"
  - ✓ Matching
  - ✓ Multiple Choice
  - ✓ True/False
  - ✓ Start with English

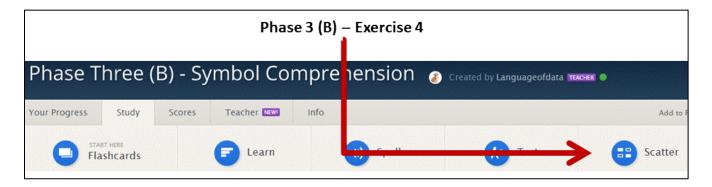
- Written
- Matching
- Multiple Choice
- ✓ True/False

#### Start With

- English
- Photos
- O Both

- 2. Select the CREGENERATE Test button
- 3. You will see your score after you complete the test.
- 4. You may repeat the test as often as you want until you feel comfortable





- 1. In order to access appropriate format, RETURN TO PHASE THREE (B) HOME PAGE BEFORE SELECTING SCATTER.
- 2. Scatter: Match the symbols and terms by clicking and dragging. Work as quickly as possible to beat record time.

### CONGRATULATIONS !!!

### You have completed Phase 3(B)!!!

# Congratulations You have now also completed all of the Quizlet Activities

### Phase 4 is a series of short case studies.

Please proceed to Phase 4 when you are ready

# **Phase 4 – Case Study Material**

### **Overview**

The case study learning program will cover five examples that use different aspects of the Language of Data.

### **Case Studies**

- Case 1 Understanding Group Comparison
  - This highlights the issues of evaluating the outcome from a randomized clinical trial.
    - When is the number of events not the same as the rate of events
      - Choosing the right statistical test
- Case 2 What is a P-Value
  - This helps to develop an intuitive understanding of p-value as a measure of statistical significance.
- Case 3 Correlation is not Cause
  - This will highlight the important concept that just because two variables are statistically related it does not mean the one variable caused another variable.
- Case 4 Why are assumptions important?
  - This will help explain how understanding the symbols will help you understand the assumptions that the authors have made.
- Case 5 The Kaplan-Meier analysis
  - This will introduce the learner to the basic concept of survival (or the time to an event, such as death) using the statistical tool called "Kaplan-Meier curves."



### Understanding Group Comparison

### **1. Case Presentation:**

Several nurses have engaged in a debate about infection control and dressing change protocol. A physician has suggested that they should stop using their current protocol and switch to a revised protocol. Moreover, he handed them an article from a prestigious journal which describes the results of a study using the new dressing change protocol. Knowing that the nurses do not have a lot of free time, he highlighted the following sentence in the results section of the study.

"There were 23 complications in 255 patients randomized to the revised protocol (intervention group). There were 41 complications in 255 patients randomized to current practice (control group). The mean rate of complications in the intervention group was significantly lower than the mean rate of complications in the control group (9.0% vs 16.1% respectively; p<0.05). "

Discussion 1a: Based only on the information provided above, what can you conclude? Answer:

> Discussion 1b: What is the "n" for each group? Answer:

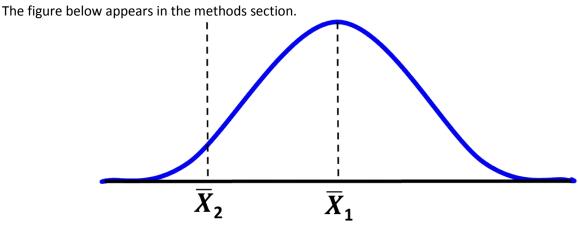
### Discussion 1c:

Which value above describes the probability that an observed effect occurred only by chance? Answer:

### 2 Digging deeper (methods):

Recall from the previous page:

"There were 23 complications in 255 patients randomized to the revised protocol (intervention group). There were 41 complications in 255 patients randomized to current practice (control group). The mean rate of complications in the intervention group was significantly lower than the mean rate of complications in the control group (9.0% vs 16.1% respectively; p<0.05). "



The figure above depicts how the hypothesis could be described visually. This tests the hypothesis that the intervention group  $(\bar{X}_2)$  mean is less than the control group  $(\bar{X}_1)$  mean. H<sub>0</sub>:  $\bar{X}_2 = \bar{X}_1$ H<sub>A</sub>:  $\bar{X}_2 < \bar{X}_1$ 

Discussion 2a: In the figure above, what do the symbols  $H_0$  and  $H_A$  represent?

Discussion 2b: In the figure above, what do the symbols  $\overline{X}_2$  and  $\overline{X}_1$  represent? Answer:

Discussion 2c: What numerical value is assigned to  $\overline{X}_2$  and  $\overline{X}_1$  ? Answer:

### **Digging deeper** (Results):

One of the nurses finds the following data in Table 2. She asks why the maximum is so high for the control group. This leads the nurses to examine the methods section of the paper which states "the number of complications for each subject was summed..."

	Current protocol	Revised protocol
	Control Group	Intervention Group
Mean	0.1607	0.0902
Standard deviation	0.6161	0.2870
Patients experiencing complications	18	23
Complications per patient (range)	2 - 5	1
Total number of complications	41	23

### **Table 2.** Control and Intervention Group Results

### **Discussion 3a:**

Knowing that the **total number of complications** is not the same as the **number of patients experiencing a complication**, Does this change your interpretation of the intervention? If so, How? Answer:

Discussion 3b: Which group had the highest overall number of complications? Answer:

### **Discussion 3c:**

Which group had the highest number of patients experiencing at least one complication? Answer:

### **Coming to consensus**

Later in the manuscript, the nurses see the following table with results listed below the table.

	Intervention	Control	Total				
Complication	23	18	41				
NO complication	232	237	469				
	255	255	510				
(X <sup>2</sup> = 1.31; 95%Cl = 0.686-2.483)							

**Table 3.** Complications by Subject

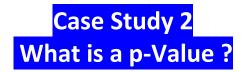
### Discussion 4a: What does the symbol X<sup>2</sup> represent? Answer:

Discussion 4b: What does the symbol **95%CI** represent? Answer:

### One of the nurses summarizes the manuscript by making two statements

- 1. We don't know if the new dressing change protocol really made a difference.
- 2. There were more patients who had complications in the intervention group and although the odds ratio implies that patients who get the new dressing change protocol are 31% more likely to have a complication... we really don't know that this is true because the 95% confidence interval ranges from about 0.7 to 2.5. So it could be that the odds ratio is 1.0 (because 1.0 is between 0.7 and 2.5) which is the same as saying "1 times as likely... or equally likely."

Discussion 4c: Is the nurse correct? Answer:



### **Case Presentation:**

For this case study, first read the article on interpreting P-values.

Olson, D. M., & Kolls, B. J. (2011). Understanding P values. Nursing, 6(6), 8-11. doi: 10.1097/01.CCN.0000407124.76718.93

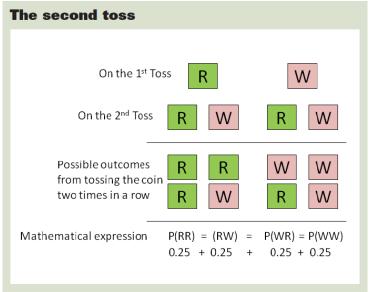
Discussion 1a: In the callout box on the bottom left of page 1, the authors write "P(R) = P(W)" If you were to read this out loud, what words would be used to explain the notation? Answer:

**Discussion 1b.** The bottom of page 1 uses the notation P(R) = 0.5. What does this notation signify? Answer:

> Discussion 1c. In the callout box on the top right of page 2, the authors write "P(RR) = P(RW) = P(WR) = P(WW)" Translate this into a short sentence. (in other words: what does this mean?) Answer:

### **Digging deeper (methods):**

Note that at the bottom of page 9 the authors provide a figure to describe the second toss of the coin (see below).



### Discussion 2a:

The authors write that there are four equal probabilities. What are the four equal probabilities presented in this paper? Answer:

Discussion 2b: If you were speaking to someone, how would you read this set of probabilities? Answer:

### **Digging deeper**

Probability has a bit of logic and algebra.

### **Discussion 3a:**

How would you write the probability of being right twice in a row versus not being right ever? Answer:

### **Discussion 3b:**

We would expect that by chance and chance alone, exactly half (0.5) of the time we toss a coin twice in a row you would guess both right or both wrong. How is this expressed as a probability? Answer:

Discussion 3c. How would you write the probability of being right twice in a row versus not being right twice in a row? Answer: In the first full paragraph at the top of page 11, the authors write "We can say that p = 0.03125"

Discussion 4a: Where does the number 0.03125 come from? Answer:

### Discussion 4b:

The authors correctly identify that the decision point for statistical significance is most often set by tradition. What is the 'traditional' set threshold for statistical significance?

### <mark>Answer:</mark>

Discussion 4c: According to the traditional threshold Which of the following values are statistically significant? A. P = 0.1234B. P = 0.0123C. P = 0.0012D. P = 0.0001

Answer:

## Case Study 3 Correlation is not Cause

### **Case Presentation:**

A nurse on your unit is reading a recent article that describes the impact of mobility on delirium. The article presents data from a multi-center study in which the investigators examined the frequency of mobility among subjects hospitalized for over 3 days. The method section of the manuscript describes that a retrospective chart audit was performed of all patients who remained in the hospital for at least 3 days (72 hours). Data was abstracted (transferred from the medical record to the research record) to include: patient demographics, the first time a patient was ambulatory, the number of IVs infusing, the use of narcotic or sedative medications, and the incidence of delirium.

The study results include the following table:

	Delirium present	No evidence of Delirium	
	(N=278)	(N=1,546)	p-value
Mean Age (S.D.)	63.3 (11.22) years	63.8 (11.18) years	0.424
Sex			0.794
Female	54%	53.1%	
Male	46%	46.9%	
Mean Ambulation day	7.8	7.0	0.039
Mean number of IV's	1.9	1.8	0.214
Infusing	1.9	1.0	0.214
Narcotic use			0.992
Yes	231(83.1%)	1285 (83.1%)	
No	47 (16.9%)	261 (16.9%)	
Sedative use			0.053
Yes	22.3%	27.6%	
No	77.7%	72.4%	

### Table 1. Main results

The unit medical director instructs the nurse manager that he is going to start ordering that all his patients must be ambulatory by day 3 to prevent delirium. He cites the study above stating that the study found a statistically significant difference in early ambulation and delirium.

### Based only on the information provided above, what can you conclude regarding:

Discussion 1a: How many patients were involved? Answer:

### **Discussion 1b:** How many patients had Delirium?

### <mark>Answer:</mark>

Discussion 1c: How many patients did not have Delirium? Answer:

### Discussion 1d:

For which variables were patients in the Delirium Group SIMILAR to patients in the No-Delirium Group?

### <mark>Answer:</mark>

### Discussion 1d:

For which variables were patients in the Delirium Group **SIGNIFICANTLY DIFFERENT** to patients in the No-Delirium Group?

### Answer:

### **Digging deeper** (methods):

This a link to a short (6-min) youtube video on types of data. Watch this video before you continue. <u>http://www.youtube.com/watch?v=hZxnzfnt5v8</u>

The physician later sent an email to all of the nurses and he included a copy of the manuscript. The nurses are reading the manuscript when they come across the following paragraph in the methods section of the manuscript.

"Data was abstracted directly from the electronic medical record. Ambulatory day was defined as the date-of-ambulation minus admission-date. The mean number of IVs was defined as the number of IV solutions infusing each day divided by the number of hospital days. Narcotic use was defined as the number of patients who received at least one narcotic drug during their hospitalization. Sedative use was defined as the number of patients who received at least one sedative medication during their hospitalization."

### **Discussion 2a:**

Which of the following variables are typically 'Nominal' type of data?

- Age (in years)
- Sex (male or female)
- Delirium present (yes or no)
- Hospital days (number of days)
- Mean number of IVs (number of IVs)
- Narcotic Use (yes or no)
- Sedative Use (yes or no)

### Answer:

### Discussion 2b: How could the variable "sedative use" be converted into an interval type variable Answer:

### **Digging deeper** (Results):

The physician has highlighted some of the sentences in the results section. The first sentence is below:

### Sentence 1.

"The number of IVs in the delirium group versus non-delirium group were summarized and reported as quality improvement data to hospital administration ( $\bar{X}_1 = 1.9$ , S.D. = 1.0;  $\bar{X}_2 = 1.8$ , S.D. = 0.81; p=0.21)."

> The physician Interpretation is that the mean number of IV's is actually higher in the delirium group because the standard deviation is 1.0 which is a perfect correlation.

### **Discussion 3a:**

Which of the following terms describes the spread of the data "mean" or "standard deviation" ? Answer:

For Discussion 3b assume the following two sets of data (each with 8 observations)

Set	Obs1	Obs2	Obs 3	Obs4	Obs5	Obs6	Obs7	Obs8	Mean
Control	10	8	9	10	8	9	10	8	9
Intervention	2	4	6	8	10	12	14	16	9

**Discussion 3b:** 

Based on the table above, which group would be expected to have a higher standard deviation (more spread out data)? Answer:

> **Discussion 3c:** What is the mean number of IVs in the delirium group? Answer:

Discussion 3d: What is the mean number of IVs in the non-delirium group? Answer:

Discussion 3e: Which group (delirium or non-delirium) had a larger standard deviation? Answer:

### **Digging deeper** (Results):

The physician has highlighted some of the sentences in the results section. The second sentence is:

### Sentence 2.

"Analysis from Table 4 indicate that 595 (38.5%) of the patients without delirium were ambulatory by the end of day 3 compared to 69 (24.8%) patients. There was a significantly higher odds of being ambulatory on day 3 and delirium free ( $X^2 = 1.55$ ; 95%CI=1.25-1.92)."

		Patient was Ambulatory by day 4					
		Yes No total					
	Yes	595	951	1546			
Did not have	No	69	209	278			
Delirium —	total	485	1339	1824			

Table 4	Ambulaton	/ Status and	Dolirium
Table 4.	AMDUIALON	/ Status and	Dennum.

The physician interpretation is that the Chi-Square indicates that there is a 55% increase in the odds of a patient who does not get out of bed by the end of day three developing delirium.

### Discussion 4a:

What information does a Chi-Square test provide?

### <mark>Answer:</mark>

### Discussion 4b:

What is the Chi-Square value that the physician refers to in his interpretation?

### Answer:

Discussion 4c: Describe the confidence interval for the Chi-Square value. Answer:

### **Coming to consensus**

One of the nurses summarizes the manuscript by making the following statement:

"Early ambulation is associated with a lower odds of experiencing delirium. But, from these data, we don't really know the direction of this relationship."

### **Discussion 5a:** In the first statement, what does the nurse mean by "the direction"?

### Answer:

Discussion 5b: Is the nurse correct in her interpretation? Answer: Another nurse makes the following statement based on the results from Table 1.

"It looks to me like patients who got more sedation had less delirium. I think that shows that we need to be more vigilant with sedating patients when they need it."

Table 1	. Main	results
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	Delirium present	No evidence of Delirium	
	(N=278)	(N=1,546)	p-value
Mean Age (S.D.)	63.3 (11.22) years	63.8 (11.18) years	0.424
Sex			0.794
Female	54%	53.1%	
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Mean Ambulation day	7.8	7.0	0.039
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Narcotic use			0.992
Yes	231(83.1%)	1285 (83.1%)	
No	47 (16.9%)	261 (16.9%)	
Sedative use			0.053
Yes	22.3%	27.6%	
No	77.7%	72.4%	

### **Discussion 5c:** What is the p value associated with this relationship? Answer:

Discussion 5d:

Is the second nurse correct in stating that patients with no evidence of delirium got more sedation? Answer:

Discussion 5e:

Is the second nurse correct in her interpretation that more sedation is associated with less delirium? Answer:

## **Case Study 4**

## Why are assumptions so important?

In the language of data, assumptions refer to *statistical assumptions*, which are the rules that underlie statistical tests and enable the mathematical equations to calculate a solution or answer accurately. *Assumptions* refer specifically to the data, the variables of interest and the scores or values available for each variable. Assumptions describe the things about the data that must be true in order for the statistical test to work correctly. You can think of assumptions as pre-requisites for using each statistical test. There are usually 3-4 assumptions for each statistical test, and they must all be "true" for the results of the test to be valid.

### **Case Presentation:**

For this case study, read the following abstract and think about the assumptions or prerequisites of the selected statistical tests. What would you assume to be true about the sample of participants?

**Background:** The purpose of this study was to investigate the effects of aromatherapy on the anxiety, sleep, and blood pressure (BP) of percutaneous coronary intervention (PCI) patients in an intensive care unit (ICU).

**Methods:** Fifty-six patients with PCI in ICU were evenly allocated to either the aromatherapy or conventional nursing care. Aromatherapy essential oils were blended with lavender, roman chamomile, and neroli in a 6:2:0.5 ratio. Participants received 10 inhalation treatments before PCI, and the same essential oils were inhaled another 10 times after PCI.

### **Results:**

- The aromatherapy group showed significantly lower anxiety (t = 5.99, p < .001) and improved sleep quality (t = -3.65, P = .001) compared with conventional nursing intervention.
- The systolic BP of both groups did not show a significant difference by time or in a group-by- time interaction; however, a significant difference was observed between groups (p = .036).
- The diastolic BP did not show any significant difference by time or by a group-by-time interaction; however, a significant difference was observed between groups (p=.011).

**Conclusion:** The aromatherapy effectively reduced the anxiety levels and increased the sleep quality of PCI patients admitted to the ICU. Aromatherapy may be used as an independent nursing intervention for reducing the anxiety levels and improving the sleep quality of PCI patients.

### Discussion 1a: What type of statistical test do the authors use to compare anxiety? Answer:

Discussion 1b: What is a t-test used for? Answer:

**Discussion 1c:** What are the two groups being compared in the t-test? Answer:

### **Digging deeper (methods):**

The symbol 't' is used to describe a t-test and implies that the scores or responses to each of the dependent variables are measured at the interval or ratio level, and are normally distributed. The background and methods sections below are copied from the abstract.

**Background:** The purpose of this study was to investigate the effects of aromatherapy on the anxiety, sleep, and blood pressure (BP) of percutaneous coronary intervention (PCI) patients in an intensive care unit (ICU).

**Methods:** Fifty-six patients with PCI in ICU were evenly allocated to either the aromatherapy or conventional nursing care. Aromatherapy essential oils were blended with lavender, roman chamomile, and neroli in a 6:2:0.5 ratio. Participants received 10 inhalation treatments before PCI, and the same essential oils were inhaled another 10 times after PCI.

### **Discussion 2a:**

By reading the background and methods section of the abstract, what are the dependent/outcome variables in this study?

### Answer:

Ratio level data are similar to interval level, but the value "zero" has meaning.

For example, variables like height and weight are ratio variables. The value of 0.0 for height is equal to "no height."

**Interval level** data includes: SCALES of data in which the values exist on a scale and the degree of difference between items is meaningful and equal across all items, but the ratio of the difference between them is not in relation to an absolute zero.

- For example, the difference between a temperature of 90 degrees and 100 degrees is the same as the difference between 40 degrees and 50 degrees. The "interval" of 10 degrees is the same.
- > Temperature is not ratio because the value ZERO does not mean 'there is no temperature.'

### Discussion 2b:

Which one of the three dependent variables is typically measured as interval level data?

### <mark>Answer:</mark>

### **Discussion 2c:**

We have established that blood pressure is ratio level data.

The two other dependent variables are anxiety and sleep. Are either of these two variables interval level data?

### <mark>Answer:</mark>

### **Digging deeper (results):**

In the results section below, the authors begin to use a variety of symbols associated with the language of data:

**Results:** Patients' state anxiety, sleeping quality, and BP. The aromatherapy group showed significantly lower anxiety (t = 5.99, P < .001) and improved sleep quality (t = -3.65, P = .001) compared with conventional nursing intervention.

- The systolic BP of both groups did not show a significant difference by time or in a group-by- time interaction; however, a significant difference was observed between groups (p = .036).
- The diastolic BP did not show any significant difference by time or by a group-by-time interaction; however, a significant difference was observed between groups (p=.011).

### **Discussion 3a:**

Which of the abbreviations or symbols used in the results section of the abstract represent a statistical concept? Which represent a relationship between variables?

### Answer:

Discussion 3b: Which of the probability values above indicate the results were not due to chance? Answer:

### **Coming to consensus**

The complete abstract is provide below

**Background:** The purpose of this study was to investigate the effects of aromatherapy on the anxiety, sleep, and blood pressure (BP) of percutaneous coronary intervention (PCI) patients in an intensive care unit (ICU).

**Methods:** Fifty-six patients with PCI in ICU were evenly allocated to either the aromatherapy or conventional nursing care. Aromatherapy essential oils were blended with lavender, roman chamomile, and neroli in a 6:2:0.5 ratio. Participants received 10 inhalation treatments before PCI, and the same essential oils were inhaled another 10 times after PCI.

### **Results:**

- The aromatherapy group showed significantly lower anxiety (t = 5.99, p < .001) and improved sleep quality (t = -3.65, p= .001) compared with conventional nursing intervention.
- The systolic BP of both groups did not show a significant difference by time or in a group-by- time interaction; however, a significant difference was observed between groups (p = .036).
- The diastolic BP did not show any significant difference by time or by a group-by-time interaction; however, a significant difference was observed between groups (p=.011).

**Conclusion:** The aromatherapy effectively reduced the anxiety levels and increased the sleep quality of PCI patients admitted to the ICU. Aromatherapy may be used as an independent nursing intervention for reducing the anxiety levels and improving the sleep quality of PCI patients.

### **Discussion 4a:**

The conclusion in the abstract states that anxiety was reduced and sleep quality was improved by the intervention. What was the average, mean, or median amount of anxiety and sleep in these subject?

### <mark>Answer:</mark>

### **Discussion 4b:**

If you were to read the full text of the article, what symbol would you look for to find the mean or the average value for anxiety or sleep quality?

### <mark>Answer:</mark>

### **Discussion 4c:**

For the variable "anxiety" the authors report the following statement in the full article: Anxiety prior to aromatherapy from ( $\overline{X}$  = 12.3, SD 4.77) compared to after aromatherapy ( $\overline{X}$  = 15.7, SD 7.81) was significantly lower (t = 5.99, P < .001). What do the symbols " $\overline{X}$ " and "SD" indicate?

### <mark>Answer:</mark>



### **Case Presentation:**

At your weekly clinic meeting, the Advance Practice Nurse presents a plan to initiate a new policy whereby the nurses working in a cardiology clinic would drive a protocol-based care delivery model for patients with atrial fibrillation. The APN cites a recent publication by Hendriks et al. (2012). One of the cardiologists at the meeting states "Not all patients with a-fib are the same... you can't protocolize everything... this won't work." The decision is made that every committee member should read the Hendriks paper and be prepared to discuss this topic next week. As you skim through the paper, you come across information in the Statistical Analysis section (bottom of page 2693), that informs you that the authors calculated Kaplan–Meier estimates and their 95% Cl.

Discussion 1a: What does the symbol 95%CI represent? Answer:

Discussion 1b: What is the definition of a confidence interval? Answer:

### **Digging deeper:**

The Kaplan-Meier estimate is most commonly used to inform the reader about survival. You should expect to find a graph with two lines that start at the same point along a Y-axis (vertical axis) and continue across a horizontal plane. The units of measure for the x-axis (horizontal axis) should be increments of time (e.g., days, months, years). The graph below (fictional data) is an example of a typical Kaplan-Meier estimate. That describes 2-year outcomes for stroke patients discharged from your hospital.

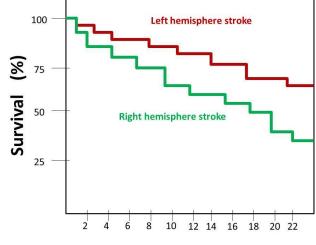


Figure A. Post-discharge survival for left vs. right hemisphere stroke

### Months post discharge

Discussion 2a: What information does the graph above describe? Answer:

Discussion 2a: Does this graph provide an n for stroke patients? Answer:

### **Digging deeper:**

Table 1 (page 2695) is titled "Characteristics of the patients according to treatment group." A portion of this table is pasted below.

Characteristic	Nurse-led care (n = 356)	Usual care (n = 356)
Age, year Male sex, <i>n</i> (%)	66 ± 13 197 (55.3)	67 ± 12 221 (62.1)
Type of AF, n (%) Paroxysmal	190 (53.4)	203 (57.0)
Persistent Permanent	68 (19.1) 75 (21.1)	44 (12.4) 84 (23.6)
Symptomatic	294 (82.6)	296 (83.1)

### **Discussion 3a:**

There are several times where the symbol 'n' is used in this table. What does the symbol 'n' represent?

### <mark>Answer:</mark>

### **Discussion 3b:** The third row in the table provides information about persistent as a type of AF. What does 68 (19.1) represent? Answer:

### **Discussion 3c:**

Which of the following three statements is correct:

- A. 19.1 % of patients with persistent AF were in the Nurse-led care group.
- B. 19.1 % of patients in the Nurse-led care group had persistent AF.
- C. Persistent AF accounts for 19.1% of the 68 patients in the Nurse-led care group.

### <mark>Answer:</mark>

Discussion 3.d: How many women were assigned to receive "Nurse-Led Care"? Answer:

### **Coming to consensus**

The Kaplan-Meier estimates from page 2697 of the Hendriks (2012) article are displayed below.

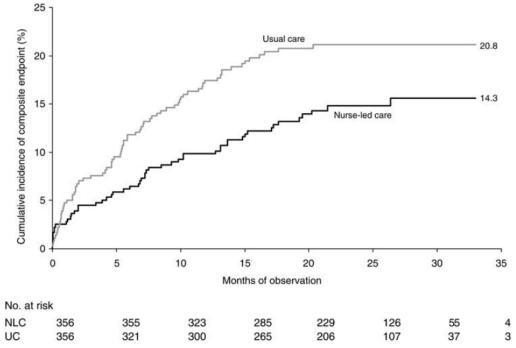
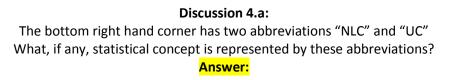


Figure 3 Kaplan–Meier estimates of the cumulative incidence of the primary outcome in both groups. The primary outcome is a composite of the first occurrence of cardiovascular hospitalization or cardiovascular death. NLC, nurse-led care; UC, usual care.



Discussion 4.b. Between 25 and 26 months, how many patients were at risk in the Nurse-Led Care Group Answer:

## You have now completed Phase IV.

## **Follow-up Assessment**

You have completed the entire workbook and you are now ready to proceed to the Follow-up Assessment.

The follow-up is similar to the baseline assessment.

### Please read all of the instructions before you begin the follow-up assessment

### Instructions:

Before you complete the Follow-up Assessment, please print out and read the Johnson et al article entitled: "Differences in level of care at the end of life according to race." SELECT THE LINK BELOW to go to this document (page 68)

Johnson. R. W., Newby, L. K., Granger, C. B., Cook, W. A., Peterson, E. D., Echols, M., ... Granger, B. B. (2010) Differences in level of care at the end of life according to race. *Am JOit Care*, *19(4)*, 335-343; quiz 344. doi: 10.4037/ajcc2010161

You will need a copy of the Johnson et al article with you when you complete the Follow-up assessment.

Take the Follow-up Assessment only once.

The Quiz is timelimited and will turn off after 20 minutes.

After you have read the article, please locate your unique username on page 5 of this workbook. You will need to enter your username to access the assessment.

When you are ready to complete the Follow-up Assessment, click the link below.

## FOLLOW UP ASSESSMENT

http://www.proprofs.com/quiz-school/story.php?title=NzAyNTAxIQHC



Be sure you have completed the Follow-up Assessment before you continue to the next page!

## **Congratulations!**

## You have completed the entire Language of Data Course.

You will receive an email from Jennifer Rogers that includes a link to a usability survey. This survey is important because it will provide us with information about how to improve this course.

Contact the Study team

If you would like to contact the study team to provide additional insight to improve the LOD workbook

Please contact Jennifer Rogers at jennifer@engagebydesign.com



Evidence-based interdisciplinary knowledge for high acuity and critical care

## CNE Article: Moral Distress and Psychological Empowerment in Critical Care Nurses Caring for Adults at end of Life

Annette M. Browning

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(2013)

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AMERICAN ASSOCIATION ∮CRITICAL-CARE NURSES



# Moral Distress and Psychological Empowerment in Critical Care Nurses Caring for Adults at End of Life

By Annette M. Browning, RN, PhD, CNS



### Notice to CNE enrollees:

A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

- 1. Identify common causes of moral distress in critical care nurses who are caring for dying patients.
- 2. Describe the concept of psychological empowerment and the 4 cognitions it encompasses.
- 3. Discuss the study findings as related to the relationship between moral distress intensity and frequency, psychological empowerment, and participant demographics.

To read this article and take the CNE test online, visit www.ajcconline.org and click "CNE Articles in This Issue." No CNE test fee for AACN members.

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Background Critical care nurses providing care for adults at the end of life may encounter moral distress when they cannot do what they believe is ethically correct. Psychological empowerment can decrease moral distress among critical care nurses. **Objectives** To describe the relationships between moral distress, psychological empowerment, and demographics in critical care nurses caring for patients at the end of life. Method A total of 277 critical care nurses were surveyed via the Moral Distress Scale and the Psychological Empowerment Instrument. Responses were scored on a Likert scale of 1 to 7. Results Moral distress intensity was high (mean 5.34, SD 1.32) and positively correlated with age (r=0.179, P=.01). Moral distress frequency was moderate (mean 2.51, SD 0.87) and negatively correlated with nurses' collaboration in end-of-life patient care conferences (r=-0.191, P=.007). Psychological empowerment scores (mean 5.31, SD 1.00) were high and positively correlated with age (r=0.139, P=.03), years of experience (r=0.165, P=.01), collaboration in end-of-life-care conferences (r=0.163, P=.01), and end-of-life-care education (r=0.221, P=.001) and were negatively correlated with moral distress frequency (r=-0.194, P=.01). Multiple regression analysis revealed that empowerment was a significant predictor of moral distress frequency ( $\beta$  = .222, *P* < .01). Conclusion The significant negative correlation between psy-

chological empowerment and frequency of moral distress in these nurses indicated that nurses with higher perceived empowerment experience moral distress less often. This finding is of particular interest as interventions to decrease moral distress are sought. (*American Journal of Critical Care.* 2013;22:143-152) ne-fifth of the patients cared for by critical care nurses die in the intensive care unit.<sup>1</sup> The American Association of Colleges of Nursing<sup>2</sup> has expressed growing concern about an increase in the use of inappropriate life-support treatments related to end-of-life care. In the past decade, awareness of potential inadequacies in caring for the dying has been increasing, and many of these inadequacies are related to the use of life support in critical care settings.<sup>3</sup> In cases of futility, aggressive medical treatment at the end of life is well documented as a cause of moral distress in critical care nurses.<sup>4</sup> Moral distress occurs when nurses are unable to perform according to what they believe to be ethically correct. Increasing psychological empowerment in nurses is a means of strengthening the impact that nurses have to innovatively influence decision making related to patient care.<sup>5</sup> Increasing psychological empowerment may be a means of ameliorating moral distress in critical care nurses caring for dying adults.

### **Background**.

The advent of life-support technology during the past half century has drastically changed the focus of caring for dying patients. Critical care units were developed in order to monitor critically ill patients appropriately, and critical care nurses were provided specialized education for the purpose of providing optimal care for critically ill patients. Although advanced technology has brought with it the promise of more efficient treatment techniques, extending life inappropriately and futile prolonging of patients' suffering have become commonplace for critical

Moral distress occurs when nurses are unable to do what they believe to be ethically correct. care nurses caring for dying patients,<sup>6</sup> thus causing moral distress in critical care nurses.

Jameton<sup>7</sup> was the first to define moral distress in the nursing literature. Moral distress was defined as discomfort or internal conflict related to ethical dilemmas encountered in nursing practice when constraints prevented the nurse from following the course

of action believed to be right. Obstacles contributing to the inability to act upon what the nurse believes to be right have many origins. Beckstrand and Kirchhoff<sup>1</sup> identified several obstacles that 864 critical care nurses perceived while providing end-of-life care, including the perception that their opinions related to end-of-life care decisions were not being recognized and valued. The highest ranking obstacles

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in this study were as follows: Families not understanding the term "life-saving measures" and its implications, families requesting life-saving measures contrary to patients' wishes, and patients' treatments continuing although painful or uncomfortable.

In 2006, the American Association of Critical-Care Nurses (AACN) identified end-of-life care challenges as a significant source of moral distress in critical care nurses. AACN has issued a position statement on moral distress, proclaiming it a serious problem in nursing.<sup>8</sup>

Psychological empowerment is a mechanism by which people gain mastery of their affairs.<sup>9</sup> In the nursing literature, empowerment has been examined on the basis of 2 conceptualizations, structural and psychological. Psychological empowerment (one's belief in one's ability to be empowered) was measured in this study.

As critical care nurses develop a more active voice in collaboration with physicians, ethics committees, and members of the multidisciplinary health care team, the facilitation of empowerment among nurses might decrease moral distress and enhance patient care outcomes at the end of life. No studies have been reported to date that specifically examine the relationship between moral distress and empowerment in nursing thus, in this study, we sought to determine if such a relationship exists.

## Moral Distress Related to End-of-Life Care

Several studies have associated levels of moral distress in nurses with the delivery of end-of-life care to patients.<sup>10-12</sup> In most of the studies reviewed, the most common phenomenon related to end-of-life care that is causing moral distress in critical care nurses is the delivery of futile care. The delivery of futile care at the end-of-life was first examined by Wilkinson,<sup>13</sup> who

built on the work of Jameton.<sup>7</sup> Multiple studies<sup>4,10,13-18</sup> have shown that futile care, where nurses perceived that the patient would not benefit from care, caused the most significant levels of moral distress in nurses.

### Theories of Psychological Empowerment

Bandura<sup>19</sup> theorized that degrees of empowerment are perceived as one's sense of self-efficacy is facilitated. Self-efficacy occurs when one's sense of self-determination is strengthened or one's sense of powerlessness is weakened. Furthermore, the strength of one's perceived empowerment determines how obstacles are viewed and the degree to which one overcomes the obstacles.<sup>20</sup>

Conger and Kanungo<sup>21</sup> took self-efficacy a step further by reiterating that true empowerment occurs when convictions of one's own effectiveness are successfully executed and not merely hoped for. Thomas and Velthouse<sup>9</sup> further postulated empowerment as multifaceted, encompassing 4 cognitions: (1) meaning, the value one attaches to one's standards, (2) competence, the belief that one is able to carry out one's beliefs in action, (3) self-determination, the sense that one has control over one's autonomy, and (4) impact, the degree to which one perceives one's work as having influence.

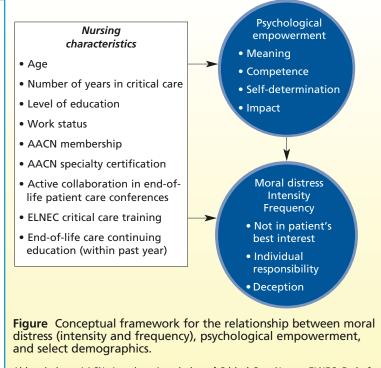
### **Conceptual Framework**

Although critical care nurses may perceive themselves as having some degree of empowerment with respect to decision making related to end-of-life care, they see themselves as often unable to contribute significantly to decisions they believe to be correct. This "gap" between nurses having empirical knowledge and not being able to apply that knowledge effectively was the impetus for this study intended to explore the association between moral distress intensity, moral distress frequency, psychological empowerment, and select demographics of critical care nurses (see Figure).

### Methods \_

### Sample

A cross-sectional descriptive survey design was used to study a target population of critical care nurses caring for adults at the end of life. A sample of 277 critical care nurses who were on AACN's e-mail newsletter list were recruited for this study. Inclusion criteria were as follows: (1) must be a critical care staff nurse and (2) must have had experience with caring for dying adults in the critical care setting before completing the survey tools. A brief paragraph describing the study was placed in the AACN newsletter for



Abbreviations: AACN, American Association of Critical-Care Nurses; ELNEC, End-of-Life Nursing Education Consortium.

4 consecutive weeks. If subscribers were interested in participating, they used a link that led them to the online survey, which started with a cover letter explaining the details of the study further.

### **Data Collection (Instruments and Procedure)**

Two valid and reliable survey instruments were used in this study, the 32-item Moral Distress Scale (MDS)<sup>10</sup> and the 16-item Psychological Empowerment Instrument (PEI)<sup>22</sup> in addition to the demographic data survey (see Figure). The MDS-32 has been tested for content validity twice.<sup>23</sup> All items were considered relevant in both testings. Test-retest reliability of the MDS-32 was 0.86 (P = .01).<sup>23</sup> The high reliability may reflect redundancy of some items. The Cronbach alpha was 0.93 (P < .01), demonstrating high reliability. The MDS was later expanded to 38 items. These additional items were unrelated to endof-life care, so the original 32-item MDS was used.

The MDS measures moral distress intensity, the level at which the nurse experiences painful feelings related to a given situation (none to great extent), and moral distress frequency, how often the nurse experiences the painful feeling associated with the distressful situation (never to very frequently) on a Likert scale from 1 to 7. The MDS uses 3 factors or subscales to measure moral distress: (1) individual responsibility (refers to the nurse participating in care not agreed with or ignoring actions one should take—20 items), (2) not in patient's best interest (refers to participating in care that the nurse considers inappropriate because of futility for the patient— 7 items), and (3) deception (refers to the nurse not addressing issues honestly, related to impending death of a patient—3 items). Data from 2 items (12 and 13) on the MDS-32 pertain to children. These 2 items were omitted from the tables presented here because of the study's focus on the care of adults; however, all 32 items were administered in the survey given to participants.

The PEI is highly reliable and valid,<sup>22,24</sup> with reported reliability coefficients ranging from 0.62 to 0.74. The PEI used 4 domains or subscales, previously defined, to measure psychological empowerment: (1) meaning, (2) competence, (3) self-determination, and (4) impact. Each domain addressed 4 items (see Figure) measuring empowerment. Items were scored as follows: 7 = very strongly agree, 6 = strongly

Most participants reported having had end-of-life care education within the past year. agree, 5 = agree, 4 = neutral, 3 = disagree, 2 = strongly disagree, 1 = very strongly disagree.

Quantitative data were collected from October 28, 2010 to November 25, 2010. From the approximately 80 000 e-mailed newsletters, 277 recipients returned the survey. The return rate was approximately 0.35%.

Participants were excluded from analyses when they left 25% or more responses blank on any given measure. For example, if a participant left 4 out of 10 responses blank on the MDS, they were left out of analyses comparing moral distress scores with other scale scores. They were included, however, in the descriptive statistics for other measures that were sufficiently completed (<25% missing).

Approval by the institutional review board of the University of San Diego for the protection of human subjects was obtained for this study. The institutional review board determined that written informed consent was not required. A cover letter approved by the institutional review board was posted on the AACN Web site, informing readers about the following information: that participation in the study was voluntary and study data were kept confidential, risks and benefits of participation, and how to contact the investigator for questions. The participants were assured of their anonymity both in data collection and the publication of data. All data were stored on a password-protected computer. No identifying information, including e-mail addresses, was included in the Excel spreadsheet uploaded from SurveyMonkey.

### **Statistical Analysis and Variables**

Percentages were used to describe the categorical variables. Appropriate correlational statistics, based

on variable level of data (continuous or categorical), were used to examine relationships among variables. Moral distress intensity and moral distress frequency were 2 separate dependent or outcome variables measured by the MDS. Multiple linear regression analysis was used to examine associations between the dependent variable of moral distress intensity and the independent or predictor variables (psychological empowerment and demographics) and the dependent variable of moral distress frequency and the independent or predictor variables (psychological empowerment and demographics) and the dependent variable of moral distress frequency and the independent or predictor variables (psychological empowerment and demographics).

### Results

The following demographics were found within the sample: The participants had a mean age of 46.9 years (SD 10.4). The mean number of years of experience working as a critical care nurse was reported as 17.45 (SD 11). Most participants (n = 234, 84.5%) were working full-time in critical care. The percentage of participants employed part-time was 11.6% (n = 32). Only 1 participant was working per diem. More than half of the nurses (54.6%) reported being active participants in end-of-life patient care conferences. Most of the responding nurses had a bachelor of science degree in nursing (47.1%); 29.2% of the participants had an associate degree in nursing; 19.7% of the nurses had a master of science degree in nursing, and 3.3% of the participating nurses were doctorally prepared. Most of the participants (55.2%) had specialty certification by the AACN, and most participants (54.6%) also reported having had end-of-life care education within the past year. A large majority of participating nurses (86%) reported being members of the AACN. Only 5.8% of the participants (n = 16) reported participation in the critical care training provided by the End-of-Life Nursing Education Consortium (ELNEC).

## Moral Distress Intensity and Moral Distress Frequency

Moral distress intensity and moral distress frequency scores ranging from 0 to 2.33 were considered low, 2.34 to 4.66 moderate, and 4.67 to 7.00 high. Scores for moral distress scale subscales and total scores were calculated separately for both intensity and frequency (Table 1).

Mean scores for items on the moral distress intensity scale ranged from 4.39 to 6.05, with a overall mean total score of 5.34 (SD 1.32). The 3 highest-scoring items for moral distress intensity were "assisting [physician] who in my opinion is providing incompetent care" (mean 6.05), "work in a situation when the number of staff is too low and care is inadequate" (mean, 5.97), and "continue

### Table 1

## Moral distress intensity and frequency of respondents (N=277) according to subscales: not in patient's best interest, individual responsibility, and deception

		Mean	(SD)
Subscale	Item	Intensity	Frequency
Not in patient's best interest	1. Follow family's wishes for patient care I don't agree with	4.81 (1.52)	4.08 (1.66)
	2. Follow family's wishes to continue life support when not in patient's best interest	5.47 (1.46)	4.45 (1.65)
	3. Follow physician's orders for unnecessary tests	5.22 (1.53)	4.28 (1.80)
	5. Initiate life-saving actions when I think it prolongs death	5.72 (1.46)	3.73 (1.71)
	15. Carry out physician's orders for unnecessary tests and treatments on terminally ill patients	4.39 (2.18)	3.71 (1.77)
	22. Prepare a terminally ill elderly patient receiving mechanical ventilation for surgery to have a mass removed	5.09 (1.91)	2.42 (1.41)
	23. Prepare an elderly severely demented patient who is a no code for placement of a gastrostomy tube	5.24 (1.87)	3.17 (1.67)
	Not in patient's best interest subscale score	5.13 (1.25)	3.69 (1.22)
Individual responsibility	4. Assist physician who performs test or treatment without patient's consent	5.27 (2.08)	2.01 (1.44)
	6. Ignore situations of suspected abuse of patient by caregivers	5.51 (2.16)	1.60 (1.17)
	7. Ignore situations of inadequate consent from patient	5.42 (1.76)	2.22 (1.52)
	8. Perform procedure when the patient is not adequately informed	5.36 (1.71)	2.21 (1.46)
	9. Carry out work assignment in which I do not feel professionally competent	5.27 (1.95)	1.91 (1.12)
	10. Avoid taking action when a nurse colleague has made a medication error	4.89 (1.84)	2.05 (1.20)
	11. Let medical students perform painful procedures on patients solely to increase their skill	5.40 (2.09)	2.00 (1.52)
	14. Assist physicians practicing procedures on a patient after cardiopulmonary resuscitation has been unsuccessful	5.09 (2.35)	1.45 (1.15)
	16. Work with "unsafe" levels of nurse staffing	5.82 (1.56)	3.57 (1.88)
	17. Carry out order to discontinue treatment because patient can no longer pay	5.36 (2.39)	1.43 (1.26)
	<ol> <li>Continue to care for a hopelessly injured patient receiving mechanical ventilation when no one will discontinue the ventilation</li> </ol>	5.88 (1.50)	3.61 (1.81)
	19. Observe without intervening when personnel do not respect patient's dignity	5.67 (1.68)	2.21 (1.68)
	20. Follow physician's order not to tell patient the truth when he/she asks for it	5.83 (1.78)	1.86 (1.24)
	21. Assist physician who in my opinion is providing incompetent care	6.05 (1.56)	2.49 (1.36)
	24. Discharge patient based on diagnosis-related groups although he has many teaching needs	5.15 (2.04)	1.95 (1.43)
	25. Provide better care for those who can afford to pay	5.20 (2.23)	1.67 (1.40)
	26. Follow the family's request not to discuss dying with a dying patient who asks about dying	5.79 (1.74)	2.22 (1.27)
	27. Follow physician's request not to discuss death with a dying patient who asks about dying	5.76 (1.86)	1.98 (1.33)
	28. Work in a situation when the number of staff is too low and care is inadequate	5.97 (1.72)	2.91 (1.79)
	32. Follow physician's request not to discuss code status with family when patient is incompetent	5.50 (2.03)	1.91 (1.43)
	Individual responsibility subscale score	5.50 (1.47)	2.15 (0.88)
Deception	29. Give medications intravenously during a code with no compressions or intubation	4.68 (2.18)	2.29 (1.506)
	30. Give only hemodynamic stabilizing medications intravenously during a code with no compression or intubation	4.49 (2.20)	2.30 (1.46)
	31. Follow physician's request not to discuss code status with patient	5.54 (2.05)	1.87 (1.37)
	Deception subscale score	4.92 (1.82)	2.16 (1.20)
	Total of all subscales	5.34 (1.32)	2.51 (0.87)

to care for a hopelessly injured patient on a ventilator when no one will discontinue the ventilator" (mean 5.88). The lowest-scoring item for moral distress intensity was "carry out [physician]'s orders for unnecessary tests and treatments on terminally ill patients" (mean 4.39).

Mean scores for items on the moral distress frequency scale ranged from 1.43 to 4.45, with an overall mean total of 2.51 (SD 0.87). The 3 highest-scoring items for moral distress frequency were "follow family's wishes to continue life support when not in patient's best interest" (mean 4.45), "follow [physician]'s orders for unnecessary tests" (mean 4.28), and "follow family

### Nurses with higher levels of perceived empowerment will experience moral distress less often.

wishes for patient care I don't agree with" (mean 4.08). The lowest-scoring item for moral distress frequency was, "carry out order to discontinue treatment because patient can no longer pay" (mean 1.43).

Total scores for both moral distress intensity and moral distress frequency were determined for each of

the 3 subscale categories (Table 1). All moral distress intensity subscale totals were high: (1) not in patient's best interest (mean 5.13, SD 1.25), (2) individual responsibility (mean 5.50, SD 1.47), and (3) deception (mean 4.92, SD 1.82).

Moral distress frequency subscales were as follows: (1) not in patient's best interest (mean 3.69, SD 1.22), (2) individual responsibility (mean 2.15, SD 0.88), and (3) deception (mean 2.16, SD 1.43). The total score for moral distress intensity was high (mean 5.34, SD 1.32), and the total score for moral distress frequency was moderate (mean 2.51, SD 0.87).

### **Psychological Empowerment**

The PEI was used to determine levels of empowerment of critical care nurses in the workplace. Data from this instrument were scored in the following manner: individual item mean scores, mean subscale scores, and a mean total score. Similar to moral distress, PEI scores from 0 to 2.33 were considered low, 2.34 to 4.66 moderate, and 4.67 to 7.00 high.

PEI items ranged from moderate (mean 3.88) to high (mean 6.22). The highest scoring PEI item was, "I really care about what I do on my job" (mean 6.22, SD 1.16). The lowest scoring item was, "I have a great deal of control over what happens in my department" (mean 3.88, SD 1.52). PEI subscale scores were all high: meaning (mean 6.06, SD 1.09), competence (mean 5.92, SD 1.02), self-determination (mean 5.03, SD 1.18), and impact (mean 4.22, SD 1.47). Overall, the total PEI mean score indicated a high degree of psychological empowerment (mean 5.31, SD 1.00).

## Correlational Analysis of Moral Distress and Demographics

Weak but significant positive correlations were found between the moral distress item "not in patient's best interest" and age (r = 0.179, P = .01) and ELNEC critical care training (r = 0.185, P = .008). Likewise weak but significant positive correlations were found between ELNEC training and the items "not in patient's best interest" (r = 0.194, P = .006) and total score for moral distress frequency (r = 0.165, P = .02). A weak but significant negative correlation was found between active collaboration in end-oflife patient care conferences and items related to deception (r = -0.191, P = .007).

## Correlational Analysis of Empowerment and Demographics

Several significant positive correlations were found between psychological empowerment and the nurses' demographics (Table 2). Significant and moderate correlations were found between empowerment related to competence and years of critical care experience (r = 0.255, P = .001). Other moderate and significant correlations were found between empowerment related to self-determination and collaboration in end-of-life care conferences (r = 0.217, P = .001) and end-of-life care education in the past year (r = .209, P = .001). In addition, a significantly positive moderate correlation was found between empowerment related to impact and collaboration in end-of-life care conferences (r = 0.253, P = .001).

All empowerment subscale scores (meaning, competence, self-determination, and impact) and total empowerment scores significantly correlated positively with end-of-life care education in the past year (r = 0.221, P = .001). No correlations were found between empowerment and AACN membership or CCRN certification; therefore, these data were omitted from Table 2.

### Moral Distress Intensity/Frequency and Psychological Empowerment

Relationships between psychological empowerment and moral distress intensity and frequency were computed by using a Pearson product coefficient. A moderate and significant negative correlation was found between moral distress frequency related to individual responsibility and empowerment related to impact (r = -0.249, P = .001) and moral distress frequency total scores and empowerment related to impact (r = -0.229, P = .002). Total psychological empowerment scores negatively correlated with moral distress frequency (individual responsibility subscale; r = -0.213, P = .004; see Table 2).

### Table 2

Correlational findings using Pearson's r coefficient

Nurses' demographics	Meaning	Competence	Self-determination	Impact	Total empowerment
Age	r=0.083	r=0.194 <sup>a</sup>	r=0.090	r=0.076	r=0.139 <sup>a</sup>
	n = 258	n = 255	n=257	n = 253	n=242
Years of critical care experience	r=0.077	r=0.255 <sup>a</sup>	r=0.110	r=0.096	r=0.165 <sup>a</sup>
	n = 257	n = 254	n=256	n=252	n=241
Work status	<i>r</i> =-0.064	r=0.005	r=0.036	r=0.151 <sup>a</sup>	r=0.034
	n = 253	n = 250	n=252	n = 249	n=238
Collaboration in end-of-life care	r=0.016	r=0.022	r=0.217 <sup>a</sup>	r=0.253 <sup>a</sup>	r=0.163 <sup>a</sup>
conferences	n = 256	n = 253	n=255	n=251	n=240
Education	<i>r</i> =-0.021	r=-0.037	r=0.116	r=0.149 <sup>a</sup>	r=0.099
	n = 258	n = 255	n=257	n = 253	n=242
ELNEC critical care training	r=0.051	r=0.093	r=0.133 <sup>a</sup>	r=0.128 <sup>a</sup>	r=0.125
	n = 256	n = 253	n = 255	n=251	n = 240
End-of-life care education in the	r=0.150 <sup>a</sup>	r=0.177 <sup>a</sup>	r=0.209 <sup>a</sup>	r=0.196 <sup>a</sup>	r=0.221 <sup>a</sup>
past year	n = 256	n = 253	n=256	n=251	n=241
Moral distress intensity					
Not in patient's best interest	r=0.032	r=0.042	r=0.015	r=0.064	r=0.064
	n = 202	n = 199	n=201	n = 196	n = 189
ndividual responsibility	r=0.119	r=0.079	r=0.056	r=0.032	r=0.085
	n = 177	n = 174	n = 175	n = 171	n = 166
Deception	r=0.144 <sup>a</sup>	r=0.059	r=0.168 <sup>a</sup>	r=0.164 <sup>a</sup>	r=0.166 <sup>a</sup>
	n = 203	n = 200	n = 202	n = 197	n = 190
Total moral distress intensity	r=0.115	r=0.062	r=0.062	r=0.057	r=0.095
	n = 170	n = 167	n = 167	n = 168	n = 159
Moral distress frequency					
Not in patient's best interest	r=-0.056	r=0.001	<i>r</i> =-0.103	<i>r</i> =-0.161 <sup>a</sup>	<i>r</i> =-0.111
	n = 202	n = 199	n=201	n = 196	n = 189
ndividual responsibility	r=-0.056	r=-0.159	<i>r</i> =-0.177 <sup>a</sup>	<i>r</i> =-0.249 <sup>a</sup>	<i>r</i> =-0.213 <sup>a</sup>
	n = 193	n = 190	n = 192	n = 190	n = 183
Deception	r=-0.041	<i>r</i> =-0.115	<i>r</i> =-0.121	r=-0.065	r=-0.097
	n = 202	n = 199	n=201	n = 196	n = 189
Fotal moral distress frequency	r=-0.064	r=-0.136	<i>r</i> =-0.161 <sup>a</sup>	r=-0.229 <sup>a</sup>	<i>r</i> =-0.194 <sup>a</sup>
	n = 186	n = 183	n = 185	n = 183	n = 176

Abbreviation: ELNEC, End-of-Life Nursing Education Consortium.  $^a$  Significance at  $\alpha$  < .05.

### Relationships between Moral Distress, Empowerment, and Demographics

Multiple regression analysis was used to test if any demographic variables combined with total PEI scores were predictors of the frequency of experiencing moral distress. The results of the regression analysis indicated that 2 predictors explained 8.40% of the variance ( $R^2 = 0.289$ ,  $F_{2,171} = 7.801$ , P < .01). It was found that nurses' having had ELNEC critical care training was a significant predictor of moral distress frequency ( $\beta = -.215$ , P < .01). Nurses who had received ELNEC critical care training had, on average, 21.5% higher scores for moral distress frequency. In addition, total psychological empowerment was a significant predictor of moral distress frequency ( $\beta$  = .222, *P* < .01). For every 1-point increase on the PEI, moral distress frequency scores decreased by 0.222 points (*P* ≤ .01). The analysis indicated that it can be predicted that ELNEC critical care trained nurses will experience moral distress more often, and nurses with higher levels of perceived empowerment will experience moral distress less often.

### **Discussion** -

Moral distress intensity was high among critical care nurses, whereas moral distress frequency was moderate to low. These findings are consistent with the results of Corley et al,<sup>23</sup> in that the frequency was

lower than the intensity, implying that the morally distressing events that the nurses experienced were not occurring often. Moral distress intensity was higher in our study than in the study by Corley et al. In our study, nurses reported the highest level of moral distress intensity in the individual responsibility domain, with the second highest level of moral distress intensity related to the items not in patient's best interest, although the difference in mean scores was negligible (0.37). In previous studies,<sup>10,13,15-18</sup> researchers reported that the highest moral distress intensity resulted from items not in the patient's best interest.

As nurses' age increased, so did moral distress intensity. Nurses participating in end-of-life patient care conferences reported less moral distress frequency in being able to address issues related to the impending death of a patient honestly. Overall, the more empowered nurses perceived themselves, the less often they experienced moral distress.

Nurses who reported having ELNEC critical care training experienced significantly greater levels of moral distress intensity and frequency in items related to "not in patient's best interest" (participating in care that the nurse considered inappropriate because of futility for the patient). This may be explained by nurses, having gained more information regarding the correct actions to take in situations of delivering futile care to dying patients, felt higher levels of moral distress because they were not able to carry out their desired actions contributing to optimal patient care. Also, few participants (16 out of the total number) reported ELNEC critical care training.

Several positive significant correlations were found between psychological empowerment and the demographics. In our study, nurses who reported participating in end-of-life care education in the past year reported higher levels of psychological empowerment in all domains. This is consistent with Corbally et al,<sup>25</sup> who conducted a qualitative study examining empowerment in 93 nurses and midwives. Education for practice was an antecedent to empowerment.

We found that as age and years of critical care experience increased, nurses reported higher levels of empowerment related to competency. Nurses who worked more hours per week were more empowered related to impact. This finding is consistent with results reported by Knol and van Linge<sup>5</sup>: in their cross-sectional study of nurses using the PEI, they found that registered nurses who worked more hours per week perceived themselves as more psychologically empowered.

We found that nurses who reported active collaboration in end-of-life patient care conferences had higher levels of empowerment related to self-determination and impact. This finding is consistent with results of a mixed-method study using the PEI and interviews done by Williamson<sup>14</sup> examining home health nurses' perception of psychological empowerment. PEI scores were high in this study, and interviews of participants identified collaboration as one of the most important facets of empowerment.

Nurses who scored higher in the following: (1) meaning (attaching greater value to their work), (2) self-determination (feeling higher levels of autonomy), and (3) impact (having greater influence at work) experienced higher levels of moral distress intensity related to deception (situations where they felt unable to address issues related to the impending death of a patient honestly). Nurses who felt more empowered may have been more distressed about not being able to actualize what they perceived as the correct actions.

However, nurses who scored higher in empowerment related to self-determination experienced moral distress less frequently when participating in situations requiring them to ignore taking actions they felt they should take (individual responsibility). Nurses who perceived themselves as more empowered related to their impact experienced moral distress less often when dealing with situations involving the delivery of aggressive care in cases of patient futility (not in patient's best interest).

### Limitations \_

In this study, we did not differentiate between geographical areas or types of facilities in which nurses practiced, nor did we take into consideration nurses' sex or culture. The sample was taken from subscribers to the AACN newsletter. This population of nurses may be more apt to feeling empowered and/or feeling greater or less levels of moral distress. The nature of convenience sampling versus random sampling may have limited the study's findings in terms of predictability and generalizability. The relatively low response rate was perhaps due to the large volume of surveys that AACN newsletter subscribers are asked to complete.

### **Conclusion**

In this study, we sought to examine the relationship between moral distress and psychological empowerment in critical care nurses related to endof-life care. The results revealed a significant positive relationship between moral distress intensity and psychological empowerment in the surveyed population of nurses; however, nurses who perceived themselves as more empowered experienced moral distress less frequently. Another pertinent finding was that nurses who participated in end-of-life patient care conferences experienced less moral distress frequency in situations related to honestly addressing issues dealing with patients facing impending death.

Nurses more advanced in age and nurses who participated in ELNEC training reported more moral distress intensity related to care that nurses considered futile for the patient. This study indicated that the following nursing demographics were significantly related to higher levels of psychological empowerment: age, years of critical care experience, work status, collaboration in end-of-life patient care conferences, level of education, ELNEC training, and end-of-life care education in the past year.

The data supported the relevance of an investigation seeking to correlate moral distress and empowerment related to select demographics as stipulated in the conceptual framework. No significant correlations were found related to AACN certification or AACN membership. Future studies are recommended to address additional demographics such as sex, critical care specialty area, and type of institution where practicing.

Despite the numerous significant positive relationships between the demographics and psychological empowerment, participants did not experience decreased moral distress intensity in relationship to increased degrees of psychological empowerment. However, the data supported that critical care nurses who perceive themselves as more psychologically empowered experience moral distress less frequently.

This study offers several insights into the continuation of a research agenda concerning the potential for decreasing moral distress in critical care nurses related to end-of-life care. Further research examining empowerment as it relates to moral distress is needed to find methods that may decrease moral distress in critical care nurses. Further exploration of how bioethical principles can be more effectively incorporated into nursing education so that nurses may be better equipped to articulate bioethical principles related to end-of-life care as they apply them to patient care situations in multidisciplinary patient care conference settings is recommended. The results of this study provide relevant data that may increase insight into future interventional studies, potentially aiding in the reduction of moral distress in critical care nurses related to end-of-life care.

FINANCIAL DISCLOSURES None reported.

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### Differences in Level of Care at the End of Life According to Race

Rebecca W. Johnson, L. Kristin Newby, Christopher B. Granger, Wendy A. Cook, Eric D. Peterson, Melvin Echols, Wanda Bride and Bradi B. Granger

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AMERICAN ASSOCIATION of CRITICAL-CARE NURSES

### End-of-Life Care



# DIFFERENCES IN LEVEL OF CARE AT THE END OF LIFE ACCORDING TO RACE

By Rebecca W. Johnson, RN, BS, L. Kristin Newby, MD, MHA, Christopher B. Granger, MD, Wendy A. Cook, RN, MSN, Eric D. Peterson, MD, MPA, Melvin Echols, MD, Wanda Bride, RN, and Bradi B. Granger, RN, PhD



### Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

- 1. Discuss the study's conclusions associated with patient preferences for the level of intensive care at the end of life.
- 2. Identify patient demographic characteristics that may influence end-of-life decisions.
- 3. Develop a personal action plan for including patient preferences in planning end-of-life care.

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**Background** Tailoring care for patients and their families at the end of life is important.

**Purpose** To examine factors associated with patients' choices for level of care at the end of life. Methods Data on demographics and level of care (full code, do not resuscitate, or withdrawal of life support) were collected on 1072 patients who died between January 1998 and June 2006 on a cardiac care unit. Logistic regression was used to identify factors associated with level of care. **Results** Median (interguartile range) age of blacks was 64 (50-74) years and of whites was 70 (62-78) years. At the time of death, the level of care differed significantly between blacks and whites: 41.8% (n = 112) of blacks versus 26.7% (n = 194) of whites chose full code (P<.001), 37.3% (n = 96) of blacks versus 43.9% (n = 317) of whites chose do not resuscitate (P= .03), and 20.9% (n = 54) of blacks versus 29.3% (n = 210) of whites chose withdrawal of life support (P=.005). After age, sex, diagnosis, and lengths of stay in intensive care unit and hospital were controlled for, blacks were more likely than whites to choose full code status at the time of death (odds ratio 1.91 [95% confidence interval, 2.63-1.39], P<.001). **Conclusions** Blacks are 1.9 times as likely as others to choose full code at time of death. Cultural differences should be acknowledged when providing end-of-life care. (American Journal of Critical Care, 2010:19:335-344)

n estimated 1 in 5 American deaths now occurs in an intensive care unit (ICU).<sup>14</sup> This shift in the past half-century to dying in the hospital contributes to the burgeoning cost of health care, to suboptimal family access to dying patients, and to a growing need for providers to address not only the needs of critical care patients, but the concomitant needs of families in crisis. Perhaps one of the greatest needs generated by this shift to dying in the hospital is the need for nurses and other care providers to gain a better understanding of patients' preferences for care at the end of life.

A unique aspect of dying in the hospital is the increased use of hospital-based technology at the end of life and the concomitant need to withdraw it. Predictably, a steadily increasing number of ICU patients die after end-of-life decisions such as forgoing cardiopulmonary resuscitation ("do not resuscitate" [DNR]) and withholding or withdrawing care.<sup>58</sup> In current studies, an estimated 90% of ICU deaths are preceded by recommendations to limit therapy,<sup>7</sup> with more than half of those deaths ending in withholding of additional support or withdrawal

### An estimated 1 in 5 American deaths occur in an intensive care unit.

of existing supportive care.<sup>8</sup> From 1988 to present, withdrawal of life support in the ICU has increased by up to 50%, depending on the hospital and the geographical region.<sup>568</sup>

Thus, the practices of withholding and withdrawing life support have become increasingly prevalent;

yet our understanding of cultural differences in how or when patients choose when or if to withdraw support is limited. Not only do decisions about level of care at end of life have profound cultural and spiritual implications, they may also significantly influence, and be influenced by, cost. In the most recent major analysis of end-of-life spending

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**Corresponding author:** Rebecca W. Johnson, RN, BS, Duke Hospital, Box 100701, 2301 Erwin Rd, Durham, NC 27710 (e-mail: johns151@mc.duke.edu). trends, Lubitz and Riley<sup>9</sup> found that 10% to 12% of the total US health care budget and 27% of the annual Medicare budget was spent on care at the end of life.<sup>9,10</sup> If family members struggle to bear the burden of such costs, the implications for end-of-life care may differ.

Therefore, although recent research on end-oflife care in the ICU has assessed trends in increased rates and costs<sup>2,3,5-8,11-18</sup> of withholding and withdrawal of life support, the understanding of patients' preferences associated with various levels of care at the end of life remains limited. As a result, factors associated with the level of care at the time of death, and in particular, culturally sensitive preferences for care, merit further investigation. Therefore, using an exploratory, retrospective review of 1072 deaths occurring during an 8-year period in the cardiac care unit (CCU) at Duke University Hospital, we sought to identify factors that might be associated with each of 3 levels of care at the time of death: full code, do not resuscitate, and withdrawal of life support. The research question was, "What patientlevel factors are associated with level-of-care preferences at the end of life?"

### Methods \_

### **Unit-Specific End-of-Life Process**

On the Duke CCU, when patients are identified as having a low likelihood of recovery, the health care team evaluates each patient and family in an established, systematic manner. A nurse who is specifically responsible for addressing end-of-life care issues assists in guiding the communication between the health care team, patients, and patients' families. During each conference, the family's understanding of the patient's status is assessed and possible options for care are discussed. If the patient is unable to express his wishes for the goal of care at the end of life, aggressive versus comfort care, the surrogate decision maker is encouraged to speak for the patient. The risks and benefits of various treatment plans are weighed for both aggressive and comfort care. Additional conferences are held on

subsequent days to evaluate the patient's progress and the ongoing appropriateness of the treatment plan. This arrangement affords the family an opportunity to assimilate information over time. As part of this care continuum, a discussion may take place regarding the option for DNR status. When appropriate, a discussion of withdrawal of life support may be initiated by either the health care team or the patient's family. The time frame between the first and final discussions varies according to the patient's status and the needs of the family.

### **Population of Patients and Data Collection**

Patients who died while in the CCU of Duke University Hospital from January 1, 1998, to June 30, 2006, were prospectively recorded in a registry that included all deaths. Descriptive data, including age, sex, self-described race, length of hospital and CCU stay, hospital and CCU admission diagnoses, cause of death, and level of care at time of death were recorded for 1072 subjects who died in the CCU. Although our data collection included Asian, black, Hispanic, Native American, white, other, and unknown, the numbers in all categories other than black and white were too small to be statistically significant. For this reason, we collapsed racial and ethnic categories into black, white, and other. Level of care at the time of death was recorded as full code, referring to patients who received aggressive life-sustaining interventions; DNR refers to those patients who received full aggressive ICU care interventions but did not desire cardiopulmonary resuscitative efforts, even if the alternative was death; and withdrawal of life support denotes patients who had life-supporting therapies such as vasopressors and mechanical ventilation discontinued when survival without such therapy was unlikely and the expected outcome was death.

All registry entries were made as deaths occurred, either at the time of death or as close to the time of death as possible. Additional data were obtained if necessary from the medical record and through discussions with the care nurse, house officer, and attending physician. The institutional review board approved the project. All subjects included in the registry were deceased, risks were deemed minimal, and consent was impractical, therefore a waiver of informed consent was obtained.

### **Analysis**

We calculated descriptive statistics to assess the frequency and distribution of patients' characteristics, including sex, age (continuous), race (Asian, black, Hispanic, Native American, unknown, or white), length of stay (continuous), diagnosis, ventilator status (receiving or not receiving mechanical ventilation), and level of care at the time of death (full code, DNR, or withdrawal of life support). We eval-

uated differences in descriptive patient characteristics among the 3 groups of care (full code, DNR, and withdrawal of life support), using analysis of variance for normally distributed, continuous variables (age and length of stay) and a  $\chi^2$  test for categorical variables. Univariate analyses were conducted to determine baseline characteristics that were associated with level of care at

Level of care at time of death was recorded for 1072 subjects who died in the cardiac care unit.

the time of death, and those variables that were significant at an  $\alpha$  of .05 were chosen to enter the multivariate model.

We then conducted multivariate modeling by using 2-step sequential logistic regression to assess these variables in combination and their relationship to level of care at the end of life. First, a multivariate logistic regression model was used to examine the association of patients' characteristics with a decision to undergo full code (yes or no). Then a second logistic regression model was used to evaluate predictors of the subsequent decision to choose withdrawal of life support as compared with DNR. The sequential approach was taken in order to obtain the most information on the contribution of individual variables (parameter weights) while accounting for interactions in the models and controlling for possible confounding variables. Timing of events was not a significant contributor in univariate analy-

ses and therefore was not included in the multivariate models. An  $\alpha$  of less than .05 was established for significance. Analyses were computed by using SAS version 9 (SAS Inc, Cary, NC).

### **Results**

### **Characteristics of the Sample**

Patients' characteristics according to end-of-life resuscitation status are summarized in Table 1. Overall, patients' ages were from 17 to 101 years (median, 69.0 years), 47% were women, and 25% were black. The overall length of stay in the

CCU was from 0 to 89 days (median, 3.0 days). At the time of death, 51.8% of patients (n = 555) were receiving mechanical ventilation. The most common CCU admitting diagnoses were myocardial

Blacks were almost twice as likely as whites and others to choose full code status and half as likely to choose withdrawal of life support.

### Table 1

Demographic characteristics according to end-of-life status<sup>a</sup>

Characteristics of patients	Full coc (n = 344		Do not resuscitate (n = 442)		Withdrawal of life support (n = 286)		Pb			
Continuous variables										
Age, y	66.0	56-75	72.0	63-79	66.5	57-75	<.001			
Length of stay, d	1.0	0-3	3.0	1-10	5.0	2-10	<.001			
		Categoric	al variables							
Sex							.42			
Men (n=565)	190	33.6	232	41.1	143	25.3				
Women (n = 507)	154	30.4	210	41.4	143	28.2				
Race										
Asian (n=4)	4	100	0	0	0	0	с			
Black (n=268)	112	41.8	100	37.3	56	20.9	<.001			
Hispanic (n = 3)	2	66.7	1	33.3	0	0	c			
Native American (n = 29)	10	34.5	12	41.4	7	24.1	c			
Other (n=2)	2	100.0	0	0	0	0	c			
Unknown (n=40)	20	50.0	10	25.0	10	25.0	c			
White (n = 726)	194	26.7	319	43.9	213	29.3	<.001			
Ventilator in place (n=555)	274	49.4	219	39.5	62	11.2	<.001			
Cardiac care unit diagnosis							.004			
Anoxia (n = 1)	0	0	1	100.0	0	0				
Arrhythmia (n=35)	16	45.7	18	51.4	1	2.9				
Cardiogenic shock (n = 22)	8	36.4	8	36.4	6	27.3				
Cardiomyopathy (n = 37)	4	10.8	14	37.8	19	51.4				
Heart failure (n=49)	12	24.5	27	55.1	10	20.4				
After cardiac arrest (n = 250)	85	34.0	78	31.2	87	34.8				
Respiratory failure (n = 67)	16	23.9	29	43.3	23	34.3				
After respiratory arrest (n = 29)	6	20.7	13	44.9	10	34.5				
Pneumonia (n = 13)	1	7.7	6	46.2	6	46.2				
Sepsis (n=66)	19	28.8	31	47.0	16	24.2				
Unstable angina (n=8)	3	37.5	3	37.5	2	25.0				
Valvular disease (n = 7)	2	28.6	2	28.6	3	42.9				
Multisystem organ failure (n=6)	3	50.0	1	16.7	2	33.3				
Pump failure (n = 31)	7	22.6	14	45.2	10	32.2				
Other (n = 19)	4	21.1	8	42.1	7	36.8				
Heart transplant rejection $(n = 2)$	1	50.0	0	0	1	50.0				
Myocardial infarction (n = 440)	157	35.7	189	43.0	94	21.4				

<sup>a</sup> Values for continuous variables are median (interquartile range). Values for categorical variables are number (%) of patients in each group. <sup>b</sup> Test of difference that generated *P* values was analysis of variance for continuous variables and  $\chi^2$  test for categorical variables. <sup>c</sup> Cell counts with possible expected count less than 5 were not run.

infarction (n = 432), after cardiac arrest (n = 242), respiratory failure (n = 64), sepsis (n = 64), congestive heart failure (n = 46), and arrhythmia (n = 33). Of the total population, 32.4% were full code at the time of death, 40.9% were DNR, and 26.7% of deaths were preceded by withdrawal of life support. Among all deaths, the length of stay (days) before death was shortest for patients who were full code status (median, 1 day; interquartile range, 0-3 days) and longest for patients who chose active withdrawal of life support (median, 5 days; interquartile range, 2-10; Table 1). Men and women had equal distributions of each of the 3 end-of-life

categories (Table 1). The proportions of men and women who died were not significantly different; however, women were older at the time of death than men were, with a higher proportion of men in the fourth to seventh decade of life and a higher proportion of women in the eighth and ninth decades of life.

Patients' characteristics according to race are summarized in Table 2. Median age was younger among blacks (64 years) than whites (70 years). The length of stay before death was similar in blacks and whites across each of the 3 levels of care at the time of death. The rate of unexpected death, based

Table 2Demographic characteristics by	race <sup>a</sup>						
Characteristics of patients	Black (n = 268)		White (n = 726)			Other n = 78)	Pb
		Continuo	us variables				
Age, y Length of stay, d	64 2	50-74 1-7	70 3	62-78 1-7	66 2	58-76 1-7	<.001 .92
		Categoric	al variables				
Sex							.008
Men	121	45.1	406	55.9	38	48.7	
Women	147	54.8	320	44.1	40	51.3	
Level of care							
Full code	112	41.8	194	26.7	38	48.7	<.001
Do not resuscitate	96	35.8	317	43.7	22	28.2	.006
Withdrawal of life support	54	20.1	210	28.9	17	21.8	.01
Ventilator in place	154	57.5	355	48.9	46	59.0	.02
Cardiac care unit diagnosis							.16
Anoxia	1	0.3	0	0.0	0	0.0	c
Arrhythmia	6	2.2	27	3.7	2	2.6	c
Cardiogenic shock	3	1.1	19	2.6	0	0.0	c
Cardiomyopathy	6	2.2	18	2.5	3	3.8	c
Heart failure	13	4.9	31	4.3	5	6.4	с
After cardiac arrest	80	29.9	157	21.6	13	16.7	с
Respiratory failure	14	5.2	48	6.6	5	6.4	с
After respiratory arrest	8	3.0	19	2.6	2	2.6	c
Pneumonia	1	0.3	11	1.5	1	1.3	c
Sepsis	17	6.3	45	6.2	4	5.1	c
Unstable angina	1	0.3	6	0.8	1	1.3	c c
Valvular disease	2	0.7	5	0.7	0	0.0	c
Multisystem organ failure	1	0.3	5	0.7	0	0.0	c
Pump failure	6	2.2	25	3.4	0	0.0	c
Other	6	2.2	12	1.7	1	1.3	c
Heart transplant rejection	2 101	0.7 37.7	0 298	0.0 41.0	0	0.0 52.6	
Myocardial infarction	101	37.7	298	41.0	41	52.0	.005

<sup>a</sup> Values for continuous variables are median (interquartile range). Values for categorical variables are number (%) of patients in each racial group. <sup>b</sup> Test of difference that generated *P* values was analysis of variance for continuous variables and  $\chi^2$  test for categorical variables. <sup>c</sup> Cell counts with possible expected count less than 5 were not run.

on a subjective assessment at the time of death by the care team, was similar in blacks and whites (8.6% and 8.3%, respectively; P = .16). Black patients were more likely to choose full code than were white patients (43% vs 27%) and were less likely to choose DNR (37% vs 44%) or withdrawal of life support (21% vs 29%; see Figure).

## Factors Associated With Full Code Status at the End of Life

A univariate analysis of variable association with the full code status was first conducted to identify those variables that were significantly related to full code status, without controlling for others. Based on these findings, length of stay (Wald  $\chi^2 = 42.4$ ; odds ratio, 0.91; 95% confidence interval [CI], 0.88-0.94; *P*<.001), race (Wald  $\chi^2 = 20.512$ ; odds ratio, 1.97; 95% CI, 1.47-2.64; *P*<

.001), and age (Wald  $\chi^2$  = 18.72; odds ratio, 0.98; 95% CI, 0.97-0.99], *P*<.001) were highly associated with full code status, as were a number of admitting diagnoses.

Next, a multivariate model, the factors significantly associated with full code status, after other variables that may have influenced level of care at the time of death were adjusted for, included length of stay, race, age, and presence of a lethal arrhythmia on admission to the CCU (Table 3). Although length of stay and age were important contributors to the model (Wald statistic, 38.58 for length of stay and 14.46 for age), and were both statistically significant (P < .001), the relationship with full code status was similar for race (Wald statistic 22.96; odds ratio, 1.91 for black vs white).

For length of stay, each incremental day of CCU stay decreased the likelihood of being full code status

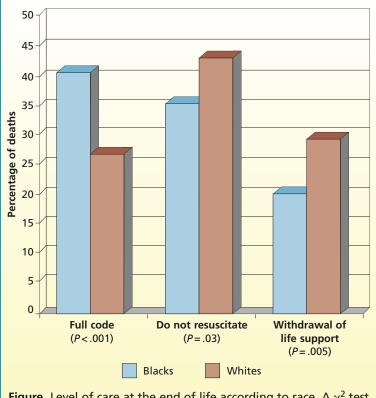


Figure Level of care at the end of life according to race. A  $\chi^2$  test of difference was used to compare groups.

### Table 3

Variables associated with full code status in 1072 patients in the cardiac care unit at the end of life<sup>a</sup>

Variable	Wald $\chi^2$	Odds ratio	95% Confidence interval	P
Sex, female vs male	2.49	0.80	0.61-1.06	.12
Age, every 10 y	14.46	0.82	0.74-0.89	<.001
Race Black vs white Black vs other	22.96 5.91	1.91 1.35	1.39-2.63 0.43-1.28	<.001 .02
Length of stay, per day	38.58	0.91	0.88-0.94	<.001
Diagnosis Arrhythmia Cardiac arrest Cardiomyopathy Chronic heart failure Other Respiratory arrest Pump failure Sepsis	5.10 0.14 2.49 0.42 0.23 0.01 1.88 1.45	1.70 0.76 0.31 0.56 0.63 0.68 1.98 0.22	0.82-3.53 0.54-1.08 0.10-0.94 0.27-1.15 0.42-0.94 0.36-1.28 0.38-10.21 0.03-1.80	.01 .71 .58 .63 .91 .17 .23

by only 9% (odds ratio, 0.91; 95% CI, 0.88-0.94; P < .001). For age, each incremental decade of life decreased the likelihood of being full code status by

18% (odds ratio, 0.82; 95% CI, 0.74-0.90; P < .001). By contrast, blacks were almost twice as likely (odds ratio, 1.91) as whites and others to choose full code status, even after other variables that may have influenced the relationship, such as length of stay in the CCU, age, and diagnosis on admission were controlled for.

In the second step of the sequential logistic regression analysis, factors associated with withdrawal from life support were evaluated (Table 4). Again, race was a significant independent contributor, with blacks half as likely as whites to choose withdrawal of life support (odds ratio, 0.54; 95% CI, 0.38–0.78; P = .006). Other variables associated with level of care at end of life remained important predictors of withdrawal of support, including age, length of stay, and diagnosis\_\_\_\_\_\_

### **Discussion**

Findings in this study suggest that preferences for care at the end of life differ significantly according to race, and also, though to a lesser extent, according to length of stay and age. Blacks are more likely than whites to choose full code status over DNR or withdrawal of life support. Similar findings regarding racial differences in preferences for end-of-life care have been reported in other settings, such as primary care,<sup>19</sup> nursing homes,<sup>20</sup> and hospice.<sup>21</sup> These prior studies suggest that blacks are less likely to complete advance directives or to pursue hospice and related types of palliative care at the end of life. Our findings show that, similar to nursing homes and hospice settings, in a critical care setting blacks are also less likely than others to limit aggressive care, and they are significantly more likely to choose full code.

### Race and Level of Care at the End of Life

Although blacks reportedly receive fewer invasive interventions at the time of diagnosis, particularly interventional procedures such as percutaneous coronary intervention and coronary artery bypass grafting,<sup>22-26</sup> the data from our study suggest that near the end of life blacks chose aggressive supportive care more often than do other races. Similarly, in a nationwide study of 10122 deaths, researchers found that blacks were more likely than whites to die in a hospital (70.4% vs 55.1%). These findings are consistent with our data and suggest that black race is associated with more aggressive end-of-life care. Similar to our study, in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),<sup>27</sup> 30% of white patients did not want cardiopulmonary resuscitation compared with 19% of nonwhite patients (relative risk, 1.62; 95% CI, 1.3-2.1).

## Length of Stay and Level of Care at the End of Life

Length of stay was also significantly associated with level of care; however, the length of stay increased across the care groups, with full codes being shortest and withdrawal of support being the longest (Table 1). The median length of stay before death was 1 day for patients who were full code, 3 days for DNR status, and 5 days for withdrawal of life support. The relationship was not unexpected because the situations surrounding full code often leave little time for lengthy discussions and require rapid decision making. Other studies evaluating length of stay as it relates to withdrawal of life support are few, and we found only 1 published study<sup>18</sup> done to evaluate this relationship in an intensive care setting. Consistent with our reflections on this finding, Wunsch and colleagues<sup>18</sup> found that, on average, the length of stay in patients who choose withdrawal of life support is longer, partly because of the families' need to process the situation and the finality of the end of life.

### Age, Sex, and Level of Care at the End of Life

Age was also associated with level of care at the end of life. As age increased, full code orders were less common than either DNR or withdrawal of life support. These findings are consistent with the SUP-PORT study,<sup>26,27</sup> in which 1650 patients were interviewed about resuscitation preferences, which showed that patients who did not want cardiopulmonary resuscitation were older (mean 65.6 vs 60.3 years, P < .001); 36.7% of patients who had "do not resuscitate status" and did not want cardiopulmonary resuscitation were 70 to 79 years of age.

A 6-year difference in the median age of blacks and whites was observed, with blacks being younger than whites. The younger age of blacks at the time of death may have contributed to their choosing a more aggressive approach to care at the end of life. However, it is important to note that the life expectancy among blacks in the United States is 5 years lower, on average, than the life expectancy for whites (mean 69.0 years for black men vs 75.3 years for white men),<sup>28</sup> suggesting that the patients in our study are consistent with the national population with regard to age at the time of death.<sup>29</sup>

In our analysis, the proportions of levels of care at the time of death were similar among men and women, and sex was not significantly associated with level of care in multivariate modeling. Similarly, in the literature, patient's sex has not been independently associated with level of care at the time of death.<sup>5,18</sup>

### Table 4 Variables associated with withdrawal of life support as compared with a do-not-resuscitate order (n = 728)<sup>a</sup>

Wald $\chi^2$	Odds ratio	95% Confidence interval	P
2.80	1.28	0.96-1.70	.09
4.80	0.90	0.80-0.99	.03
7.71 0.15	0.54 0.83	0.38-0.78 0.44-1.57	.01 .70
19.43	1.05	1.02-1.05	<.001
6.35 8.33 0.51 0.52 1.52 1.05 0.16 0.53	0.11 2.11 1.52 0.86 1.50 1.53 1.54 2.68	0.02-0.84 1.47-3.02 0.64-3.62 0.41-1.84 1.00-2.23 0.86-2.71 0.27-8.76 0.86-8.36	.01 .004 .47 .47 .22 .31 .69 .10
	x <sup>2</sup> 2.80 4.80 7.71 0.15 19.43 6.35 8.33 0.51 0.52 1.52 1.05 0.16	$\begin{array}{c c} \chi^2 & ratio \\ \hline \chi^2 & ratio \\ \hline 2.80 & 1.28 \\ \hline 4.80 & 0.90 \\ \hline 7.71 & 0.54 \\ 0.15 & 0.83 \\ \hline 19.43 & 1.05 \\ \hline 6.35 & 0.11 \\ 8.33 & 2.11 \\ 0.51 & 1.52 \\ 0.52 & 0.86 \\ 1.52 & 1.50 \\ 1.05 & 1.53 \\ 0.16 & 1.54 \\ \hline \end{array}$	$\begin{array}{c c c c c c c c c c c c c c c c c c c $

However, women in most studies are older at the time of death than men, as was true in our study.<sup>2,30</sup>

### **Implications for Practice**

Our study was not designed to determine the specific factors underpinning the observed association of race with end-of-life decisions. Literature suggests 3 major reasons, including spirituality, distrust of the health care delivery system, and the col-

lective community that influence the making of end-of-life decisions among blacks. Because spirituality is widely reported to be a fundamental tool for coping with the experience of death, particularly among blacks,<sup>31,32</sup> the results of our study may not be surprising. Understanding the nature and importance of black spirituality may allow us to assist black patients and families through the death and dying process in a manner that is harmonious with their culture.

Distrust of the health care delivery system may also be an important factor in decision making at the end of life among blacks. The historical root of distrust stems from generations of perceptions of unequally rendered services, abuses in medical experimentation, and economic injustice.<sup>33</sup> Such perceptions have led to a general loss of credibility of health care providers and institutions.

A third factor that may influence decision making by blacks at the end of life is the collective com-

Spirituality, distrust of the health care delivery system, and the collective community may affect decisions among blacks. munity.<sup>31</sup> Black culture places a strong value on the "collective" or family, friends, and the faith community. Honoring members of this community, especially family, is a central focus of the "collective" culture and making decisions without consensus of the community is considered disrespectful. Arranging for inclusion of family members, faith community, and clergy in discussions and decision making is an important way to assist black patients at the end of life.

Other possible reasons for differences in end-oflife choices include our approach in discussing the end of life; patients' and family members' understanding of the choices at the end of life; patients' and families' circumstances or previous experience with end-of-life decision making; or differences in beliefs regarding appropriate care at the end of life.

Although our standard unit approach is consistent for all patients, the specific course that discussions take is unique and tailored to meet the needs of the individual patient and family. Tailoring that occurred in the context of care to address the specific needs of the patient and family included varying the actual timeline for decision making; addressing families' past experience with hospitalized family members, illness, and death; and using effective communication techniques to work closely with individual family dynamics. Each of these variations may influence the tailored approach taken in planning the continuum of care at the end of life.

### Limitations

Because data were collected in a cardiac intensive care unit, and only on patients who died, the results may be specific to this population of patients. Our findings may be a reflection of cultural differences in the southeastern United States and may not be generalizable to other regions of the United States. A third limitation is the inability to evaluate the degree to which findings may be confounded by educational or socioeconomic factors. Although we recognize the importance of the relationship between socioeconomic status and endof-life preferences,<sup>34</sup> we did not collect individuallevel socioeconomic data in this study. However, we know that of all cardiac patients cared for at Duke University Hospital, 35% are black and 58% are white, and that this is a proportionally accurate representation of Durham County.35 Of those Durham county residents, a higher percentage of blacks are at poverty level (20% of blacks and 8.5% of whites) and are unemployed (8.9% of blacks and 2.7% of whites).<sup>35</sup> These data suggest that black patients represented in this study were likely to be

disproportionately socioeconomically disadvantaged compared with whites. If so, as suggested by Volandes and colleagues,<sup>34</sup> this disadvantage may affect their health literacy levels and may be reflected in their choices for care at the end of life.

In addition, patients whose end-of-life care began in the CCU but ended in another unit were not captured in this data set. It is also possible that patients who died before having the opportunity to complete an advanced directive could result in the appearance of lower DNR rates at the time of death. However, we do not suspect any systematic bias related to age, sex, or race in transfer of these patients from the CCU, nor do we expect differential patterns of death by race that would materially changeour results.

### Conclusions

In the cardiac intensive care setting, where terminal disease is common, race has a significant association with level of care at the end of life. When other variables such as age, sex, length of stay, and admitting diagnosis are controlled for, blacks are more likely than whites to choose a status of full code. Sensitivity to this difference may be important to providing better end-of-life care.

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