

# Having an Effective Goals of Care Conversation

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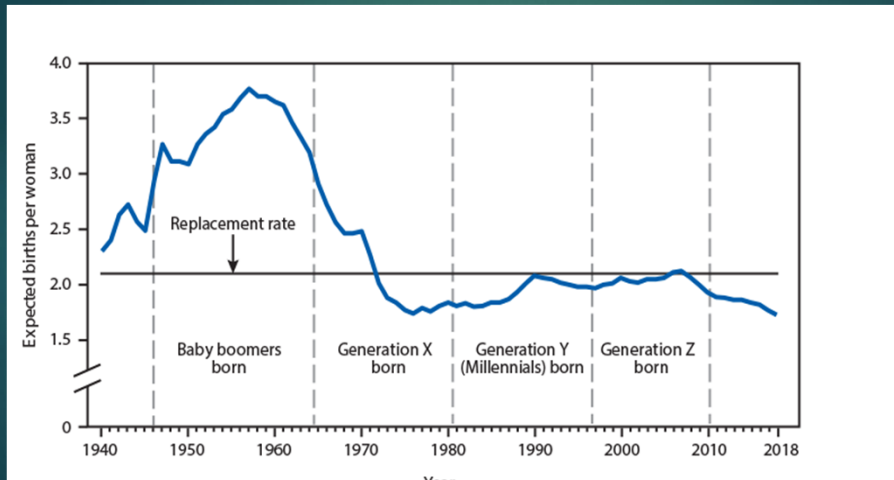
## Speaking of goals... Here are mine for this presentation

Know the definition of "Goals of Care".

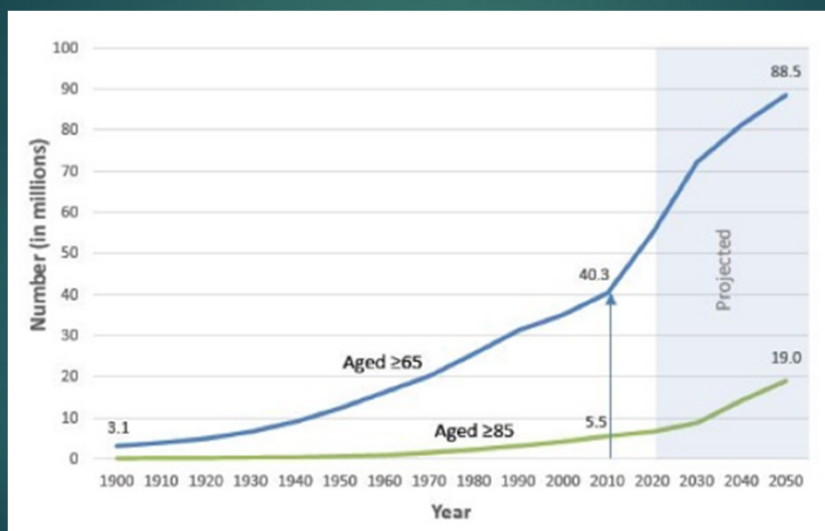
Be able to identify the patient for whom a goals of care conversation is appropriate.

Be able to explain why a goals of care conversation is such an important skill for a hospitalist physician.

Be familiar with a methodical approach to use in engaging a patient in a goals of care conversation



## Numbers of Elderly People



## Special Article

## The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up?



Dale Lupu, MPH, PhD, Leo Quigley, MPH, Nicholas Mehfoof, MPH, and Edward S. Salsberg, MPA  
Center for Aging, Health & Humanities (D.L.), George Washington University School of Nursing, Washington, District of Columbia; George Washington University School of Nursing & Health Workforce Institute (L.Q., N.M., E.S.S.), Washington, District of Columbia, USA

## Abstract

**Context.** The need for hospice and palliative care is growing rapidly as the population increases and ages and as both hospice and palliative care become more accepted. Hospice and palliative medicine (HPM) is a relatively new physician specialty, currently training 325 new fellows annually. Given the time needed to increase the supply of specialty-trained physicians, it is important to assess future needs to guide planning for future training capacity.

**Objectives.** We modeled the need for and supply of specialist HPM physicians through the year 2040 to determine whether training capacity should continue growing.

**Methods.** To create a benchmark for need, we used a population-based approach to look at the current geographic distribution of the HPM physician supply. To model future supply, we calculated the annual change in current supply by adding newly trained physicians and subtracting physicians leaving the labor force.

**Results.** The current U.S. supply of HPM specialists is 13.35 per 100,000 adults 65 and older. This ratio varies greatly across the country. Using alternate assumptions for future supply and demand, we project that need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. Supply will range from 8100 to 19,000.

**Conclusion.** Current training capacity is insufficient to keep up with population growth and demand for services. HPM fellowships would need to grow from the current 325 graduates annually to between 500 and 600 per year by 2030 to assure sufficient physician workforce for hospice and palliative care services given current service provision patterns. *J Pain Symptom Manage* 2018;55:1216–1223. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Physician workforce, physician supply, hospice and palliative medicine physician workforce, fellowship

## Introduction

The use of palliative care and hospice has grown rapidly in the past two decades. The silver tsunami

hospital-based palliative care at exemplar program staffing levels.<sup>1</sup> Spetz et al<sup>2</sup> found that only 66% of hospital palliative care programs had a funded physician position in 2012–13, despite such staffing being

## Supply/Demand Imbalance

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"It is neither sustainable nor desirable that palliative care specialists manage all the palliative care needs of all seriously ill patients."

Consensus Report from the Center to Advance Palliative Care

1120

J.A.M.A., April 1, 1961

## What to Tell Cancer Patients

A Study of Medical Attitudes

Donald Oken, M.D., Chicago

NO PROBLEM is more vexing than the decision about what to tell the cancer patient. (Although the word cancer is neither a medical term nor a specific entity, common sense considerations provide a basis for use of this general term. As used in the present work, the term should be understood to apply to all malignant neoplasms of characteristicly grave prognosis.) The situation is an ever recurring one and the questions involved are knotty. What should the patient be told? How and when should this be done? The manner in which such questions are handled is crucial for the patient and may determine his emotional status and capacity for function from that time on. It is easy enough to decide to follow a course which will "do least harm," but it is far from simple to determine just what course that is. The issues involved are complex factors which are difficult to assess, weigh, and place in proper perspective.

In his attempt to work out some solution, the doctor needs all the help he can get. The issues are a favorite and, often, heated topic of "corridor consultations." Often the opinion of a psychiatrist is sought; but psychiatric knowledge provides no clear and unequivocal answers. A considerable number of authors have attempted to provide assistance by describing their own views and approach. These writers, often wise and distinguished teachers drawing on long experience, offer solutions based on that

A questionnaire and interviews were used to study the policies of 219 physicians about "telling" cancer patients. Ninety per cent indicated a preference for not telling. Although clinical experience was cited by three-quarters as the major policy determinant, the data bear no relation to experience or age. Instead, inconsistencies, opinionatedness, and resistance to change and to research were found which indicated emotion-laden *a priori* personal judgments as the real determinants. Feared reactions to telling (i.e., suicide) could rarely be substantiated. Equally undocumented assumptions were given as justifications for telling. Underlying were feelings of pessimism and futility about cancer. The strong feelings mobilized by our deep and serious concerns for cancer patients, and our difficulties in helping them, stimulate denial mechanisms. These responses, unfortunately, operate as interferences to progress in cancer therapy.

Friesen<sup>1</sup> queried 100 cancer patients and found 89

90% of physicians indicated that they preferred **NOT** to tell their patients of a cancer diagnosis!

# Patients Want to Know

## GENERALLY

96% OF AMERICANS INDICATED THAT THEY WOULD WANT TO BE TOLD OF A DIAGNOSIS OF CANCER

85% WOULD WANT TO BE GIVEN A REALISTIC ESTIMATE OF THEIR LIFE EXPECTANCY

# Goals of Care-Definition

## Use and Meaning of "Goals of Care" in the Healthcare Literature: a Systematic Review and Qualitative Discourse Analysis

Katharine Secunda, MD<sup>1,2</sup>, M Jeanne Wippsa, MA, BCC<sup>3</sup>, Kathy J Neely, MD, MA<sup>1,4</sup>, Eytan Smulowicz, MD<sup>1,4</sup>, Gordon J Wood, MD<sup>1,4</sup>, Ellen Panazzo, LCSW<sup>5</sup>, Joan McGrath, RN<sup>6</sup>, Anne Levenson, MD<sup>1,2</sup>, Jonna Peterson, MLS<sup>1,5</sup>, Elsa J Gordon, PhD, MPH<sup>1,6,7,8</sup>, and Jacqueline M Kruser, MD, MS<sup>1,2,7</sup>

<sup>1</sup>Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>2</sup>Department of Medicine, Division of Pulmonary and Critical Care, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>3</sup>Northwestern Memorial Hospital, Chicago, IL, USA; <sup>4</sup>Department of Medicine, Division of Hospital Medicine, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>5</sup>Galler Health Sciences Library and Learning Center, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>6</sup>Department of Surgery, Division of Transplantation, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>7</sup>Center for Health Services and Outcomes Research, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; <sup>8</sup>Center for Bioethics and Medical Humanities, Northwestern University Feinberg School of Medicine, Chicago, IL, USA.

**BACKGROUND:** The specific phrase "goals of care" (GOC) is pervasive in the discourse about serious illness care. Yet, the meaning of this phrase is ambiguous. We sought to characterize the use and meaning of the phrase GOC within the healthcare literature to improve communication among patients, families, clinicians, and researchers.

**METHODS:** A systematic review of the English language healthcare literature indexed in MEDLINE/PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Scopus was performed in October of 2018. We searched for all publications with the exact phrase "goals of care" within the title or abstract; no limitations on publication date or format were applied; conference abstracts were excluded. We used qualitative, discourse analysis to identify key themes and generate an operational definition and conceptual model of GOC.

**RESULTS:** A total of 214 texts were included in the final analysis. Use of GOC increased over time with 67% of included texts published in the last decade (2009-2018). An operational definition emerged from consensus within the published literature: the overarching aims of medical care for a patient that are informed by patients' underlying values and priorities, established within the existing clinical

**DISCUSSION:** The use of the phrase "goals of care" within the healthcare literature is increasingly common. We identified a consensus, operational definition that can facilitate communication about serious illness among patients, families, and clinicians and provide a framework for researchers developing interventions to improve goal-concordant care.

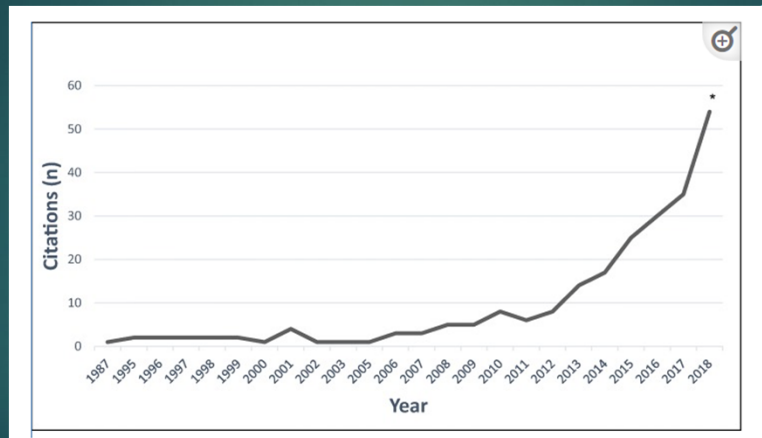
**KEY WORDS:** palliative care; terminology; terminal care; systematic review; discourse analysis.

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### INTRODUCTION

The specific phrase "goals of care" (GOC) is used pervasively by clinicians, researchers, and health policymakers who aim to provide the best possible care for patients with serious illnesses. Despite widespread

# Goals of Care Use in Literature



## Goals of Care Definition

*Palliative Medicine* 1987; 1: 136-148

### A comparison of hospice and hospital: care goals set by staff

**Barry Lunt** Senior Research Fellow, Community Medicine, University of Southampton and  
**Cherie Neale** Production Co-ordinator, Countess Mountbatten House, Southampton

**Key words:** motivation, organizational objectives, palliative treatment, terminal care

It has been suggested an important difference between hospice and hospital care is that hospice care is more geared to the attainment of patient and family goals, and that these goals concern a broader range of comfort, psychosocial, and rehabilitation issues. This study investigated whether such differences exist. Structured interviews were conducted with doctors and nurses in two NHS hospices, and three medical and two surgical wards of a district general hospital (DGH), to ascertain their goals of care and treatment for random samples of newly admitted terminally ill cancer patients (29 in the DGH and 29 and 28 in the hospices). DGH doctors set fewer goals in total, dealing with fewer issues, than hospice doctors or DGH nurses, and took longer to do so. Hospice and DGH nurses did not differ in the number or content of goals set, or speed of goal setting. DGH doctors set fewer goals concerning rehabilitation and the patient's emotional state



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The specific phrase “goals of care” (GOC) is used pervasively by clinicians, researchers, and health policymakers who aim to provide the best possible care for patients with serious illnesses. Despite widespread

“Despite widespread use, the meaning of this phrase is **ambiguous** and **lacks consensus** or operational definition”



# Goals of Care Definition

GOC are operationally defined as the **overarching aims of medical care**

for a **patient** that are informed by **patient** underlying **values and priorities**,

established within the existing **clinical context**, and used to guide decisions about the use of or limitation on specific medical interventions.

## Overarching aims of medical care

"Overarching"

"Big picture"

"Global"

"Aim"

"Purpose"

"Direction"

"Telos"



# Telos



Translated variously as "end," "goal," or "purpose." According to Aristotle, we have a telos as humans, which it is our goal to fulfill. This telos is based on our uniquely human capacity for rational thought.

# Patient's Values and Priorities



Developed in the context of the patient's values

Patient's priorities and rankings of relative values

# CONTEXT



Patients with disease which is typically considered to have a poor prognosis (dementia or advanced cancer)

Patients who have reached a phase of any disease for which cure was not possible or death was imminent

Patients were receiving care within a specific healthcare setting where incurable, serious, life limiting, and life-threatening disease illnesses are common (Nursing home, emergency department, intensive care unit)

# Clinical Context



Appropriate

Attainable

Realistic

Reasonable

Possible

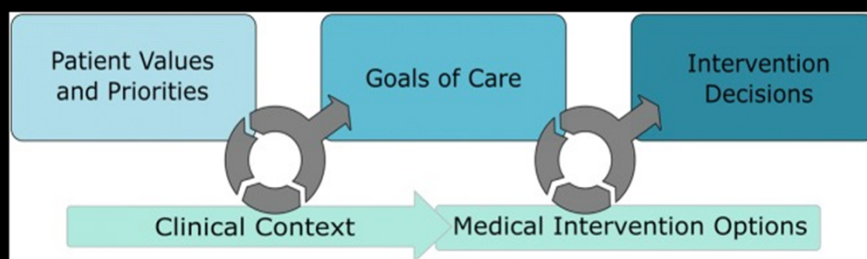
Woody Allen-"I don't want to achieve immortality through my work. I want to achieve it though not dying."

# Medical intervention decisions

A Goal of Care is NOT a medical intervention plan

Goal of Care describes a construct to guide medical intervention decisions

"How will a test or intervention help achieve the patient's goals?"



# Goals of Care-Importance

Provide patient autonomy and patient centered care

Avoid unwanted care

Identify valued care

Confer psychological support for patients and their families

# Goals of care conversation-who ?

Metastatic Cancer

Dementia

Admission from a long-term care or skilled nursing facility

Chronic illness (CHF, COPD, ESRD) with a prior ICU admission

Chronic illness greater than age 85

"Surprise" question

# The “Surprise” Question



“WOULD YOU BE SURPRISED  
IF THIS PATIENT DIED IN THE  
NEXT 12 MONTHS?”

## Importance



Lack of communication leads to default “aggressive treatment”

Longer length of stay

Higher 30-day readmission rates

Journal of Pain and Symptom Management, Volume 58, Issue 5, November 2019, Pages 864-870

# GOALS of CARE

Sit down

Communication study

Effect of sitting vs. standing on perception of provider time at bedside:  
A pilot study

Kelli J. Swayden<sup>a</sup>, Karen K. Anderson<sup>b</sup>, Lynne M. Connelly<sup>c</sup>, Jennifer S. Moran<sup>d</sup>,  
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## ARTICLE INFO

### Article history:

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### Keywords:

Provider-patient communication

Physician behavior

Patient satisfaction

Patient care outcomes

Quality improvement

## ABSTRACT

**Objective:** Patients commonly perceive that a provider has spent more time at their bedside when the provider sits rather than stands. This study provides empirical evidence for this perception.

**Methods:** We conducted a prospective, randomized, controlled study with 120 adult post-operative inpatients admitted for elective spine surgery. The actual lengths of the interactions were compared to patients' estimations of the time of those interactions.

**Results:** Patients perceived the provider as present at their bedside longer when he sat, even though the actual time the physician spent at the bedside did not change significantly whether he sat or stood. Patients with whom the physician sat reported a more positive interaction and a better understanding of their condition.

**Conclusion:** Simply sitting instead of standing at a patient's bedside can have a significant impact on patient satisfaction, patient compliance, and provider-patient rapport, all of which are known factors in decreased litigation, decreased lengths of stay, decreased costs, and improved clinical outcomes.

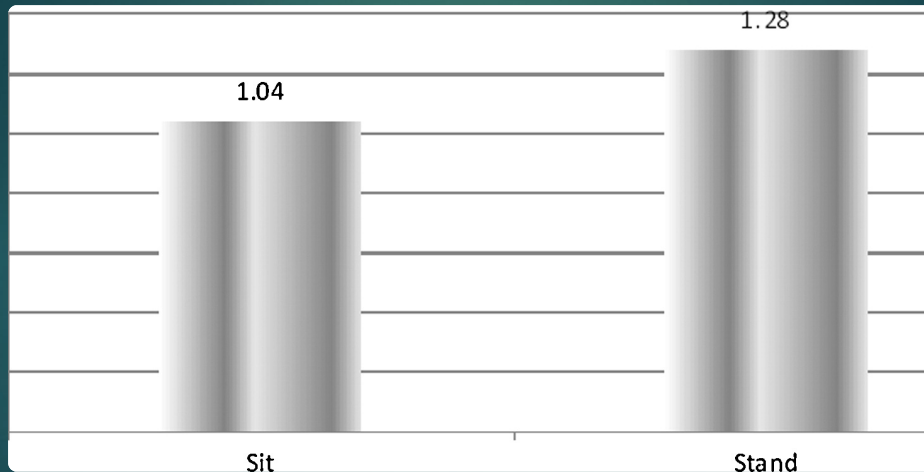
**Practice implications:** Any healthcare provider may have a positive effect on doctor-patient interaction by sitting as opposed to standing during a hospital follow-up visit.

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## 1. Introduction

length of visit in the outpatient family practice setting, noting that  
patient perception of provider time at bedside was a significant factor in

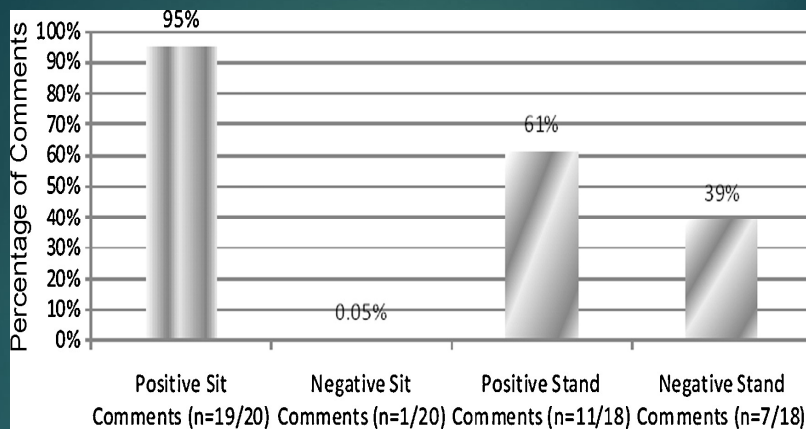
# Post operative patients



Time spent



# Comments



- "The doctor took the time to sit and listen."
- "He sat down long enough to get all of my questions answered."
- "I didn't have time to ask the doctor any questions."
- "He was in and out of my room before I even knew what was going on."

# Goals of Care Conversation

Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction\*

Jonathan R. McDonagh, MD; Tricia B. Elliott; Ruth A. Engelberg, PhD; Patsy D. Treece, RN, MN; Sarah E. Shannon, PhD, RN; Gordon D. Rubenfeld, MD, MSc; Donald L. Patrick, PhD, MSPH; J. Randall Curtis, MD, MPH

**Objective:** Family members of critically ill patients report dissatisfaction with family-physician communication about withdrawing life support, yet limited data exist to guide clinicians in this communication. The hypothesis of this analysis was that increased proportion of family speech during ICU family conferences would be associated with increased family satisfaction.

**Design:** Cross-sectional study.

**Setting:** We identified family conferences in intensive care units of four Seattle hospitals during which discussions about withdrawing life support were likely to occur.

**Participants:** Participants were 214 family members from 51 different families. There were 36 different physicians leading the conferences, as some physicians led more than one conference.

**Interventions:** Fifty-one conferences were audiotaped.

**Measurements:** We measured the duration of time that families and clinicians spoke during the conference. All participants were given a survey assessing satisfaction with communication.

**Results:** The mean conference time was 32.0 mins with an SD of 14.8 mins and a range from 7 to 74 mins. On average, family members spoke 29% and clinicians spoke 71% of the time. Increased proportion of family speech was significantly associated with increased family satisfaction with physician communication. Increased proportion of family speech was also associated with decreased family ratings of conflict with the physician. There was no association between the duration of the conference and family satisfaction.

**Conclusions:** This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. Future studies should assess the effect of interventions to increase listening by critical care clinicians on the quality of communication and the family experience. (Crit Care Med 2004; 32:1404-1408)

**Key Words:** end-of-life care; family satisfaction; communication; death; dying; critical care

Shut up  
At least some...

Death is unfortunately a common occurrence in the intensive care unit (ICU); a recent study suggests that approximately 29% of deaths in the United States occur after a stay in the ICU (1). The majority of deaths that occur in the ICU throughout North America and Europe involve withholding or withdrawing life-sustaining therapy (2-6). At the

time this decision occurs, most patients are unable to communicate for themselves, and therefore communication about decision making is often delegated to family members and clinicians (7). This decision making frequently occurs in the context of a "family conference" in which clinicians and families discuss the patient's condition and prognosis and the therapeutic options. Communication with clinicians is extremely important to family members: Families rate the communication skills of clinicians as having equal or higher importance than clinical skills (8). Interventions to increase communication with the family have been shown to reduce ICU length of stay for patients who ultimately die (9-11), but there is

expertise with family communication. Furthermore, studies suggest that ICU family conferences frequently do not meet families' needs for communication (12-14). Recent recommendations call on critical care clinicians to improve communication with families and to consider this an important part of high-quality care (15-17), and yet few studies suggest how communication might be improved. We examined communication during ICU family conferences concerning withdrawing life-sustaining treatments or the delivery of bad news. The overall aims of the study were to describe the content and process of clinician-family communication about end-of-life care occurring as part of ICU family conferences and to eval-

\*See also p. 1609.  
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Received in final form for publication May 10, 2004.

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**Interventions:** Fifty-one conferences were audiotaped.

**Measurements:** We measured the duration of time that families and clinicians spoke during the conference. All participants were given a survey assessing satisfaction with communication.

**Results:** The mean conference time was 32.0 mins with an SD of 14.8 mins and a range from 7 to 74 mins. On average, family members spoke 29% and clinicians spoke 71% of the time. Increased proportion of family speech was significantly associated with increased family satisfaction with physician communication. Increased proportion of family speech was also associated with decreased family ratings of conflict with the physician. There was no association between the duration of the conference and family satisfaction.

**Conclusions:** This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. Future studies should assess the effect of interventions to increase listening by critical care clinicians on the quality of communication and the family experience. (*Crit Care Med* 2004; 32:1484-1488)

**Key Words:** end-of-life care; family satisfaction; communication; death; dying; critical care

Death is unfortunately a common occurrence in the intensive care unit (ICU); a recent study suggests that approximately 20% of deaths in the United States occur after a stay in the ICU (1). The majority of deaths that occur in the ICU throughout North America and Europe involve withholding or withdrawing life-sustaining therapy (2-6). At the

time this decision occurs, most patients are unable to communicate for themselves, and therefore communication about decision making is often delegated to family members and clinicians (7). This decision making frequently occurs in the context of a "family conference" in which clinicians and families discuss the patient's condition and prognosis and the therapeutic options. Communication with clinicians is extremely important to family members. Families rate the communication skills of clinicians as having equal or higher importance than clinical skills (8). Interventions to increase communication with the family have been shown to reduce ICU length of stay for patients who ultimately die (9-11), but there is

expertise with family communication. Furthermore, studies suggest that ICU family conferences frequently do not meet families' needs for communication (12-14). Recent recommendations call on critical care clinicians to improve communication with families and to consider this an important part of high-quality care (15-17), and yet few studies suggest how communication might be improved. We examined communication during ICU family conferences concerning withdrawing life-sustaining treatments or the delivery of bad news. The overall aims of the study were to describe the content and process of clinician-family communication about end-of-life care occurring as part of ICU family conferences and to eval-

\*See also p. 1490.  
From the Department of Medicine, School of Medicine URM, TBE, FAE, POF, GOR, JRC, Department of Biomedical Nursing and Health Systems, School of Nursing (SES, JRC, JRC), and Program in Social and Behavioral Sciences, Department of Health Services, School of Public Health (JRP, JRC), University of Washington, Seattle, WA.  
Received in final form for publication May 10, 2004.

There was no association between the duration of the conference and family satisfaction.

The duration of the physician's opening monologue was an average of 4.2 mins and a range from no opening monologue at all to a maximum of 14.4 mins.

There was a significant and positive association between the length of the opening monologue and the length of the conference  
Longer conferences having longer opening monologues

SPIKES Protocol-MD Anderson Cancer Center, Toronto-Sunnybrook Regional Cancer Centre  
SUPER-Duke  
REMAP-Dana Farber, Univ of Pittsburg, Univ of Washington  
Serious Illness Conversation Guide-Ariadne Laboratories and Dana-Farber

## Serious Illness Conversation Guide

### CONVERSATION FLOW

- 1. Set up the conversation**
  - Introduce purpose
  - Prepare for future decisions
  - Ask permission
- 2. Assess understanding and preferences**
- 3. Share prognosis**
  - Share prognosis
  - Frame as a "wish...worry", "hope...worry" statement
  - Allow silence, explore emotion
- 4. Explore key topics**
  - Goals
  - Fears and worries
  - Sources of strength
  - Critical abilities
  - Tradeoffs
  - Family
- 5. Close the conversation**
  - Summarize
  - Make a recommendation
  - Check in with patient
  - Affirm commitment
- 6. Document your conversation**
- 7. Communicate with key clinicians**



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# SET UP THE CONVERSATION



## SIT DOWN

Introduce purpose

Prepare for future decisions

Ask permission

# Set Up the Conversation



"I'd like to talk about what is ahead with your illness and about your wishes in advance about what is important to you so that I can make sure to provide you with the care you want — is this okay?"

## ASSESS UNDERSTANDING

What is your understanding about where you are with your illness?

"How much information would you like for me about what is ahead?"

## ASSESS INFORMATION PREFERENCES

How much does your patient WANT to know?

"How much information about what is ahead of with your illness would you like to know from me"?

# SHARE PROGNOSIS (if they asked)

"I want to share with you my understanding of where things are with your illness"

# SHARE PROGNOSIS

## UNCERTAIN:

"It may be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time, but I am worried that you could get sick quickly, and I think it is important to prepare for that possibility"




# SHARE PROGNOSIS



## FUNCTION:

*"I hope this is not the case, but I am worried that this may be as strong as you feel, and it is likely to get more difficult"*




# SHARE PROGNOSIS



## TIME:

*"I wish we are not in this situation, but I am worried that the time may be short"*  
(Days to weeks, weeks to months, months to a year)



# SHARE PROGNOSIS



Avoid medical jargon

Allow SILENCE

## Explore Key Topics



Goals

Fears and worries

Sources of strength

Critical abilities

Trade-offs

Family

# Goals

“What are your most important goals if your health situation worsens?”

# Fears or Worries

“What are your biggest fears or worries about the future?”

# Sources of Strength



“What gives you strength as you think about the future?”

“

# Critical Abilities



“What abilities are so critical to your life that she cannot imagine living without them?”

# Tradeoffs

“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

# FAMILY

“How much does your family know about your wishes?”



# Close the conversation



Summarize

Recommend

Affirm Commitment



# Close the conversation



Sounds like \_\_\_\_\_ is very important to you. Keeping that in mind, and what we know about your illness at this state **I recommend:**

Does this plan seem to you?

I will do everything I can to help you through this



# SPIKES Protocol

- ▶ **S**et Up
- ▶ **P**erception
- ▶ **I**nvitation
- ▶ **K**nowledge
- ▶ **E**motions
- ▶ **S**ummary

## Set Up

Privacy

Who would you like to be present?

SIT DOWN

Make a connection with the patient

Make sure you allot sufficient time

**REMEMBER THE TISSUES!**



## Perception

"What have you been told about your medical situation so far?"

"What is your understanding of the reasons that we did the MRI?"



## Invitation

"How would you like me to give you the information about the test results? "

"Would you like for me to give you all of the information, or just a summary? "

# Knowledge



Warning shot

"Unfortunately I have got some serious news to tell you"

"I am sorry to have to tell you that..."

# Knowledge



Start with the level of comprehension and vocabulary of the patient

Nontechnical language

Avoid excessive bluntness

Give information in small chunks

Periodically check the patient's understanding

# Emotions



Observe

Identify

Confirm the reason for the emotion

Give the patient time to express his or her feelings

Do not be afraid of silence

# Strategy-Summary



Check patient's understanding and expectations.

“Are you ready to discuss the next steps?”

Establish “Goals of Care”

Frame hope in terms of what is possible to accomplish

# Things NOT to say:

"You have a very bad cancer, and unless we you get treatment immediately you are going to die. "

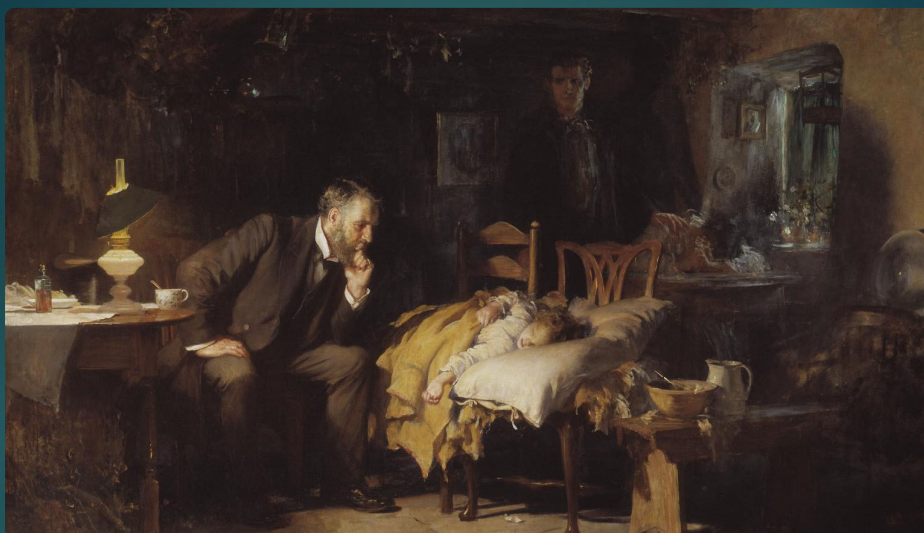
"There is nothing more we can do. "

"You have to..."

"Withdraw care"

"This not good. You die soon. "

<https://www.nejm.org/doi/full/10.1056/NEJMvcm191305>



## The Doctor

Luke Fildes

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