

Decision-Making about Goals of Care For Hospitalized Medical Patients

PHYSICIAN VERSION

We would greatly appreciate your participation in this questionnaire which addresses communication and decision-making about goals of care with seriously ill hospitalized patients and their families.

Goals of Care

We define communication and decision-making about **goals of care** as a conversation in which, ideally, a patient or family member and the healthcare team establish the goals of treatment (e.g., cure, prolongation of life, comfort) and agree upon the types of life sustaining technology that will (or will not) be used to achieve those goals (e.g., CPR, mechanical ventilation, dialysis, intensive care unit admission, feeding tubes, or intravenous hydration).

In this questionnaire, we are interested in your perspective about:

- (1) The importance of various barriers to communication and decision-making about goals of care with seriously ill hospitalized patients and their families
- (2) Your suggestions to improve communication and decision-making about goals of care with these patients and their families
- (3) Your perceived role and the role that others may play in communication and decision-making about goals of care with these patients and their families

- **This questionnaire will take approximately 15 minutes to complete.**
- **Please select the single best response to each question unless otherwise requested.**
- **All responses will remain confidential.**

Section 1

Barriers to Discussions about Goals of Care

Scenario: A 70 year old patient who has severe COPD (on home oxygen), is housebound, and requires assistance for most activities of daily living, is admitted to the medical ward under your care with an exacerbation of their COPD. The patient's acute symptoms have resolved. You are uncertain about the patient's goals of care and preferences regarding the use (or non-use) of life sustaining technology.

Barriers Related to the Patient/Family

1. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency and circle the best response from 1 = Extremely Unimportant Barrier to 7 = Extremely Important Barrier.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) Patient does not have an advance directive						
1	2	3	4	5	6	7
b) Patient has an advance directive but it lacks sufficient detail						
1	2	3	4	5	6	7
c) Patients' difficulty accepting their poor prognosis						
1	2	3	4	5	6	7
d) Patients' difficulty understanding the limitations and complications of life sustaining therapies						
1	2	3	4	5	6	7
e) Lack of patient capacity to make decisions about goals of care						
1	2	3	4	5	6	7
f) Family members' difficulty accepting their loved one's poor prognosis						
1	2	3	4	5	6	7
g) Family members' difficulty understanding the limitations and complications of life sustaining therapies						
1	2	3	4	5	6	7
h) Lack of agreement amongst family members about goals of care						
1	2	3	4	5	6	7
i) Language barriers						
1	2	3	4	5	6	7
j) Differences in approach to discussing goals of care in some cultures						
1	2	3	4	5	6	7

Barriers Related to the Role of Physicians

2. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) Uncertainty in estimating prognosis						
1	2	3	4	5	6	7
b) Lack of training to have these conversations (e.g. not sure what to say, etc.)						
1	2	3	4	5	6	7
c) Desire to avoid being sued						
1	2	3	4	5	6	7
d) Desire to maintain hope						
1	2	3	4	5	6	7

Barriers Related to the System or External factors

3. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please rate the importance of the following barriers in preventing **you** from talking to them and/or their family members about the patient's goals of care. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
a) Lack of time to have conversations with patients/family						
1	2	3	4	5	6	7
b) Lack of availability of substitute decision maker(s)						
1	2	3	4	5	6	7
c) Uncertainty about who is the substitute decision maker						
1	2	3	4	5	6	7
d) Lack of an appropriate location to maintain patient confidentiality and privacy						
1	2	3	4	5	6	7
e) Insufficient remuneration for this activity						
1	2	3	4	5	6	7
f) Lack of pre-existing relationship with patient/family						
1	2	3	4	5	6	7
g) Lack of awareness of what other members of the care team have said						
1	2	3	4	5	6	7
h) Disagreement among healthcare team about goals of care						
1	2	3	4	5	6	7

Other Barriers

4. Reflecting on your most recent month on an acute medical ward, for patients such as the one described in the above scenario, please describe any **other barriers** in preventing **you** from talking to them and/or their family members about the patient's goals of care and rate their importance. As you rate the importance of each barrier, consider both the magnitude of the barrier and its frequency.

Extremely Unimportant Barrier	Very Unimportant Barrier	Somewhat Unimportant Barrier	Neither Important nor Unimportant Barrier	Somewhat Important Barrier	Very Important Barrier	Extremely Important Barrier
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a) Other Barrier (please specify): _____

1 2 3 4 5 6 7

b) Other Barrier (please specify): _____

1 2 3 4 5 6 7

c) Other Barrier (please specify): _____

1 2 3 4 5 6 7

d) Other Barrier (please specify): _____

1 2 3 4 5 6 7

Section 2

Suggestions to Improve Communication and Decision-Making about Goals of Care

1. Reflecting on the barriers which you rated as **Very Important** or **Extremely Important** in Section 1, what specific suggestions do you have about ways to overcome these barriers and make it easier for health care providers to talk with patients and their family members about goals of care?

2. What is currently working well to promote communication and decision-making about goals of care between health care providers and patients and their family members?

Section 3

Health Care Providers' Role in Communication and Decision-Making about Goals of Care

Please consider the same scenario as in Section 1: A 70 year old patient who has severe COPD (on home oxygen), is housebound, and requires assistance for most activities of daily living, is admitted to the medical ward under your care with an exacerbation of their COPD. The patient's acute symptoms have resolved. You are uncertain about the patient's goals of care and preferences regarding the use (or non-use) of life sustaining technology.

Consider that the process of communication and decision making can be broken down into the following steps: initiating the conversation, exchanging information, coaching, and deciding.

Willingness to Participate in Communication and Decision-Making about Goals of Care

Extremely Unwilling	Very Unwilling	Somewhat Unwilling	Neither Willing nor Unwilling	Somewhat Willing	Very Willing	Extremely Willing
1. Rate your willingness to <u>initiate discussions</u> about goals of care <i>with</i> patients such as these, and their families.						
1	2	3	4	5	6	7
2. Rate your willingness to <u>exchange information</u> (e.g., disclose diagnosis, prognosis and elicit values) <i>with</i> patients such as these, and their families, who are trying to reach a decision about goals of care.						
1	2	3	4	5	6	7
3. Rate your willingness to be a <u>decision coach</u> (clarifying values, assisting with weighing options for care, etc.) <i>for</i> patients such as these, and their families, who are trying to reach a decision about goals of care.						
1	2	3	4	5	6	7
4. Rate your willingness to participate in <u>making a final decision about</u> goals of care <i>with</i> patients such as these, and their families.						
1	2	3	4	5	6	7

Participation of Health Care Professionals in Communication and Decision-Making about Goals of Care

For each category of hospital-based health care professionals listed below, please rate how acceptable you would find it for that group of individuals to be involved with each of the following activities:

5. Initiating discussions about goals of care:

Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician						
1	2	3	4	5	6	7
b) Resident						
1	2	3	4	5	6	7
c) Bedside nurse						
1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)						
1	2	3	4	5	6	7
e) Social worker						
1	2	3	4	5	6	7
f) Other (specify): _____						
1	2	3	4	5	6	7

6. Exchanging information (e.g., disclose diagnosis, prognosis and elicit values):

Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician						
1	2	3	4	5	6	7
b) Resident						
1	2	3	4	5	6	7
c) Bedside nurse						
1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)						
1	2	3	4	5	6	7
e) Social worker						
1	2	3	4	5	6	7
f) Other (specify): _____						
1	2	3	4	5	6	7

7. **Decision coach** (clarifying values, assisting with weighing options for care, etc.):

Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician						
1	2	3	4	5	6	7
b) Resident						
1	2	3	4	5	6	7
c) Bedside nurse						
1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)						
1	2	3	4	5	6	7
e) Social worker						
1	2	3	4	5	6	7
f) Other (specify): _____						
1	2	3	4	5	6	7

8. **Making a final decision** about goals of care:

Extremely Unacceptable	Very Unacceptable	Somewhat Unacceptable	Neither Acceptable nor Unacceptable	Somewhat Acceptable	Very Acceptable	Extremely Acceptable
a) Staff physician						
1	2	3	4	5	6	7
b) Resident						
1	2	3	4	5	6	7
c) Bedside nurse						
1	2	3	4	5	6	7
d) Advance practice nurse (i.e., clinical nurse specialist or nurse practitioner)						
1	2	3	4	5	6	7
e) Social worker						
1	2	3	4	5	6	7
f) Other (specify): _____						
1	2	3	4	5	6	7

Section 4 Personal Demographics

1. What is your current position?

- PGY-1
- PGY-2
- PGY-3
- PGY-4 or above
- Staff physician (If yes, how many years have you been in independent practice? _____ years)

2. a) For residents, how many weeks of a Medical Teaching Unit rotation have you completed so far during your residency?

_____ weeks

2. b) For staff physicians, on average, how many weeks per year do you work on a Medical Teaching Unit?

_____ weeks

3. Where did you graduate from medical school?

- Canada
- United States
- United Kingdom / Ireland / Australia / New Zealand
- Europe
- Asia
- Middle East
- Central or South America
- Africa
- Other: _____

4. Have you ever worked on a formal palliative care consultation or inpatient service (includes resident rotation)?

- Yes
- No

5. Please indicate if you have formal specialty training in a field other than general internal medicine? (check all that apply)

- Critical Care
- Respiriology
- Cardiology
- Endocrinology
- Gastroenterology
- Geriatrics
- Hematology
- Infectious Diseases
- Medical Oncology
- Nephrology
- Rheumatology
- Other (please specify): _____

6. Please rank your current level of skill in having goals of care discussions and making goals of care decisions with patients and families:

Limited (skill not developed)	Fair	Average (skill comparable to colleagues at same level)	Very Good	Expert (skill comparable to a palliative care physician)
1	2	3	4	5

7. Please rank your priority (1 to 5) for learning this skill:

Low Priority (not of interest or already mastered)				High Priority (#1 on personal learning agenda)
1	2	3	4	5

8. a) Have you received any formal training regarding communication with patients and families about goals of care?

- Yes → If yes, please answer question 8b
- No

8. b) Please rate the quality of the formal training you received regarding communication with patients and families about goals of care

Extremely Low	Very Low	Moderately Low	Neither High nor Low	Moderately High	Very High	Extremely High
1	2	3	4	5	6	7

9. What is your age?

_____ years

10. What is your sex?

- Male
- Female

11. Do you see yourself as:

(Check only one)

- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.)
- West Asian (e.g., Iranian, Afghan, etc.)
- Korean
- Japanese
- Native American
- Other: _____

12. Please indicate your religious background:

(Check only one)

- | | |
|---|---|
| <input type="checkbox"/> Roman Catholic | <input type="checkbox"/> Buddhist |
| <input type="checkbox"/> Protestant Christian | <input type="checkbox"/> Hindu |
| <input type="checkbox"/> Orthodox Christian | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Other Christian | <input type="checkbox"/> No religious affiliation |
| <input type="checkbox"/> Muslim | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Jewish | |

13. How important is spirituality or religion in your life?

Extremely Unimportant	Very Unimportant	Somewhat Unimportant	Neither Important nor Unimportant	Somewhat Important	Very Important	Extremely Important
1	2	3	4	5	6	7

14. Have you had personal experience with a close family member or friend being hospitalized in an intensive care unit?

- Yes
- No

Thank you for your participation in this survey!
Please return this survey in the provided envelope.