

Date: _____

Time: _____

**RIVERSIDE GRANT
PALLIATIVE CARE INTERVIEW QUESTIONS**

Goal: to obtain patient perspectives on their ED visit, in order to develop an appropriate ED triage tool for Palliative Care

PATIENTS:

1. **Diagnosis of CHF / COPD / Dementia** (circle one)
2. **Family Member Present? Y / N**
3. **Interview conducted with: patient / family member or caregiver / both** (circle one)
4. **Is family or caregiver present? Y / N**

1. Understanding of presenting problem

- a. What was the reason you went to the emergency room?
- b. Have you been to the ED in last year for the same problem?
 - i. If so how many times?
- c. Is there anything outside of the hospital that could have prevented you coming to the ED? (if no answer, 'sometimes people say that that they come to the ED because they couldn't get an appointment with their primary care provider, some equipment at home broke, they couldn't afford the equipment they needed, or they ran out of a prescription – would anything like that have helped you to avoid coming to the ED?)

2. Length of ED Visit

- a. How long was the wait to see a provider?
- b. How long was the wait to resolve your problem / receive treatment?
- c. Were you kept informed of the progress made with the management of your condition?

3. Interaction / communication

- a. How did your ED Doctor / Nurse (circle one) communicate with you about your condition?
- b. What could have been improved about the communication and interaction with your provider in the ED?
- c. What information would you have liked to receive?

4. Palliative Care

- a. Do you have an illness that might limit your lifespan?
- b. What are your fears?
- c. What are your goals in managing your health?
- d. Do you have a living will?
- e. Have you have a family member or other caregiver that can make decisions for you?

5. Patient Preferences

- a. Do you feel you were offered choices related to your care today?
- b. Do you feel you were a part of your medical planning?
- c. Do you understand your current illness?
- d. Have you had a chance to speak with your doctor about treatment options?

6. Symptom Management

- a. Did your nurse / doctor (circle one) ask you if you had pain?
- b. Was your pain treated in the ED today?
- c. Do you have other symptoms that are bothering you?
- d. Were your other symptoms discussed and treated today?

7. Improvements

- a. What was the best thing about your ED visit?
- b. What would have been more helpful to you during your ED visit?
- c. Is there anything else you wanted to share about your ED visit today?

Date: _____

Time: _____

STAFF:

1. Please specify your role in the ED:
 - a. Physician (**faculty / resident**)
 - b. Nurse (**RN / ARNP / LPN / ?**)
 - c. Technician
2. What shift do you most commonly work? **Days / Evenings / Nights (circle one)**
3. How many years of experience do you have in Emergency Medicine? _____

1. Easy identification of palliative patients in ED

- a. How do you identify patients with life-limiting illness in the ED?
- b. What parameters do you use to identify a hospice patient?
- c. What parameters do you use to identify a palliative care patient?
- d. What would be helpful to improve the process of identifying palliative and hospice patients in the ED?
- e. What is most challenging in caring for chronically ill and end of life patients in the ED?

2. Palliative consultation

- a. Do you know how to consult palliative care or refer a patient to hospice?
 - i. When do you?
 - ii. Where do you?
 - iii. How do you?
- b. What would simplify the process of referring patients to palliative care for consultations?
- c. What are barriers to consulting Palliative Care?

3. Communication / Interaction with patient

- a. What specific areas could you use some assistance with in communicating to patients and families dealing with chronic and end of life illness?
- b. What is most challenging in communicating and interacting with palliative care patients in the ED?
- c. What would be helpful to improve communication with palliative care patients in the ED?

4. General Development

- a. What triggers in the ED should initiate a Palliative Care consult?
- b. What would be important to consider when developing such a triggers?

Riverside Grant Survey

ED Physicians (FACULTY)

1. Have you ever referred an ED patient for a palliative care consult?

No--- Yes--- Rarely---- Frequently----

2. Do you ask your ED patients about advanced care directives (DNR, who makes their decisions, etc)?

No---- Yes----

3. How do you determine baseline functioning of chronically ill ED patients regarding activities of daily living (ambulation, eating, bathing, etc.) ?

Ask during H and P----- Nursing notes----- Do not ask----- Other-----

4. Do you read the case management notes in EPIC?

No--- Yes--- Rarely---- Frequently----

5. What is the most challenging issue you deal with in caring for patients with frequent ED visits that have the diagnosis of:

CHF

COPD

Dementia

Riverside Project ED Screening Tool Draft

1. General Information

Relation of person providing information (circle): Patient parent child sibling other: _____

Patient Age: _____ Date of ED Visit: _____ Mode of Arrival: Car EMS Bus Private ALS other _____

Arrived from: home nursing home another hospital specialty hospital shelter other: _____

Key Caregiver(s): Who helps take care of you/patient or do you take care of yourself? Self Someone else

Name: _____ Relation: _____ Phone: _____

What physician is taking care of most of your medical problems (Primary care and/or specialists)

Do you make your own health care decisions? Yes No

If you were unable to make healthcare decisions, who would you select to make those choices?

Name: _____ Relation: _____ Phone: _____

Do you have any advanced directives such as a Living Will, Do Not Resuscitate or Allow Natural Death orders?: Yes No

If yes, which ones: (circle all that apply): Living Will Do Not Resuscitate Natural Death

2. Language Is English your primary language?: Yes No If no, what is your primary language? _____

REALM-R: Unable to complete _____ Unable to speak < 6 words _____ Realm-R Score _____

3. Disease State: Do you or the person you are caring for/represent have one or more of the following advanced illnesses or symptoms:

Chronic Obstructive Pulmonary Disease (COPD) or other chronic lung disease? Y N	Oxygen dependent Y N	SOB at rest Y N	Bed bound more than 3 months? Y N Wt loss despite tube feedings? Y N Unable to care for self? Y N
Congestive Heart Failure (CHF) or other chronic heart disease? Y N	Oxygen dependent Y N	SOB at rest Y N	Bed bound more than 3 months? Y N Wt loss despite tube feedings? Y N Unable to care for self? Y N
Dementia, stroke, failure to thrive or Alzheimer's disease? Y N	Oxygen dependent Y N	SOB at rest Y N	Bed bound more than 3 months? Y N Wt loss despite tube feedings? Y N Unable to care for self? Y N
Cancer? Y N Metastatic, recurrent? Y N	Oxygen dependent Y N	SOB at rest Y N	No further curative treatment? Y N Bed bound more than 3 months? Y N Wt loss despite tube feedings? Y N Unable to care for self? Y N
Kidney Failure Y N Liver Failure? Y N	Oxygen dependent Y N	SOB at rest Y N	Bed bound more than 3 months? Y N Wt loss despite tube feedings? Y N Unable to care for self? Y N
Other conditions such as HIV or AIDS, Parkinson's or ALS? Other: _____	Oxygen dependent Y N	SOB at rest Y N	Bed bound more than 3 months? Y N Wt loss despite tube feedings? Y N Unable to care for self? Y N

- a. Have you ever been told you have a limited time to live because of your disease? Y N
- b. Have you had more than one ED visit in the last 3 months related to your disease(s)? Y N
- c. Have you had 2 or more hospital admissions for your disease in the last 6 months? Y N
- d. Have you had admission(s) to an ICU for your disease in the last 6 months? Y N

4. Is your ED visit today because of (related to): Check all that apply:

Difficult to control physical symptoms (nausea, shortness of breath, fatigue, etc.)		Difficult to manage or increasing emotional symptoms	
Uncontrolled pain		Feeding problems or weight loss	
Caregiver burnout or unavailable		Need for medications	
Need for equipment			

5. Functionality/Performance

Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair

6. Nutrition Is your oral intake: normal reduced sips none feeding tube

7. Pain and Symptom Assessment Circle the number that best describes your symptoms during the past week:

Pain	0 1 2 3 4 5 6 7 8 9 10 Worst possible pain
Tiredness	0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness
Anxiety or worry	0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety
Nausea	0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea
Weakness	0 1 2 3 4 5 6 7 8 9 10 Worst possible weakness
Drowsiness	0 1 2 3 4 5 6 7 8 9 10 Worst possible drowsiness
Distress	0 1 2 3 4 5 6 7 8 9 10 Worst distress
Shortness of breath	0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath

8. Comments and Notes

Riverside Project ED Screening Tool Provider Feedback Form

1. Provider description (please check one category):

ED Attending Physician ED Resident (PGY1, PGY2, PGY3)

ED Nurse Palliative Care Nurse ED Case Manager ED Physician Assistant

2. Feedback after reviewing completed ED screening tool:

Was any of the information contained on this form unknown to you after basic review of the triage note and EMR snapshot (new information)? Yes No

What were the two most helpful items from the form?

Will your management or orders for the patient change since reviewing the ED Screening Tool?

Yes No

If Yes, what will you do differently or add?

Thank you for your feedback!

ECOG Performance Status

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here for health care professionals to access.

ECOG PERFORMANCE STATUS*	
Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

* As published in Am. J. Clin. Oncol.:

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

REALM-R

Description of the Test

The REALM-R is a brief screening instrument used to assess an adult patient's ability to read common medical words. It is designed to assist medical professionals in identifying patients at risk for poor literacy skills. The REALM-R is a **word recognition** test – not a reading comprehension instrument. Adults are asked to de-code or pronounce words. The test takes less than 2 minutes to administer and score.

Preliminary data regarding the REALM-R has been published in the *Journal of General Internal Medicine* December 2003; 18:1036-1038.

Administration and Scoring:

1. Give the patient the laminated copy of the REALM-R word list. Attach the examiner record form to the clipboard. Hold the clipboard at an angle such that the patient is not distracted by your scoring procedure.

In your own words, introduce the REALM-R to the patient:

In a research setting or for research purposes:

"It would be helpful for us to get an idea of what medical words you are familiar with. What I need you to do is look at this list of words, beginning here [point to first word with pencil] . Say all of the words you know. If you come to a word you don't know, you can sound it out or just skip it and go on."

If the patient stops, say, "Look down this list [point] and say the other words you know."

In a clinical setting:

"Sometimes in this office, we may use medical words that patients aren't familiar with. We would like you to take a look at this list of words to help us get an idea of what medical words you are familiar with. It will help us know what kinds of patient education to give you. Start with the first word [point to 1st word with pencil], please say all of the words you know. If you come to a word you do not know, you can sound it out or just skip it and go on." If patient stops do as above.

****Special Note:** Do not use the words "read" and "test" when introducing and administering the REALM-R. These words may make patients feel uncomfortable and unwilling to participate.

"Please say these words for me?"

2. If the patient takes more than 5 seconds on a word, encourage the patient to move along by saying,

“Let’s try the next word.”

If the patient begins to miss every word or appears to be struggling or frustrated, tell the patient,

“Just look down the list and say the words you know.”

3. Count as an error any word that is not attempted or mispronounced (see “Special Considerations” for pronunciation/scoring guidelines).

4. Scoring options:

1) Place a check mark on the line next to each word the patient pronounces correctly.

OR

2) Place an X on the line next to each word the patient does not attempt or mispronounces.

Scoring should be strict, but take into consideration any problems which could be related to dialect or articulation difficulties. Use the dictionary if in doubt. Count as correct any self-corrected word. ***In our study we chose to define ‘at risk patients’ as those with a score of six or less.***

Special Considerations for Administration and Scoring:

Examiner Sensitivity:

Many low literate patients will attempt to hide their deficiency. Ensure that you approach each patient with respect and compassion. You may need to provide encouragement and reassurance.

A positive, respectful attitude is essential for all examiners. (Remember, many people with low literacy feel ashamed.) Be sensitive.

Visual Acuity:

If the patient wears glasses, ask him/her to put them on for this test. The REALM-R is designed to be read by persons with 20/100 vision or better. For vision of 20/100 or better I have used a font size of 18. In my studies we have excluded patients with worse vision. The REALM has a visually impaired version using a font size of 28.

Pronunciation:

Dictionary pronunciation is the scoring standard.

Dialect, Accent or Articulation Problems:

Count a word as correct if the word is pronounced correctly and no additions or deletions have been made to the beginning or ending of the word. For example: A patient who says "jaundiced" would not receive credit for the word "jaundice"; "directs" would not receive credit for the word "directed"; "colon" would not receive credit for "colitis". Words pronounced with a dialect or accent should be counted as correct provided there are no additions or deletions to the word. Particular attention should be paid for patients who use English as a second language.

REALM-R Examiner Record

Patient Name/
Subject # _____ Date of Birth _____

Date _____ Clinic _____ Examiner _____

Reading Level _____
Grade Completed _____

fat	_____	fatigue	_____
flu	_____	directed	_____
pill	_____	colitis	_____
allergic	_____	constipation	_____
jaundice	_____	osteoporosis	_____
anemia	_____		

Fat, Flu, and Pill are not scored. We have previously used a score of 6 or less to identify patients at risk for poor literacy.

Score _____

Attention: Shands Jacksonville
Emergency Department (ED) Patients
and Families

Palliative Care is:

- family centered
- provided at any time during your illness
- provided by a team (physician, nurses, social worker, and nurses)

AND

- Includes help with relief of pain, other symptoms, and stress
- Improves communication between patients and their families, and doctors
- Is NOT the same as hospice or end-of-life care

If you feel you may benefit from Palliative Care or would like to learn more, please ask your ED nurse or doctor to dial 904-244-4095 or you can call directly.

If you receive a recording Monday-Friday (8am-5pm) someone will call you back that day. If you leave a message after hours or on the weekends, we will call you back on the next business day.

If your loved one has a serious illness with long term symptoms you may benefit from ***Palliative Care***.

Serious illnesses include:

Cancer

Cardiac Disease
(congestive heart failure)

Lung Disease (COPD)

Kidney Failure

Alzheimer

HIV/AIDS

Stroke

...and more

Often these diseases result in frequent trips to the ED and hospital admission

Integrative Palliative Care ED Nurse Screening Note Template for EPIC

Patient Name

Date of Birth

Date of visit

Subjective:

Patient is a age y.o. female who has present to ED with,

Subjective:

This visit was requested by Dr.

Patient Active Hospital Problem List:

No active hospital problems.

Past Medical History

Diagnosis

Date

- CHF (congestive heart failure)
- HTN (hypertension)
- HLD (hyperlipidemia)
- OSA (obstructive sleep apnea)
- Diabetes mellitus
- CAD (coronary artery disease)
MI in 1996
- PE (pulmonary embolism)
S/p greenfield filter

No past surgical history on file.

No family history on file.

Allergies:

Spiritual history:

Religious affiliation:

Spiritual request:

Patient/Family Area of greatest concern: { :30421437}

Palliative Performance Scale Total: *** %

Karnofsky Scale:{ :30422522}

Assessment & Recommendations:

Symptoms: This patient has experienced symptoms: { :30434830}

Pain Assessment: { :304034516}

Medical Decision Making: Advance Care Planning Completed: Other (comment)
(by proxy daughter and son)

Next of Kin Not Residing with Patient: (list names)

Phone contact numbers:

Ward of the State: No

Palliative Care Consultation Triggers – Emergency Department:

- Pt transferring from LTC
- Identification of medical decision maker
- Allow natural death – DNR/DNI goals of care discussion
- Pt actively dying and considering hospice and/or palliative care
- Palliative care consulted on previous admission
- Multiple admissions to the hospital (2 or more within 6 months) with same symptoms
- Pt with advanced disease with frequent infections
- Sudden acute event, such as a CVA, MI in the setting of multiple chronic illnesses
- Advance disease considering Peg tube, enteral feeding or trach placement
- Disease triggers: Malignant Neoplasm, esp. Lung Cancer; Aspiration Pneumonia, COPD, Heart Failure, Septicemia, Bone Mets, Renal Failure, Hemorrhagic Stroke, Advanced Cervical Cancer; Hepatoma
- Multiple chronic and co-morbid medical conditions
- Pre-hospital or emergency department cardiac arrest survivor
- Pre-hospital or ED intubation with multiple medical problems
- Need for ventilator withdrawal
- Clarification of goals of care needed

To request a palliative consult, please call (904) 407-7700 and enter into STAR.

Palliative care is provided by an integrated multidisciplinary team, including representatives of the professions of medicine, nursing, social work and chaplaincy. The team addresses the physical, emotional and spiritual needs of any patient with severe or life-threatening illness who is undergoing curative or life-prolonging care.

To request a palliative consult, please call (904) 407-7700 and enter into STAR.

ShandsJacksonville
Integrative Palliative Care

Is it time to order a
Palliative Consultation?

ShandsJacksonville
Integrative Palliative Care