



National Hospice and Palliative Care Organization End Result Outcome Measures

COMFORTABLE DYING PROTOCOL

MEASURE QUESTION:

“Was your pain brought to a comfortable level within 48¹ hours of your admission to the hospice program?”

RATING SCALE:

YES or NO or UNABLE TO COMMUNICATE

POPULATION AND SAMPLE SIZE

100% of the hospice’s patients will be given a thorough pain assessment (including physical, functional, emotional and spiritual components) upon admission.

Patients are eligible for this study question if they:

- Acknowledge they are uncomfortable because of pain at the time of admission. See #1 in Procedure, below.
- Communicate and understand the language of the person asking the question.
- Are able to self-report
- Are at least 18 years of age or older

PROCEDURE:

1. On admission, prior to any numerical 0-10 scoring (not part of the study) the nurse will ask the question “Are you uncomfortable because of pain?” If the patient says “**yes,**” and meets the other criteria above, the patient enters the study.
2. The nurse documents all responses on the **Patient Core Measure Sheet**, and then proceeds with the assessment that leads to an intervention, following the hospice’s customary practice for documentation.
3. The evaluation of the effectiveness of the pain management regimen will always be based on the intensity of each patient’s pain, but for this study the following will also occur: within 72 hours after the first 48 hours of admission the patient’s nurse or designee will, prior to any other form of scoring, ask the question: “Was your pain brought to a comfortable level within 48 hours of your admission to the program?” The yes or no response to that question is then documented. If the patient is unable to self-report, check unable to self-report or unable to communicate.

Document the reason the person is unable to self-report – discharged due to death, unable to self-report due to disease process, discharged alive, unable to self-report for other reasons.

4. This follow-up assessment can be completed by a nurse or physician in person or by telephone, but the patient must **self-report** his/her own response to the question by answering “yes” or “no.” The hospice staff should not:
 - Interpret a patient’s nonverbal response based upon observation, or
 - Use the response of another person, such as a staff person or family member to substitute for the self-report.

Using language that is more natural or familiar to the patient is permissible, providing the question of



achieving comfort within a prescribed time frame is kept intact. For example, it is permissible on Tuesday to ask a patient admitted on Saturday afternoon if they were “comfortable by Monday afternoon.”

Guiding the patients to a particular answer however is not permissible. For example, saying “You’re not in pain now are you?” or “You’re not comfortable are you?” is not permissible.

The study is not intended to supplant the usual procedures the hospice has for pain assessment, treatment, documentation or follow-up, including management of side effects.

SCENARIOS YOU MIGHT ENCOUNTER:

1. It is close to 72 hours and you are doing the follow-up by phone and the patient is unavailable to talk. Do you continue to try to reach the patient even if it would be past the 72 hours?
Yes. You want to visit or talk with the patient as close to the 48 hours as possible so the information is still fresh in the patient’s mind. The longer you go beyond the 72 hours, the greater the risk for inaccurate information.
2. The patient recently transferred to your hospice from another hospice. Is the patient eligible to participate in the study?
Yes. The patient is a new admission to your hospice.
3. The patient was discharged from the hospice and readmitted later. Is the patient eligible to participate?
Yes. The patient is a new admission to your hospice.
4. You visit or phone the patient for the follow-up and find the patient unavailable. A family caregiver offers to respond on behalf of the patient. Is this acceptable?
No. The information must be reported by the patient only.
5. You are doing your paperwork and realize you forgot to ask a patient the follow-up question. You know based on your visit with her how she would respond to the statement. Is it OK for you to write in the response you know the patient would have given you?
No. The information must be reported by the patient only.
6. The patient responds to the statement by saying something like “almost,” “sorta,” “I guess,” “not really,” “yes, but I’m still not real happy with it.” What do you document?
The appropriate documentation would be “No,” regardless of the amount of work, time and energy put forth on symptom relief already.
7. Some patients may be admitted in severe pain. Asking them the questions as they are written may seem inappropriate. ***For patients in severe pain, some leeway in asking the questions is acceptable. For example: “Your pain is making you very uncomfortable, is that right?” The second question regarding unacceptability may be waived in such extreme circumstances. Remember however that some people will find varying levels of pain acceptable, so asking the second question may be important. Try “I’m assuming your level of pain is unacceptable, is that right?”***



SELF DETERMINED LIFE CLOSURE PROTOCOL

MEASURE QUESTIONS:

Do you want to avoid hospitalization if your condition worsens?

Do you want cardiopulmonary resuscitation if your heart or lungs stop working?

RATING SCALE:

YES or NO or UNDECIDED.

POPULATION AND SAMPLE SIZE

100% of the hospice's patients are expected to receive a thorough assessment (including physical, functional, emotional and spiritual components) upon admission. This aspect of the end result outcomes study is intended to determine the extent to which clinical interventions are consistent with preferences expressed by the patient or legal representative.

PROCEDURE:

1. The patient/surrogate responses to these measures are determined and documented by a nurse or social worker on or within 48 hours of admission. However, you may record preference changes on the **Patient Core Measure Sheet**.
2. It is most desirable to have the patient respond if they are alert and oriented. If they are not, the law allows legally designated surrogates to guide decision-making. The patient may have an advance directive such as a living will, or have assigned Power of Attorney for Health Care to a friend or family member other than the closest relative. Determine which surrogate has the legal right to guide decision-making and check off the appropriate box in the Respondent row.
3. Upon admission or during any subsequent change in preference, the nurse or social worker fills in the date, the respondent's identification, reads the 2 questions related to hospitalization and CPR and documents the preference for each.
4. Following the patient's discharge by death, the team or chart reviewer circles the appropriate Yes or No in the Discharge Date column, entering the date of death (DOD).
5. The measure is not intended to supplant the usual procedures the hospice has for preference assessment, documentation or follow-up.
6. The procedure for determining what constitutes a hospitalization is complex. Please refer to the written description at the end of this document.

SCENARIOS YOU MIGHT ENCOUNTER

1. Upon admission, the patient or surrogate does not respond clearly to the question concerning a preference regarding cardio-pulmonary resuscitation, like "I don't know, I need time to think about it."
Circle undecided
2. In response to the hospitalization question, the patient or family member says "If I have an infection that can be treated I want to be hospitalized; if my general condition is worsening I don't."
Circle No. While the question is about "worsening condition," hospitalization may be required to determine the cause of the new condition and the patient has said they want to be hospitalized for



treatment of certain conditions.

3. The family does not wish the discussion of cardio-pulmonary resuscitation to be initiated with the patient, yet the patient is capable of meaningful discussion (no surrogate involved).

The measurement cannot occur, so the patient is not included in this aspect of the study. Complete the pain level questions and return the Patient Core Measure Sheet.



GENERAL QUESTIONS

1. Re: The Comfortable Dying Measure and Wednesday or Thursday Admissions: Do I follow-up with patients on the weekends?
Yes, ordinarily the on-call staff would do it.
2. Is an admission from another hospice, a new admission?
Yes.
3. Is a discharge from hospice to home health and back to hospice a new admission?
Yes
4. If patient is unable to self-report on the pain question what do I do?
You collect the information that you can, but you do not document a pain report from others on the measure sheet. You of course document caregivers reports in the hospice medical record.
5. If family doesn't want to wake patient, what do I do?
Have them call back if the patient is uncomfortable when he wakes up. Document your call.
6. If the patient wants CPR but family and staff believe it will be futile what do I do?
Monitor the patient's condition. Often as patients approach their death they change their minds. It is not necessary to bring this up on every visit; clinical judgment is involved. The measure is not intended to be more important than the person.

CORE MEASURE SUMMARY SHEET

Use the Core Measure Summary Sheet to document the *Comfortable Dying* and *Self-Determined Life Closure* questions. This sheet also asks for some general information including: Patient diagnosis, gender, age, ethnicity, and any reasons for excluding the patient from the study. It also asks what other language is spoken other than English.

What is a hospitalization for a hospice patient?

The term “hospitalization” has meanings for patients that may not coincide precisely with providers’ traditional definitions of hospitalizations. The Medicare Hospice Benefit “general inpatient” regulation similarly expands the concept. For example, “is admission to a SNF under general inpatient care a hospitalization?” Technically, no. Nursing homes are not licensed as hospitals. But if patients are sent to SNF’s to receive higher level (general inpatient) care than that available at home or at the skilled level, and that care is similar to the care the same patient could receive in a hospital, it is reasonable to consider it a hospitalization.

Interpretations are even more complex when considering a patient’s perspective. Patients and families will advise hospice staff that they look forward to spending time in the special inpatient environments created by the hospice, even as they state they want to avoid hospitalization. We have learned it is not the mere fact of being transferred out of the home that is of concern to many patients, but where and what they are being transferred to. Patients are often fearful that the wrong thing will happen to them in hospitals where the care is not tailored to the needs of a dying dependent patient. Prominent national studies tell us that their fears are realistic. If dying is the ultimate “experience,” it is important to pay attention to the circumstances that contribute to the best experience, regardless of necessary setting.



Patient Driven Definition. “Avoiding hospitalization” is a theme in many consumer surveys regarding end of life care. Looking more specifically at what consumers fear will happen, the following issues are identified:

- 1) Loss of control,
- 2) Loss of identity,
- 3) Fear that treatments will be performed against their will,
- 4) Inability to have significant others around,
- 5) Fear that responses to toileting problems will not be addressed in a timely or dignified way,
- 6) Fear that symptoms will not be effectively managed; “hospitals are geared toward cure, not comfort.” And for some,
- 7) Fear of acquiring hospital bred infections

A Philosophy of Care Regardless of Setting. Patients who have signed an informed consent for hospice care are to receive that care regardless of the care setting, until they notify their physician of a change in preference. Consequently, hospices are expected to work with staff in acute and skilled care settings to insure that patients’ preferences are met, that they will neither be isolated nor abandoned to their illness, that their special communication needs will be facilitated and that symptoms will be effectively addressed. The goal is for the care delivery to appear seamless when a change in setting is necessary.

The greatest opportunity for this to happen is when staff from the hospice and inpatient setting work collaboratively. Joint care planning, shared documentation and daily communications contribute to the success of this effort. When the items identified above are offset by such collaborative team efforts it is reasonable to say that the hospice has taken responsibility to help patients avoid what they fear: what hospitalization *represents*, not its bricks, mortar or license.

Implications for Dataset. Every hospice that fills out the dataset sheet on the hospitalization measure will have to ask itself a number of questions regarding its inpatient relationships in order to accurately reflect its ability to help patients avoid loss of control and the fearful things identified above. It was the opinion of the expert panel of the Outcomes Forum to not just focus on the licensure of the inpatient care setting in asking the hospitalization question, but to look at what lies behind the question. That means that all transfer sites need to be evaluated in their potential to help the hospice team provide the care that the patient anticipates.

That means, if it is not possible to substantially direct and influence the care of patients the hospice should designate all transfers from home to that facility as a hospitalization. If collaboration between settings is high, and “the bricks disappear,” such a transfer is not counted as a hospitalization. The specific criteria for collaboration follow, with examples of what is and is not a hospitalization.

In summary, this is acknowledged to be a variant view of “hospitalization.” Its definition is driven by patient perception and expert knowledge of patients’ concerns, not by the mere fact of contractual relationships and licenses. Those who are interested in determining how hospices vary in keeping patients at home are encouraged to look at the hospice’s % of patient days spent in routine home care, compared to hospices of similar (budgetary, geographic, bed availability) profiles.

Types of inpatient settings	Is this a hospitalization?	
	YES	NO
Admission to a hospital or SNF where all of the following apply: 1) Hospice staff communicate with hospital staff or patient/family daily ; 2) Treatment care plan is jointly derived; 3) Hospice staff document in hospital's medical record 4) The hospice monitors the quality of care provided to hospice patients in the hospital		X
Admission to a hospital or SNF* where any of the following apply: 1) Hospice staff do not communicate with hospital staff or patient/family daily ; 2) Treatment care plan is not jointly derived; 3) Hospice staff cannot document in hospital's medical record 4) The hospice does not monitor the quality of care provided in the inpatient setting	X	
Discharge to a non-contract SNF	X	
Admission to a freestanding hospice inpatient facility for general inpatient care		X
Admission to an inpatient unit in a hospital or SNF that is managed by the hospice		X

* Patients may receive “general inpatient care” in some SNFs, as they do in hospitals.