

Soliciting the Patient and Family Story

Once you have set a safe context for the palliative care discussion soliciting the patient's and family's "story" requires considerable shift from the traditional medical interview. First the patient and family are not used to having a discussion primarily requesting them to share their perspective (expertise). It is discussion they are likely not expecting or prepared to have. Second, in the stressful context of advanced, chronic illness just living each day requires major effort and makes it harder to reflect on goals and values. "How do I make it through TODAY?" takes precedence over "How do I want to live my life?" or "What are my underlying values and goals?" Having a structured set of questions that provides a framework upon which the patient and family can share their story is helpful for both the clinician and the patient. The following questions are a suggested framework for you to use in soliciting the patient's and family's "story."

1. How do you understand your situation?
2. What do you want to be sure we discuss today?
3. From where do you draw your strength to cope with this situation?
4. What are your past experiences in caring for others with serious illness? With significant loss?
5. Who is your "family" that will support you?
6. What are your goals? Often an effective way to approach this question is to ask:
 - * What are you hoping for?
 - * What are your greatest concerns or fears?
7. What else do you want me to know about who you are and what you believe?

The exact wording of each question and the order they are asked is less important. What is important is that you develop a framework and explicit set of questions that you are comfortable using. So feel free to modify the suggested questions above. Not all questions will be needed with every patient/family and sometimes-additional questions will be needed.

An essential skill in soliciting the patient's and family's story is to not stop with the initial, first response to a question. The first response is only a starting point for exploring the story in more depth. You need to provide an opportunity for the patient and family to reflect and go more deeply into their story. Three types of questions commonly used to promote such reflection are:

- * Probing Questions : Could you tell me more about not wanting to be a burden on your children?
- * Clarifying Questions: Could you help me understand what you mean by being a burden on your children?
- * Requesting Specific Examples or Stories: Could you share a story or give a specific example of what you mean by being a burden on your children?

Your goal is to go deeply enough into the patient and family story that you understand how medical care can support them in living a life that makes sense to them and is consistent with their values and story. When you reach the point where you adequately understand the story to fulfill your role as a physician you can stop, but until you reach this level of understanding you need to keep exploring.

One of the major barriers that prevents clinicians from successfully soliciting the patient's and family's story is their professionalized role of identifying problems and offering solutions. As the patient and family describe their story clinicians will inevitably recognize problems they are trained to treat. It is a core part of what professionals are trained to do. Often once such a problem is recognized the clinician will interrupt the patient's and family's story and offer a solution based upon the clinician's professional knowledge. As these interruptions recur the thread of the story is lost in the wealth of treatment options and medical issues that the treatments raise. It is important to emphasize that the goal of soliciting the patient's and family's story is to understand their lived experience. It is not to identify problems and offer solutions. While this is an important clinical role, in the best practice model, this role is delayed to a later time. The clinician first needs to understand the patient's and family's values, goals and story in enough depth to appreciate what problems as well as goals the patient and family have defined as important. Then the clinician needs to assess how medical treatment's impact these patient/family defined goals and problems. Is medical care causing or exacerbating a problem? Helping to meet an important goal? Or having no meaningful effect?

Identifying problems and offering solutions before understanding the patient and family story is problematic for several reasons including:

- * The clinician is deciding what is a problem based upon his/her professional perspective. It may or may not be a problem from the patient and family perspective.

- * The clinician has a bias to identify problems that have high value from her/his cultural perspective. Thus problems that are not of high value to the clinician are often overlooked. For doctors this means physical problems dominate over emotional, psycho-social and spiritual issues.

- * The solutions offered are based upon the cultural context of the clinician and have little or no grounding in the patient's and family's lived experience. Again for physicians this means solutions are often drugs or medical treatments to control physical disease and rarely include emotional, psycho-social and spiritual interventions to support living a life that makes more sense to the patient and family.

- * By focusing on problems to be fixed everyone is diverted away from identifying positive goals to be lived by the patient and family.

Developing the ability to avoid identifying problems and offering solutions prematurely is essential to successfully soliciting the patient's and family's story.

Another common barrier to successfully soliciting the patient's and family's story is getting caught up in details that are important but peripheral to the story. The clinician needs to facilitate the interview in a manner that allows the story to unfold. If an important but peripheral issue arises the clinician needs to move the discussion back on track so he or she is continuously working towards a deeper understanding of the patient's and family's values, goals and story.

Developing a story that integrates the differing perspectives of the patient and central family members into a shared or common story is another important goal for the clinician as he or she solicits the story. The following steps are helpful in assisting the patient and family in developing a common story:

- * Make sure all members of the "family" the patient identifies as important have the opportunity to voice their story. Directly asking each member the suggested questions is the best way of assuring they have a chance to share their story.

- * After soliciting every person's story emphasize the common themes they all share **and agree upon**. Be sure you have identified the correct themes and all parties agree with them.

- * After soliciting every person's story emphasize themes where there is disagreement. Clearly define what the differing themes are and exactly how they disagree with each other.

Once the areas of disagreement have been clearly identified explore with the family ways of reaching consensus. If reaching common ground is not possible then hold open the clearly defined differences as areas for future exploration.

Responding to Patient/family Cues: Specific communication techniques:

The BPM that is being presented embeds within it the crucial importance of gaining the patient and family story (values and goals). A transparent and safe environment to explore the patient and family perspective including emotions, meanings, fears and hopes is purposefully created. However, even if this approach is not mindfully included communication research with patients and families living with life limiting, chronic illnesses has shown that patients and families will provide cues to the physician that they have important personal and emotional concerns they wish to discuss. In the communication literature such moments are given a variety of names including "empathic moments," patient "cues" and patient "clues." This discussion will use the term *patient cues*. These moments arise when the patient or family member communicates verbally or non-verbally that they have concerns that possess highly emotional content. Being able to recognize patient cues is an important communication skill that you should be mindful of while you are viewing the videos and participating in clinical encounters.

Several studies have looked at how often significant patient cues occur in clinical encounters with advanced cancer patients and their physicians (Butow PN, Brown RF, Cogars et al, Oncologists Reactions to Cancer Pts Verbal Cues, Psycho-oncology 11:47-

58 2002). On average patient cues occurs 2-3 times a visit. Physicians can respond to these cues with either “terminators” (verbal and/or non-verbal responses) that focus on biomedical facts and ignore the emotions being expressed or with “continuers” (verbal and/or non-verbal responses) that respond to the emotions being expressed and encourage the patient/family to share more about the their concerns. On average physicians use “terminators” 85% of the time when such cues occur, even when the patient/family offer repeated cues. In the Best Practice Model patient “cues” are windows of opportunity to explore the patient’s story in more depth. In observing clinicians who have demonstrated mastery of this model the use of “NURSE” statements in responding to patient “cues” has been found to effectively open up these windows of opportunities. These statements acknowledge the patient’s emotional concerns and create space for them to describe how they feel. “NURSE” is an acronym that stands for the following types of statements:

- **Naming:** One effective way of responding to a patient’s emotional cues is to name them to yourself. This requires you to be “mindful” of your own emotional responses during the interview (develop an “observer self”). Once you have identified the emotion you can suggest to the patient this emotion exists. “It sounds like being a burden on your family is quite upsetting to you?” Be careful to only suggest what you have named. Most people don’t want to be told how they feel but appreciate when you recognize how they feel.
- **Understanding:** Sensitively sharing your understanding of the difficult situation a patient/family is experiencing is another way of responding to cues. “I can’t imagine how hard it must be for you to be receiving such a difficult diagnosis.”
- **Respecting:** Acknowledging the depth of people’s emotional feelings can be done both verbally and non-verbally. One important verbal way of showing respect is to praise a patient’s coping skills. “I am impressed by the courage you have demonstrated by participating so fully in this difficult discussion.”
- **Supporting:** Statements that demonstrate your commitment to provide care and support the patient and family are of great value. Many patients are worried about being abandoned by his/her physician(s) if they should fail to improve or choose to stop active treatment. If truthful, statements that emphasize you will be taking care of the patient no matter what happens are important. “Our team is here to support you no matter what happens.”
- **Exploring:** Such statements are similar to the probing responses previously described. They encourage the patient/family to tell you more about how they are feeling. Additionally providing empathy is another way of exploring the patient’s cue. The best empathic statements link the “I” of the physician with the “you” of the patient. “I sense how upset you are at receiving this difficult news. Can you share more about how you are feeling right now?”

It is important to recognize that many patients will find it difficult to express emotions or share their fears and concerns until they have developed a trusting relationship with you. Using NURSE statements in response to patient cues most often leads to the formation of such a trusting relationship but not always. If you sense the patient is not ready to explore or share his/her deeper feelings then shifting to the **Ask-Tell-Ask** approach is

another strategy that is often used by skilled clinicians. The **Ask-Tell-Ask** approach includes the following concepts/steps:

- Before giving more information it is important to explore what the patient already knows or wants to know.
- By asking the patient what they already know you get a sense of their language and metaphors (how they make sense of their situation)
- You can then tell the patient more effectively what they want and need to know. In general you want to give limited information at a ninth grade level with no more than three pieces of information. Avoid medical jargon and a patho-physiology lecture.
- Once you have told the patient then you need to ask them what they actually understood you to say. So that you can confirm you have given them the information they wanted and needed and they understood it correctly.

A typical **Ask-Tell-Ask** exchange might go something like this:

- Physician: Can you tell me what is the most important issue you want to discuss today?
- Patient: I want to know how well my congestive heart failure is being controlled.
- Physician: Before I do that can you share with me your understanding of how things are going?
- Patient: Well my legs are still swollen, I'm short of breath just walking around the house even with oxygen, and I feel weak and tired most of the time. I don't think it's being controlled very well at all.
- Physician: I agree your heart failure is not well controlled. We have tried everything medically we can think of to improve your condition. There just aren't any more pills or shots that can improve things. We are in a tough spot with no good options. What questions do you have? How do you feel about what I just shared?

You are strongly encouraged to read more about these techniques by following the [Oncotalk](#) link and reading Module 1: Fundamental Communication Skills. Oncotalk is a program lead by Tony Back MD to improve Oncology Fellows communication skills. Tony is on staff at the Seattle Cancer Care Alliance and a national authority in this area.