Answers to Qualitative Research Section

The clinical Question: In patients with **terminal** diagnoses, are there ways in which health care providers can help them prepare for **death?**

The search strategy: Using the key terms and concepts from the clinical question, you first type in "terminal" and your search engine will map you to the MESH heading *Terminal Care*. You will want to "focus" your search because the article is MAINLY about terminal care. Similarly, you will enter "death" and your search engine will map you to several choices, the best one being the MESH heading *Attitude to Death*. You will want to "focus" that one as well. Combining these two terms gives you 661 articles, so next you will want to use a methodologic filter (a set of search terms meant to select papers that use a particular methodology.) For qualitative studies, you want to find articles that are either interview studies or focus groups. Because the MESH heading for *focus groups* is underneath Interviews in the subject heading tree, if you "explode" interviews you will get all the articles indexed to interviews as well as focus groups.

The search:

1.	***Terminal care/**	**6124**
2.	***Attitude to Death/**	**3352**
3.	**1 and 2**	**661**
4.	**exp Interviews/**	**7400**
5.	**3 and 4**	**9**

The paper: In search of a good death: Observations of Patients, Families, and Providers. Ann Intern Med. 2000;132:825-832

Notes:
*** denotes 'focus'; exp denotes 'explode'**

Comments on the teaching tips:

General Comments: Most of us are much more attuned to quantitative methods and have little intuition for qualitative ones. Thus each of the tips makes use of comparison to help clarify the unique properties of qualitative research. In addition, each tip is structured to drive home the point that qualitative research is ***defined by the methodology, NOT by the research question or topic of study***. Thus one can use qualitative or quantitative methods to answer any question, whether it be about quality of dying or breakfast foods!

Tip 1: A completed version of table I is included on the next page.

Tip 2: As noted in the general comments, you can address many of the same questions using each methodology. For example, spiritual awareness can be examined using in-depth interviews with patients and their families and also be assessed through a closed ended survey tool.

Tip 3: If you set up each group with a clear view of what the methodologic "rules" are, you will find this an incredibly enlightening exercise. It is likely that the group will agree that the qualitative methodology produces more useful information than the quantitative methodology- in addition, the quanlitative researchers each get to eat the donuts whereas, depending on the experimental design, the quantitative group may or may not eat! You might try to gently nudge the qualitative group to be as descriptive and open-ended as possible whereas you must be sure that the quantitative group tests a particular hypothesis.

Tip 4: The nice thing about the comparison of these two articles is that they relate to the very same topic, by the same authors but use different methods. Each paper is methodologically strong but contributed a different

Table 1: Compare and Contrast Quantitative and Qualitative Research

	Quantitative Research	Qualitative Research
What kind of information is being gained?	Tests well defined hypotheses Determines, **whether** (benefits, risks, harm) or **how much** (prognostic, diagnostic value)	Insight into emotional and experiential phenomena in health care; interpretive research (Generates hypotheses) Determines **what**, **how** & **why**
Type of Reasoning?	Deductive	Inductive
Methods (Types of study designs used)	- Clinical Trials (RCT for therapy / harm) - Epidemiologic Data (Cohort for prognosis) - Diagnostic Test Study Close-ended survey	Interviews (semi-structured, in-depth, individual and focus groups) Field Observation (direct vs indirect) Document Analysis (journals, charts, correspondence)
Product of the work (i.e. what will be reported in your results section)	Explicit measured outcomes	Narrative, story that describes and explains social phenomena
Measurements and Questions (Open vs Close ended)	Closed	Open
Statistical Considerations	Can apply quantitative statistics	Can not apply quantitative statistics, results are open to interpretation
Sample Size Issues	Explicit numbers of patients are targeted to reach clinical / statistical significance based on the frequency of the observed outcome	Adequately, in-depth observations; *Theoretical saturation* of themes (*informational redundancy)* breadth of observations and depth of each observation made; data collection until you produce data in enough detail to represent the experience
Sources of Bias	Measurement selection Measurement error Reported via confidence intervals and statistical significance Most strongly associated with item validity	Investigator coding and interpretation Reported via kappa statistic of agreement beyond chance Checked by informant review of investigator interpretations Most strongly associated with item reliability

Assessing Validity: Is there a truthful correspondence of results to a presumed " objective reality."

Methodologic rigor:
1. Is the study designed to address its research question and objectives appropriately?
2. Methods section: should include, participant selection, methods of data collection, comprehensiveness of data collection, procedures for analyzing data and corroborating findings.

User's Guide to the Medical Literature: Critical Appraisal Worksheet for Qualitative Research:

Validity Criteria	
Steinhauser, KE. et. al. In search of a good death: observations of patients, families, and providers. Ann Int Med. 2000;132:825-832	
What is the Research Question?	What are the attributes of a good death, as understood by various participants in end-of-life care?
1. Were participants relevant to the research question?	Yes. Physicians, nurses, social workers, chaplains, hospice volunteers, patients, and recently bereaved family members were all involved.
2. Was participant selection well reasoned?	Yes. The participants involved the full spectrum of persons involved with end-of-life care. In addition, participants were recruited from a variety of settings including a private, tertiary care hospital, a VA hospital, a local community hospice in Durham, NC Nonphysician providers: recruited from convenience samples generated by e-mail and departmental advertising. Physician recruitment: stratified by level of appointment, then randomized the lists and recruited in order ensuring that the overall group represented each career level. Patient recruitment: HIV and oncology patients recruited by telephone. Stratification for ethnicity Family members: stratified random sample of recently bereaved relatives of veteran patients who had died 6 months to 1-year prior.
3. Were the data collection methods appropriate for	Methodology included focus groups and in-depth interviews. Focus groups included 6 to 8 participants and were stratified

the research objectives and setting? (Field observation, interviews, document analysis)	by ethnicity with trained facilitators of the same race as the participants in each group.
4. Was the data collection comprehensive enough to support rich and robust descriptions of the observed events?	Appendix describes protocol for focus group discussion. Particular care was taken to ensure reliability and exhaustiveness of the data collection and analysis. 1. Exhaustiveness: focus groups were conducted until same themes were repeated and no new themes emerged. 2. After repeatedly analyzing the focus group transcripts, in-depth interviews were conducted with the most talkative and the quietest member of each group. This was done to ensure that no new themes arose and also to give the more quiet participants the chance to voice possible silent, but dissenting viewpoints.
5. Were the data appropriately analyzed and the findings adequately corroborated?	1. Focus groups and interviews were transcribed from audiotapes. 2. Constant Comparisons Methodology was used for coding. Using this method, 4 investigators independently read examples of the transcripts and analyzed them for recurrent themes. Summaries were then compared for agreement. 3. 70 attributes of a 'good death' were identified and collapsed into 6 broad domains. 4. Illustrative quotes were included
Results	
What are the results of the study? How evocative and thorough is the description?	The study describes the 6 domains are important components of a good death: 1. Pain and symptom management 2. Clear decision making 3. Preparation for death 4. Completion 5. Contributing to others 6. Affirmation of the whole person

	Each domain is described and illustrated by a quote from the focus groups in interviews that captures the spirit of the domain. Of note, the 6 domains contain four that have been previously incorporated into palliative care paradigms, however the importance of *contributing to others* and *affirmation of the whole person* were previously unrecognized in their role at the end of life. This is a perfect example of how a qualitative, open-ended methodology can expand our paradigms of care.
Applicability to patient care	
How do the results of this study help me care for the patients? Does this study help me understand the context of my practice?	These data enhance awareness to those domains that are important in end-of-life care. Attention to these aspects of the dying patient's experience will enhance the quality of their death. Yes.
Does this study help me understand my relationships with my patients and their families?	Yes. These data provide a road map to assist in the navigation of end-of-life issues.

Resolution of the clinical scenario:

Mr. W's diagnosis turned out to be stage IV squamous cell esophageal cancer. The team had discussed his end of life wishes with him and he did not wish to be resuscitated. Because he wanted to be able to swallow, he did elect palliative XRT and chemotherapy with 5-FU/Cisplatin. He had a PEG placed for nutrition. The patient died 6 weeks after he presented to the ER. His death was in the hospital when he was receiving chemotherapy. The same team of residents who originally admitted him was caring for him. He began to experience delirium, then rather quickly and unexpectedly died. He was on morphine for pain control, he was not resuscitated and his family did not wish to have an autopsy. Following this patient's death, the team expressed regrets that they had not discussed his spiritual needs and that he died without a clear mental status.