

Chapter 2: ***What is Patient Focused, Family Centered Medical Care?***

With (NAME), I felt a strong sense of advocacy for her, and no, I'm not a medical person. Again, I have some common sense, and I do have a heart. Some of my questions used to be somewhat like well if you don't do that, what does that mean. I would make them answer... You need to because sometimes they would act hurried, and they would act rushed, and they would look at their watch. I made a conscientious decision that I don't really care what you have to do. It really is not my problem, and I'm sympathetic to everyone in this hospital, but my concern right now is this patient here in this bed, and I would make them answer questions. I would call them, and I would ask for pager numbers, and I would ask how I could reach somebody. Sometimes it used to annoy me if I went to the nurse's station and they were busy, and they wouldn't even look up, but I would say excuse me, excuse me, I have a question, or I need some help with something.

*Who
advocates
for dying
patients?*

We have created a health care system that too often is organized around the needs of the institution, and we lose site of what is important – providing competent, coordinated, and compassionate care. Increasingly, a patient and his or her family are faced with navigating their way through a health care system that is not responsive to their needs. Simple courtesies are lost, sad to say. Donabedian noted that “achieving and producing health and satisfaction, as defined for its individual members by a particular society or subculture, is the ultimate validator of the quality of care.”¹ Similarly, the Institute of Medicine defined quality of health care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”² Central to both of these definitions is a consumer perspective and medical care that is consistent with current professional knowledge.

*Quality care reflects
two perspectives:
medical outcomes
and health care
consumers (i.e.,
patients and their
families).*

In the development of the dying patient and after-death bereaved family surveys, we have relied on both input from dying persons and their families regarding what they believe is important to defining high quality medical care and a review of existing professional guidelines. First, we conducted an extensive review of existing guidelines that examined the domains and key processes of care that were judged by experts and consumer organizations as important to high quality medical care. Second, focus groups and in-depth interviews were conducted with bereaved family

members and dying persons. This latter research effort focused on capturing what was important from the patients' and families' perspectives. Throughout this resource guide, we have used these interviews and family members' stories to provide important insights into what we see as the key to the quality of medical care for dying persons and their families – patient focused, family centered medical care.

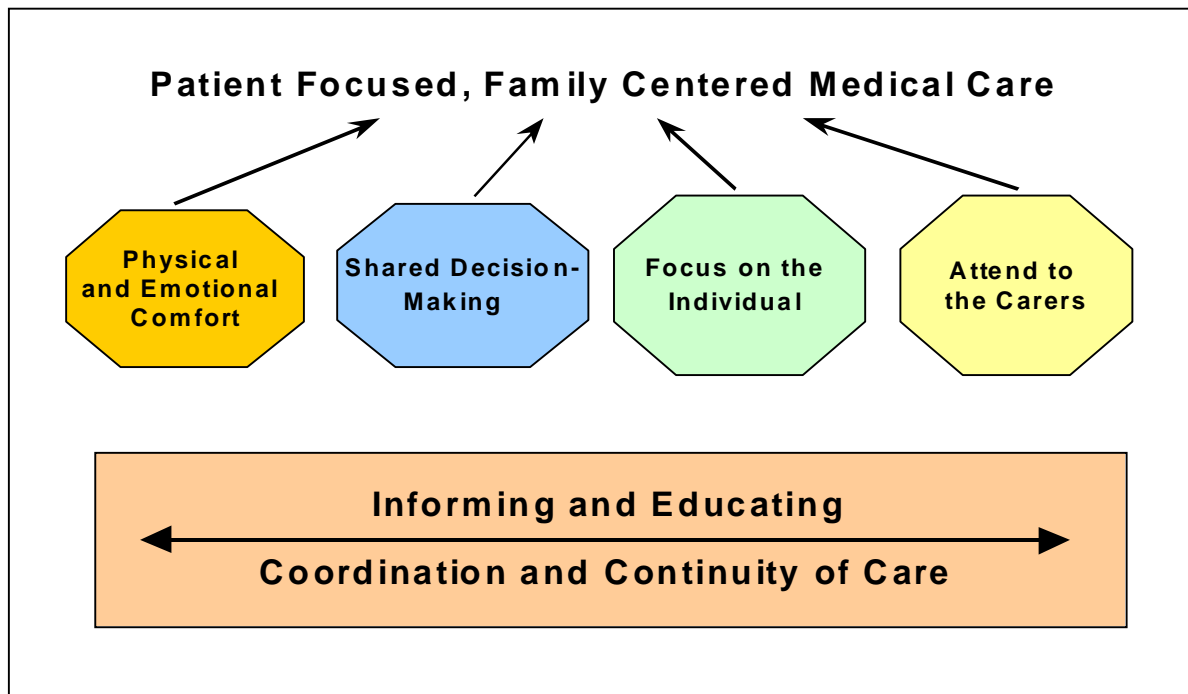


2.1 Components of Patient Focused, Family Centered Medical Care

Four key elements constitute patient focused, family centered medical care. Health care providers and institutions must:

1. provide the desired physical comfort and emotional support,
2. promote shared medical decision-making,
3. treat each person as an individual by understanding their needs and expectations,
4. attend to the needs of those who care for and love the dying person.

How does your facility fare in meeting the challenge of these four elements?



As shown in the above diagram, there are two key care processes that are cross-cutting and important for achieving patient focused, family centered medical care. First, patients and family members must be informed and educated to the extent that they desire. As one of the bereaved family members stated, “you know what to expect, how you can help, and what you

Knowing what to expect can ease and even prevent fears and anxieties.

can expect.” The key is that dying persons and their families need to understand the disease and its future trajectory, their role in living with that disease, and most importantly what they can expect from you as their health care provider.

The second important care process is coordination and continuity of care. Too often, dying persons and families reported that they felt abandoned at their time of greatest need. In the last month of life, dying persons and their family usually receive medical care from a home care agency, acute care hospital, hospice and/or a nursing home. Key to high quality end-of-life care is coordination of care across these diverse health care settings. For these dying patients and their families, there is not a series of discrete episodes. This experience structures their lives and their struggles with their illnesses.

Patient focused, family centered medical care cannot be achieved without attention to the coordination and continuity of care. It seems bizarre that an acute care hospital can spend thousands of dollars and weeks of effort on a seriously ill, dying patient and all the next set of health care providers get is one piece of paper that lists medications and treatments. There needs to be better “hand off” of seriously ill persons. The receiving health care providers must know what to expect, what to monitor, and, especially, who this person is.

A dying person’s experience is continuous across settings of care.

What are this person’s desires, expectations, and values?

2.2 Identifying Opportunities to Improve

Listening to what dying persons and their loved ones say is key to examining whether your institutions provide patient focused, family centered medical care. The survey tools included in the Toolkit provide your institution with measurement tools to capture their perspectives. Previous satisfaction surveys have relied solely on rankings of the quality of care (i.e., Thinking about your medical care, how would you rate the explanation of medical tests? Would you say: Excellent, Very Good, Good, Fair or Poor?). To answer this question, the dying person or their family member will have to perform a mental calculation that involves asking several issues – Did that patient have any medical tests? Did someone explain those tests to them?

“Are you satisfied?” is a complex question.

What was their expectation regarding that explanation? Finally, how would they rank that institution using the scale that was provided to them?

A key problem with using typical satisfaction scores is that patient expectations are low and persons are reluctant to criticize health care providers resulting in the skewed distribution (i.e., everyone says either “excellent” or “very good”). In response to this concern, the Picker Institute has developed new measurement tools to measure the patient's experience called “Patient Centered Reports.” A Patient Centered Report (PCR) asks a question about a specific process of care in such a way that patient expectations or social acquiescence does not confound the answers.³ For example, a PCR asks “Did the staff explain the medicine that you are taking for pain in a way that you can understand?” In contrast to a ranking of “very good”, a PCR provides you with information to guide quality improvement efforts.

PCRs identify a specific area or process that can be targeted for improvement.

PCRs are summarized into problem scores. Each of the major domains (as shown in the above figure) have at least two problem scores that define that domain. A problem score is the count of the number of responses that indicate an opportunity to improve. For example, consider the following question from the retrospective after death interview.

While [PATIENT] was at [LAST PLACE], how often were you or other family members kept informed about [PATIENT'S] condition - always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

The challenging nature of quality end-of-life care means that all institutions and providers have opportunities to improve.

Any response other than “always” is considered a problem or an opportunity to improve. A problem score counts the number of opportunities to improve in each of the problem score proposed for each of the four essential domains. Table 1 lists each of the problem scores or scales and states the objective for that sub-domain.

Table 1.
Domains and Problem Scores for the After-death Bereaved Family
Member Interview

Domain	Problem Score	Objective
<i>Comfort</i>	Physical Comfort	The dying persons discomfort is recognized and they receive their desired level of comfort
	Emotional Support	Same
<i>Shared Decision Making</i>	Advance Care Planning	Health care providers communicate and negotiate with the patient regarding goals of care and formulate plans, including contingency plans, so that their preferences are honored
	Informing and Making Decisions	Patients and their families are informed about their illness, its disease trajectory and prognosis. Medical decisions should reflect the patients' desired involvement and informed preferences.
<i>Focus on the Individual</i>	Respect, Dignity, and Kindness	The dying person is treated with respect and dignity. This includes helping the patient achieve their desired level of control over their functioning and daily activities.
	Achieving Closure	The dying person and family are able to achieve desired closure in personal relationships and transcendence.
<i>Attend to the Caregivers</i>	Emotional Support including both prior and after the patient's death	The family receives the desired support at time prior to and after the patient's death, including appropriate referral for bereavement services.
	Self-efficacy in providing hands on care	Family caregivers have the confidence in their ability to help the dying person in management of their medical care.

The dying are a small, yet vulnerable population that provides a true test of whether health care organizations provide competent, coordinated, and compassionate health. Patient focused, family centered medical care recognizes the important role that family and friends play in caring for persons dying of serious and progressive illnesses. The focus of medical care must be on the dying person; yet, key to the well being of the dying person is the support provided to family prior to and after his death. The Toolkit of Instruments to Measure End of Life Care has a survey tool for both the dying person and the bereaved family member following that person's death. In the bereaved family member interview, we ask the respondent to report on his/her observations as an expert witness and on his/her own perceptions of interactions with the health care team. In the next chapter, we will walk you through using either of these instruments to conduct an audit – a small study to identify opportunities to improve and enhance the quality of care.

Reference List

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