

Putting the Patient and Family Voice Back into Measuring the Quality of Care for the Dying



Toolkit of Instruments to Measure End of life Care (TIME)

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Living Well With a Life Defining Illness

- z Re-engineer Advance Directives*
- z Change the Culture - Education*
- z Develop Measures of and Demand Quality of Care*
- z Create Systems of Care that Deliver Quality Medical Care*



What is so different about end-of-life care?



While one is dying, life takes on a new shape – values change. Things once ignored become more important.

What is more important to this woman?

Mammogram rates or being treated by the same provider with compassion.

Develop Measures



- z If you don't measure it..
You won't improve it!*
- z Essential to examining
the quality of care for
the dying is both the
dying persons and their
loved one voice*

Role of Measurement



- z Clinical Assessment - measures to guide patient management*
- z Research - assess phenomenon of interest*
- z Quality Improvement - information to reform or shape how care is provided*
- z Accountability - allows the comparison of health care providers*

Types of Measures



- z **Process measure** -- what you do to the patient--
e.g..., Did the nurse ask about whether you have pain?
- z **Outcome measure** -- benefit to the patient --Did the care you received at Hospice Care of Rhode Island provide you with the desired level of pain control?

Typical Satisfaction Measure



- z Typical satisfaction measure asks a person to rate a particular service on a scale of "Excellent to Poor" or choose from "very satisfied to very dissatisfied.."*
- z Requires a complex calculation of recall of that services, their expectation of that service, and then how to rank on the scale provided by that question*

Satisfaction



- Z Corporations must become obsessed with listening to consumers for “the race will go to those who listen most intently (and respond).***

Tom Peters

- Z I can't get no satisfaction...I can't get no satisfaction...and I tried ...and I tried... That what I say...No Satisfaction .. No.. No..***

Jagger & Richards

- Z As I grow older, I pay less attention to what men say. I just watch what they do.***

Andrew Carnegie

Problems with Satisfaction (Rankings of the Quality of Care)



- z Social desirability and acquiescence*
- z Lowered expectations*
- z Skewed distributions -- everyone responds "excellent"*
- z Meaning of categories may not be equidistant steps. "Very good" may be a problem with "good" a major calamity.*

Measuring the Dying Person and Their Loved Ones Perspective

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graph TD; A[Measuring the Dying Person and Their Loved Ones Perspective] --> B[Reports]; A --> C[Preferences or Unmet Needs]; A --> D[Rankings];
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Reports

Were you told the purpose of your medication in a way you could understand?

Preferences or Unmet Needs

Would you like someone to spend more time helping you eat?

Rankings

Thinking about your medical care, how would you rate the explanation of medical tests?.. Would you say.. Excellent...

Patient Centered Reports



- z What is important in palliative care? Key is responsiveness to dying persons and their love ones expectation and needs.*
- z Patient Centered Reports asks about specific events that are important to medical care with questions phrased in such a way to minimize patient's expectations or personal relationship with health care providers. For example,*

"Were you told of the purpose of your medication in a way that you can understand?"

Historical Context

Z *"When I first met David Tasma, he was a Jew who had lost his faith, a Pole who had lost his homeland, and ghetto survivor who had lost friends, family, and material possessions. At the age of 40, he was dying. In the months that followed we talked again and again about how the passage of end of life could be made easier and by the time he died, the idea for St. Christopher's Hospice had been born.. St. Christopher's is now in its thirtieth year. We have never lost sight of the values that were so important to David: commitment to openness, openness to challenge, and the absolute priority of patients' own views on what they need."*

Dame Cicely Saunders

Patient Centered Reports

- z Strong face/clinical validity - problem areas are actionable*
- z Focus is on consumer perspective-- and not rates of CPR, days spent in ICU, etc. Heterogeneity - reasonable person may desire different treatments. Preferences (and hence treatment decisions) are related to survival.*

Vision for TOOLKIT



- z Measures must be patient focused, family centered, clinically meaningful and manageable as well as psychometrically valid, reliable, and responsive.*
- z Initial focus on quality improvement. In the future, with experience..measures could be used for accountability, but accountability is a political process*
- z Measures must incorporate patient and family perspective -- patient focused, family centered medical care*
- z Measures examine both the process as well as outcomes. Future research is needed to understand interrelationship.*

Overall Strategy For Toolkit

- z Conduct focus groups with dying persons and their love ones**
- z Review guidelines for key processes of care**
- z Perform review of the evidence that these process result in quality medical care**
- z Create both retrospective family interview and prospective patient interview**




Overall Strategy For Toolkit



- z Core module that is applicable across settings of care**
- z Additional modules that would allow the user modify the survey to their own particular needs**
- z Reports would come with resource guide that would suggest next steps to improving the quality of care**

For every rate, there must be a numerator and a denominator



- z For the past three decades, clinical practice and public policy there is recognizable and definable state of being "terminally ill"*
- z Even with the best statistical models, uncertainty is inherent in the determination of prognosis*

Is it time to terminate using the word “TERMINALLY ILL” ?

94 y/o with acute MI,
low blood pressure,
short of breath at rest...

Is she “terminally ill”?



The Concept of “Terminal Illness”



Dying

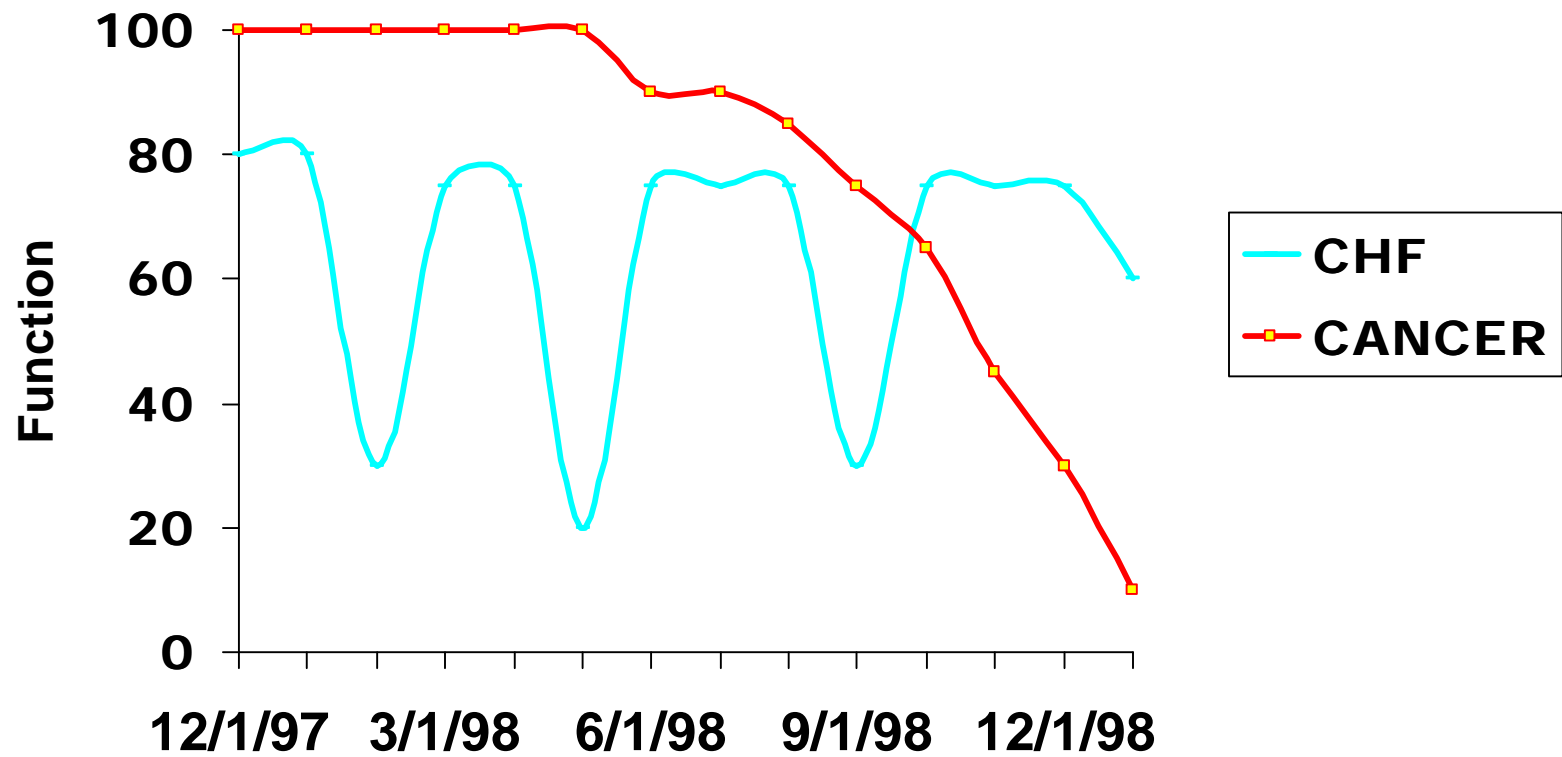


Active
Treatment

Comfort
Care



Life Threatening Illness —————> Actively Dying



A Recommended Solution



- z Guidelines on defining two states -- persons living with “life threatening illness” and those who are “actively dying”*
- z Interview bereaved family members about their perceptions of the quality of medical care*

Why the Family?



z *World Health Organization defines palliative care as obtaining the best quality of life for the patient and their loved ones*

Role of the Family



- z Medical care not only impacts on the "patient", but the family!*
- z For older and dying patients, a family member may be the only persons able to report on the quality of medical care*

Family voice



"They kind of turned us over to hospice...there should have been more overlap between the health care team and hospice...I called to tell (the doctor) that (the patient) hadn't eaten in 24 hours... And (the patient) died two hours later. The doctor said hospice was in charge of his care... the hospice people didn't even know us... we should have had more information about what would happen when we got home, both for symptoms and medical care."

z 31 y/o mother caring for actively dying husband who failed his third BM transplant and her two year old at home...

Focus Groups

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Research Questions



- z What do family members know about the quality of care of the dying?*
- z What time period(s) is the family able to report on?*
- z What can they tell us about the last week of life?*
- z How do family members reach conclusions about quality of care?*

Settings of Care

(AZ, MA, NY)



- z Academic Health Center*
- z Hospice*
- z Home Care with Visiting Nurse Service*
- z Nursing Home*
- z Community Medical Center*

Recruitment



- z IRB approval*
- z Family members contacted 3 months to 1 year after the death*
- z All were contacted by mail and given the opportunity of no further contact*
- z Exclusions -- trauma, suicide, under 18 years of age*

Recruitment



- z Contact initiated by institution where death took place*
- z Picker received a list of possible participants*
- z Telephone recruitment using standard script*
- z Confirmation letter -- telephone reminder call*

The Focus Group Sessions

February -- May 1999



- z Informed consent*
- z Audiotaped and videotaped*
- z demographic forms*
- z 2 + hours*

Focus Group Participants



- z 42 participants in 6 groups*
- z 70% Caucasian, 17% African-American, 13% multi-racial*
- z Mean age was 61 years (range 33-80)*
- z 71% were women*
- z 88% had completed at least some college*

Moderator's Guide



- z Let people tell their stories*
- z What does quality of life at the end of life mean to you?*
- z What do you think it meant to your loved one in their final days?*
- z What would they say about the care they received at the end of life?*

Post-group Evaluation



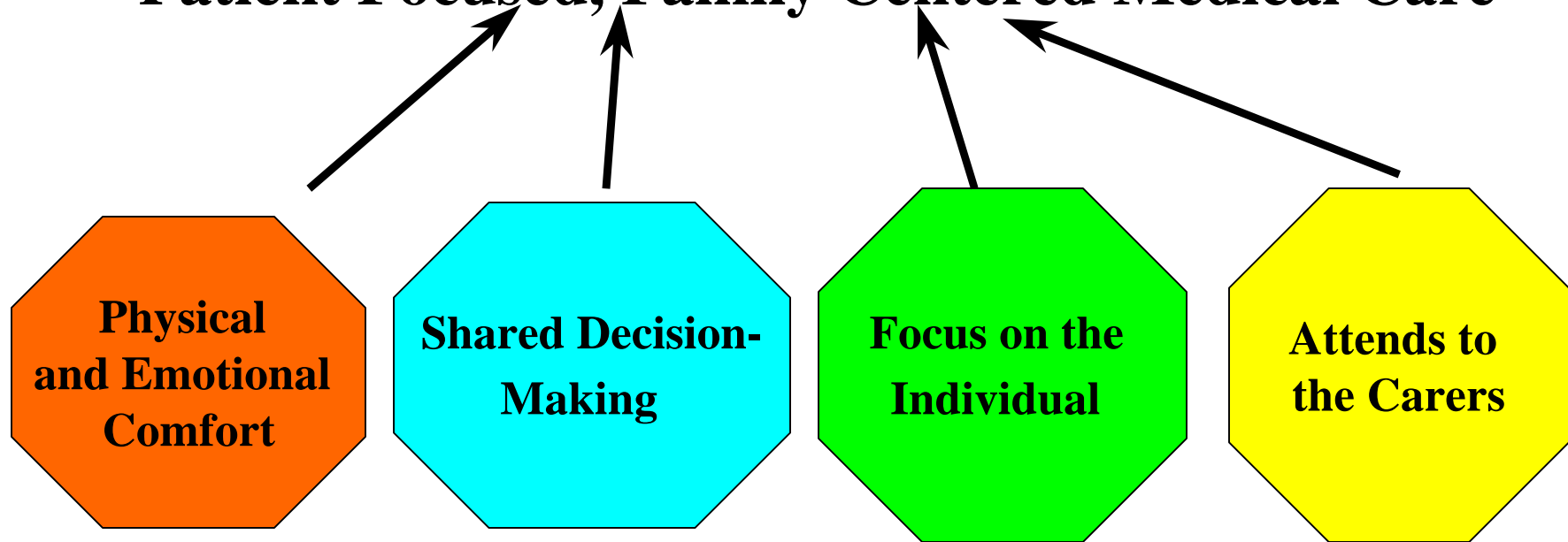
- z Were you recruited for this study in a sensitive manner?*
- z Was the focus group experience helpful to you?*
- z Did the focus group experience cause you distress?*

What Did We Learn?



- z Medical care must be patient-focused and family-centered*
 - y provide the desired physical and emotional comfort*
 - y promote shared medical decision-making*
 - y treat each person as an individual*
 - y attend to the needs of those who care for and love the dying person*

Patient Focused, Family Centered Medical Care



Informing and Educating

“you know what to expect, how you can help, and what you can expect.”

Coordination and Continuity of Care

“but after a certain point, you wonder who’s in charge”

Physical Comfort



z *"In terms of my husband, I know what was most important to him was to be free of pain. He was being cared for if he would not be in terrible pain."*

z *"During those last days... the nurses would come in at least every 15 minutes. They'd ask, is everything okay? Do you need anything? We'd push the button, and they would be there."*

Shared Decision-making



- z "She said she didn't want any more operations. Now they wanted to go in but they couldn't cure her. We had all these people coming to say that maybe my mother was mentally incompetent -- saying she should have the surgery."*
- z Rhonda talking about her experience with her mother's treatment. She left the hospital that night with the feeling that she was "trying to kill" her mother by not consenting to the surgery.*

Focus on the Individual

Achieving a sense of control



- z "He had trouble speaking because his mouth was so dry. He wasn't given adequate fluids. And this was a man, who my mother mentioned, bathed, got in and out of the bathtub everyday, shaved every day and brushed his teeth meticulously. He had almost all his teeth and nobody gave him the materials to do oral hygiene. He had foul breath odor. No one helped him bathe and he could bathe fine with all his props in place."*
- z "She enjoyed being taken outside. The home health aides didn't do that. It helps. It helps anybody."*

Focus on the Individual

Achieving Closure



- z "If there had been some way that he could not have been so incoherent, maybe he could have communicated with us a little bit. There is a way if they'll take the time to allow the patient and family to communicate... if they'll take the time to do that."*
- z "And maybe if one of the nurses or the Rabbi could have come to me and said, you have to realize she is going to die... I would have liked to have held her more. I would have liked to have her die in my arms and that's not what happened."*


Focus on the Individual

Respect and Compassion



- z "He got very bad care. I have to say that the shaving and all those things that make you feel like a human being and not one of the rejected and the lost, they don't do unless you force them in some way."*
- z "Respect and dignity to me should be most and best that we can give anyone that is being dependent upon someone else to care for them. That was not given. For them to feel secure in their surroundings."*


Focus on the Individual-- NOT Factory Health Care



z *My name is Ken. I've experienced both compassionate healthcare and also factory healthcare at various times, and I thought if sharing my experience could assist in institutions being more compassionate, then that would be a positive outcome*


z *.. when I first went into the hospital with my mother it was very mechanical. It seemed to me the spiel they gave you. They went through this whole thing, because you are in a whole other emotional state. And it seems like it's a ritual, I was hearing it but I'm thinking, "My mother is dying. I'm hearing this outside person telling me all these things....." I'm like hello! I know they meant it, but it didn't sound like it, it sounded real routine.*

Attend to the needs of those who care for the dying



With Ruth, 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 because I think you're right. 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


Attend to the needs of those who care for the dying



Advocacy as family burden --

- z "And you are there when she is calling the nurse and the nurse doesn't respond. And you are thinking if they are not doing it while I'm here, being the advocate, what are they doing when I'm not here? And I was there most of the day, but I didn't sleep there at night."*
- z That's the strongest word you've used. Everyone needs an advocate, no matter what your situation is. We found hospice was our advocate. I gave up fighting when hospice came in."*


Attend to the needs of those who care for the dying



Self efficacy --

- z "I'm glad I did it (keep her at home) but I think towards the end...giving the medications and upping the medications seemed so fast. All of the sudden now she is on all this morphine and all this whatever it is. And that kind of bothered me too. It really did. Because it was like, my God, I'm giving her this stuff. Am I giving her too much? I'm not a trained medical person."*
- z "I, being the caregiver, I was scared to death. I mean I'm not a nurse. I don't have that experience."*


Attend to the needs of those who care for the dying



Trust and Confidence --

- z "All we can do -- it's like travelling in a foreign land-- you know you take advice from people and decide whether you trust them enough to follow it."*
- z I visited my mother as least once a week. And now I'd see her with oxygen and I'd say, what's going on here? Why didn't you call me?"*


Attend to the needs of those who care for the dying



Support and emotional well-being --

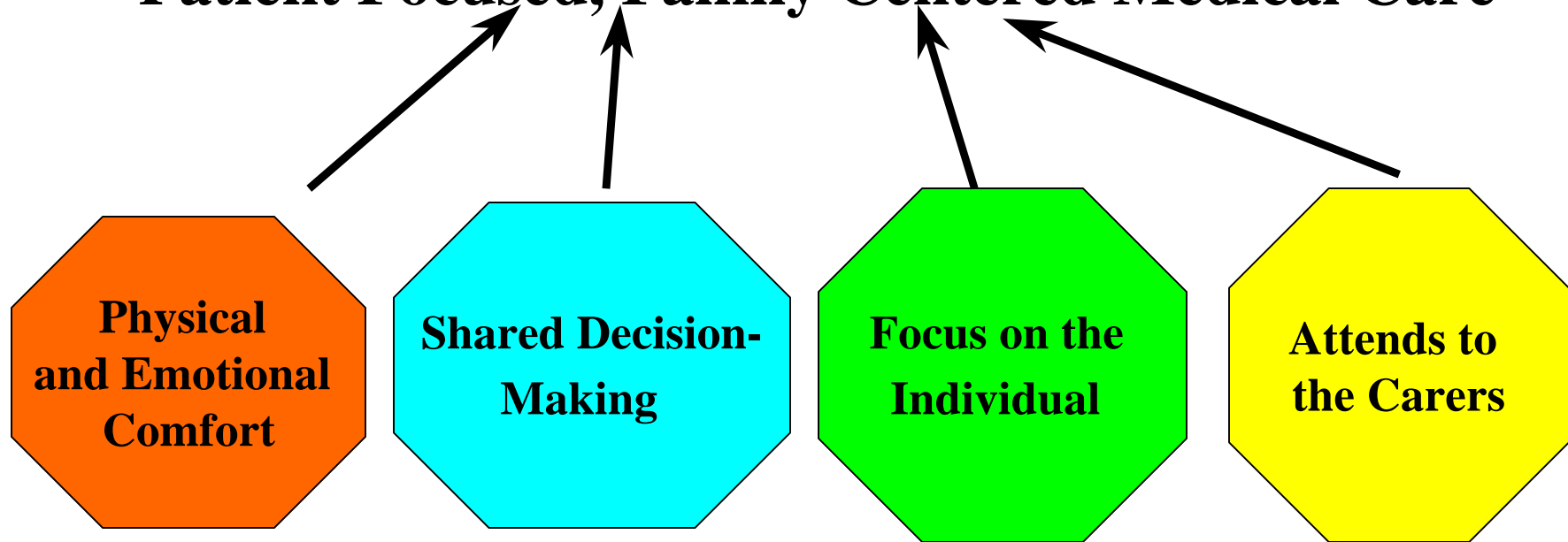
- z "I was not prepared for how it actually went. I was not prepared for my emotions. And afterwards, actually I did go to several bereavement things. They were beneficial. I needed to vent."*
- z "That last month though I knew she was going to die, I didn't have any feedback from _____. It would have been nice to have been able to sit in a group like this."*
- z "And possibly _____ could take a lesson from hospice and care for those who are left behind."*

For the dying (and all persons)...



- z Medical care must be patient-focused, family-centered.*
 - y Provide the desired physical and emotional comfort*
 - y Promote shared medical decision-making*
 - y Focus on the individual*
 - y Attend to the needs of those who care and love the dying person*

Patient Focused, Family Centered Medical Care



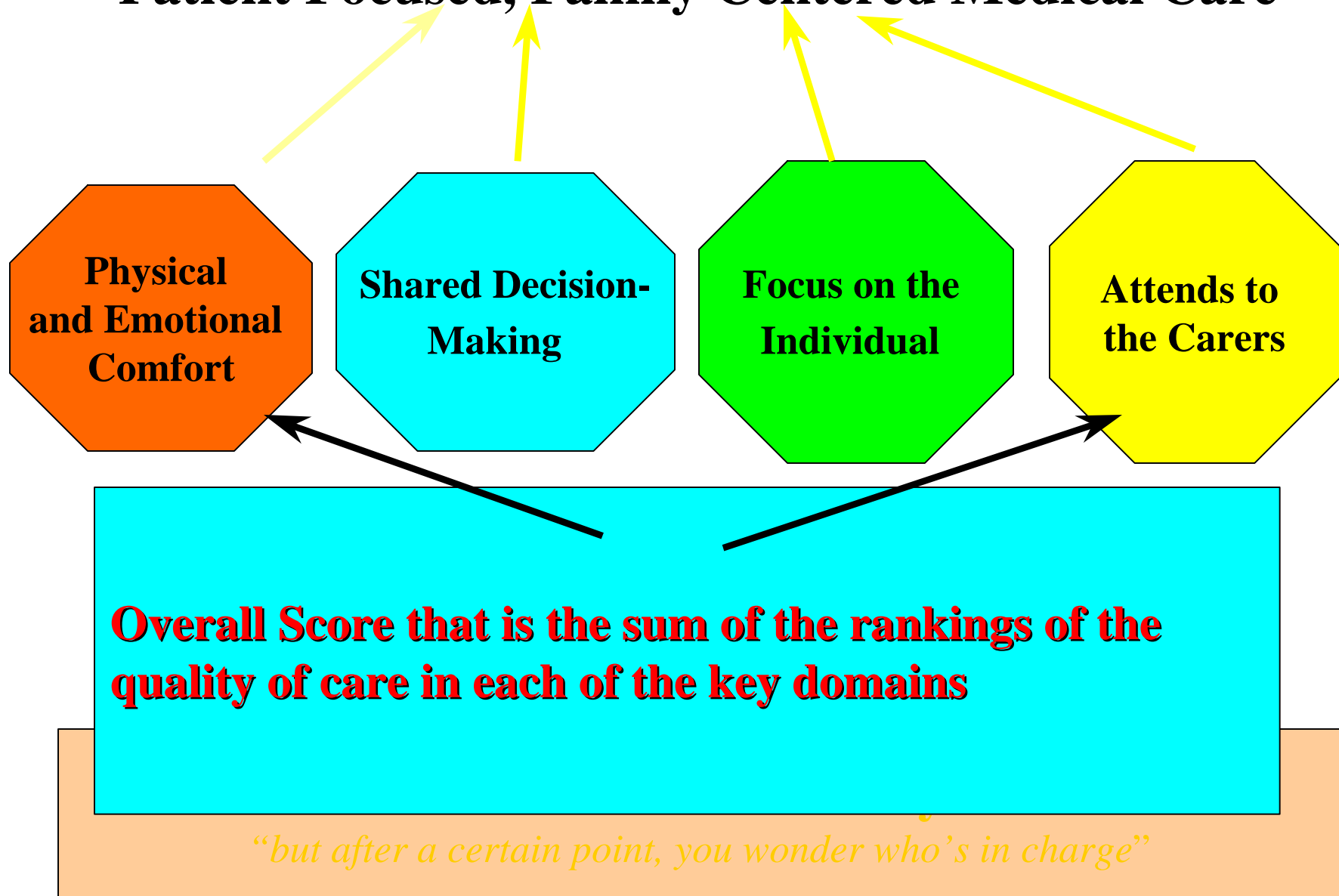
Informing and Educating

“you know what to expect, how you can help, and what you can expect.”

Coordination and Continuity of Care

“but after a certain point, you wonder who’s in charge”

Patient Focused, Family Centered Medical Care



Patient Focused, Family Centered Medical Care



New Ranking Questions

INTRODUCTION: In the next set of questions, I am going to read some statements to you on what (these health care institutions and) you should expect regarding the quality of medical care. Then, I will ask whether that goal was met by those health care providers involved in the medical care of (PATIENT) in the last month of life.

Important to high quality medical care is that the staff of (NAME of INSTITUTION) should --

Communicate with the patient and family so that they understand the (PATIENT's) illness and likely outcomes of care.

.How well do you think that (NAME OF HEALTH CARE PROVIDER/ INSTITUTION) did in achieving this goal?) Choose a number on the scale of 0 to 10, where 0 is the communication failed to meet that expectation and 10 is greatly exceeded that expectation

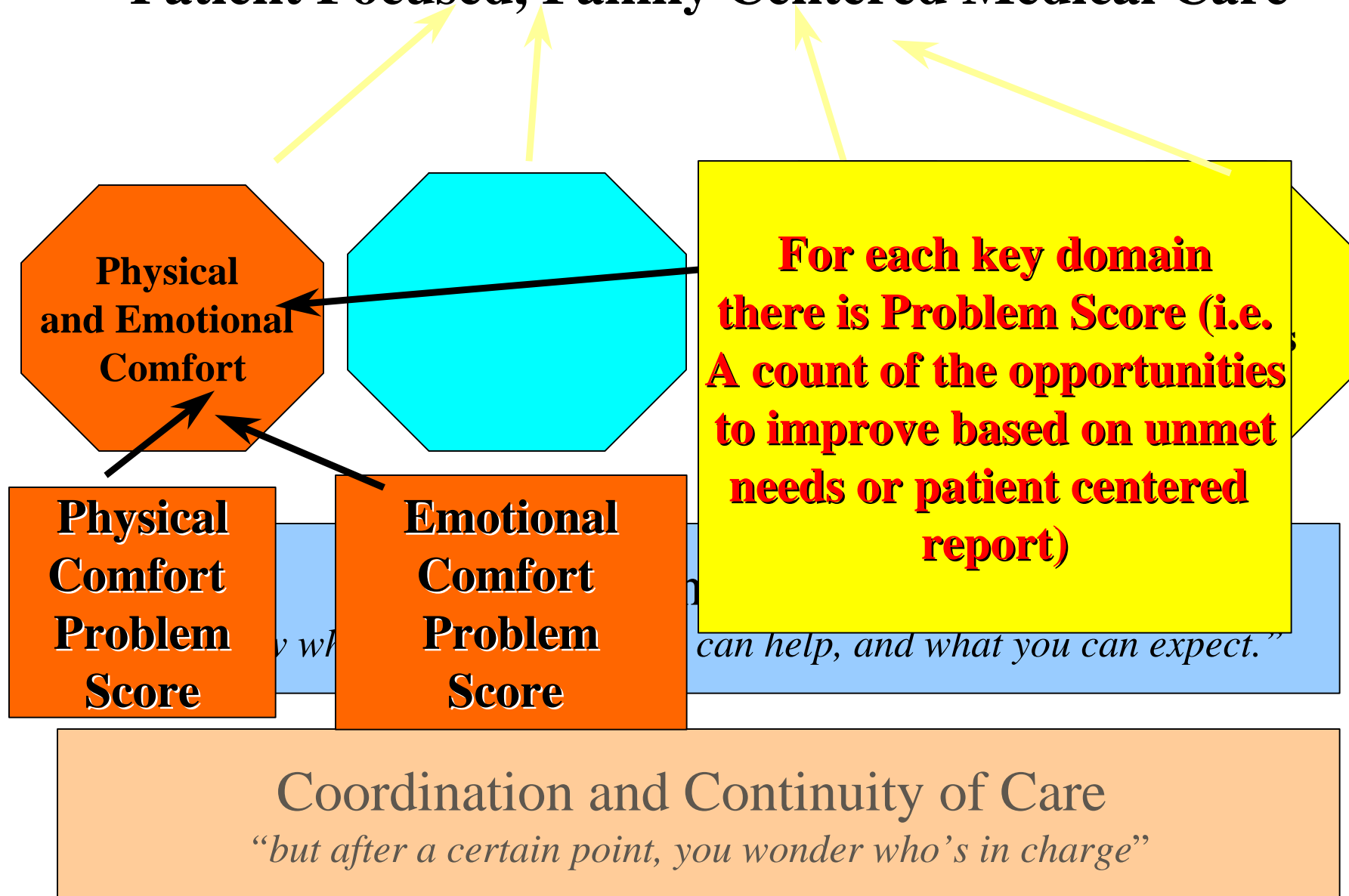
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Communication

	(x)	(sd)
Hospital (n=44)	6.5	(3.4)
Nursing Home (n=24)	6.6	(3.8)
VNA (n=11)	7.1	(4.1)
Hospice (n=17)	9.2	(2.1)

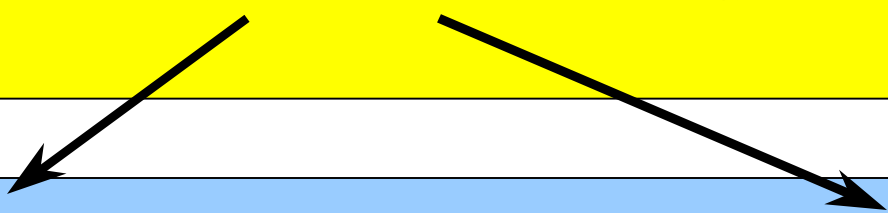
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Patient Focused, Family Centered Medical Care



Patient Focused, Family Centered Medical Care

IN ADDITION, THERE WILL BE TWO CROSS CUTTING PROBLEM SCORES FOR TWO KEY PROCESSES OF CARE ACROSS THE FOUR KEY DOMAINS



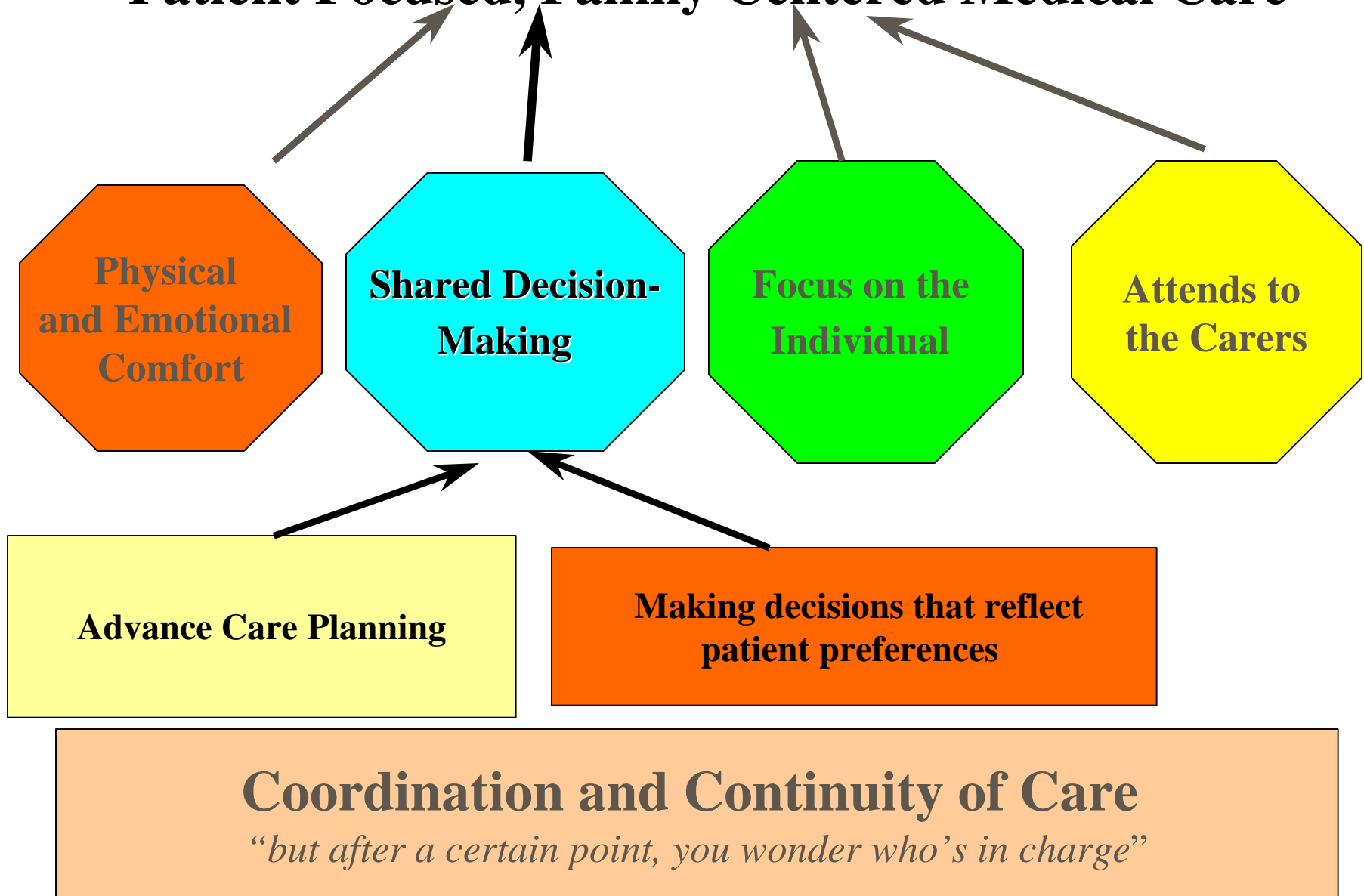
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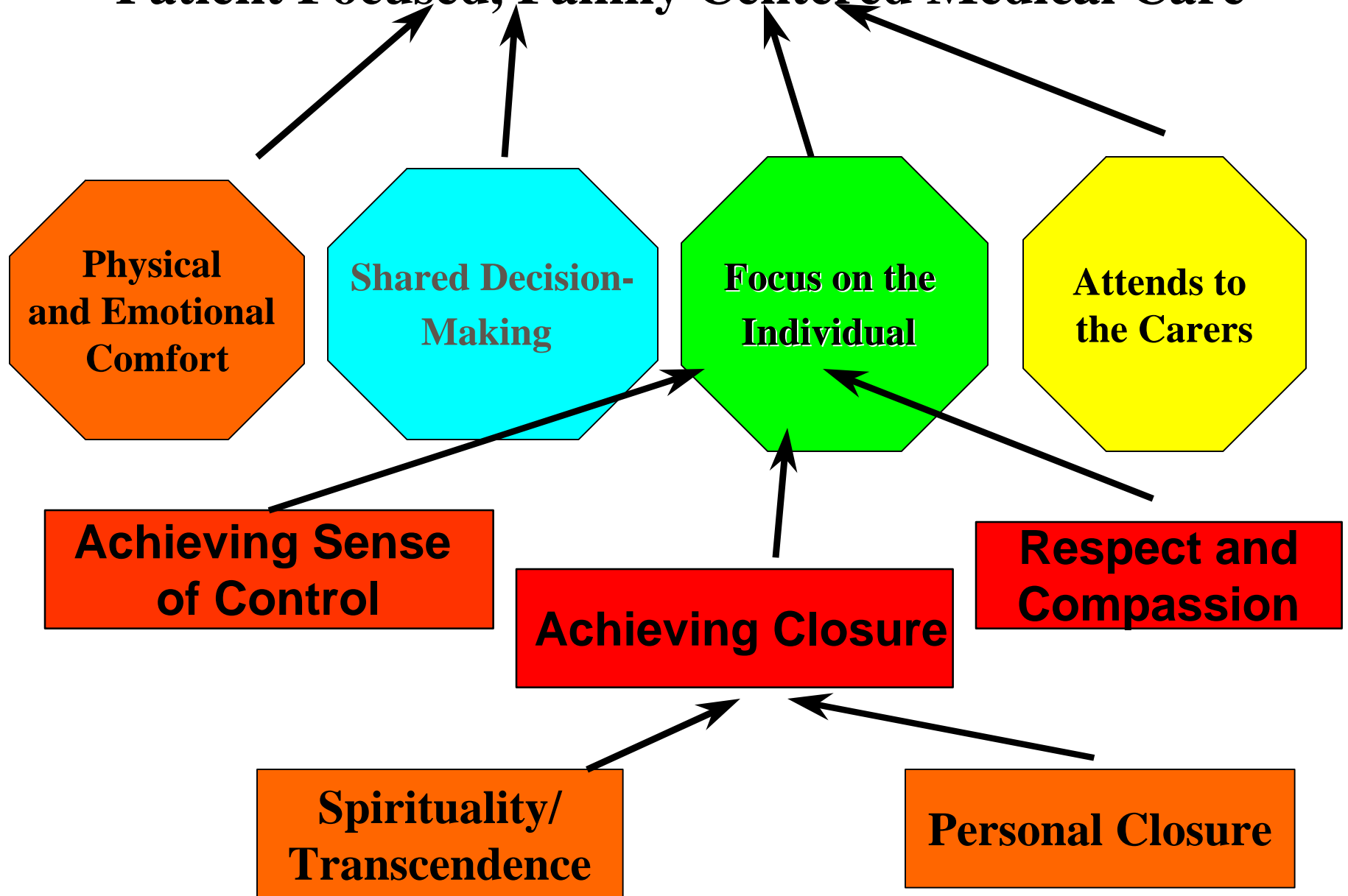
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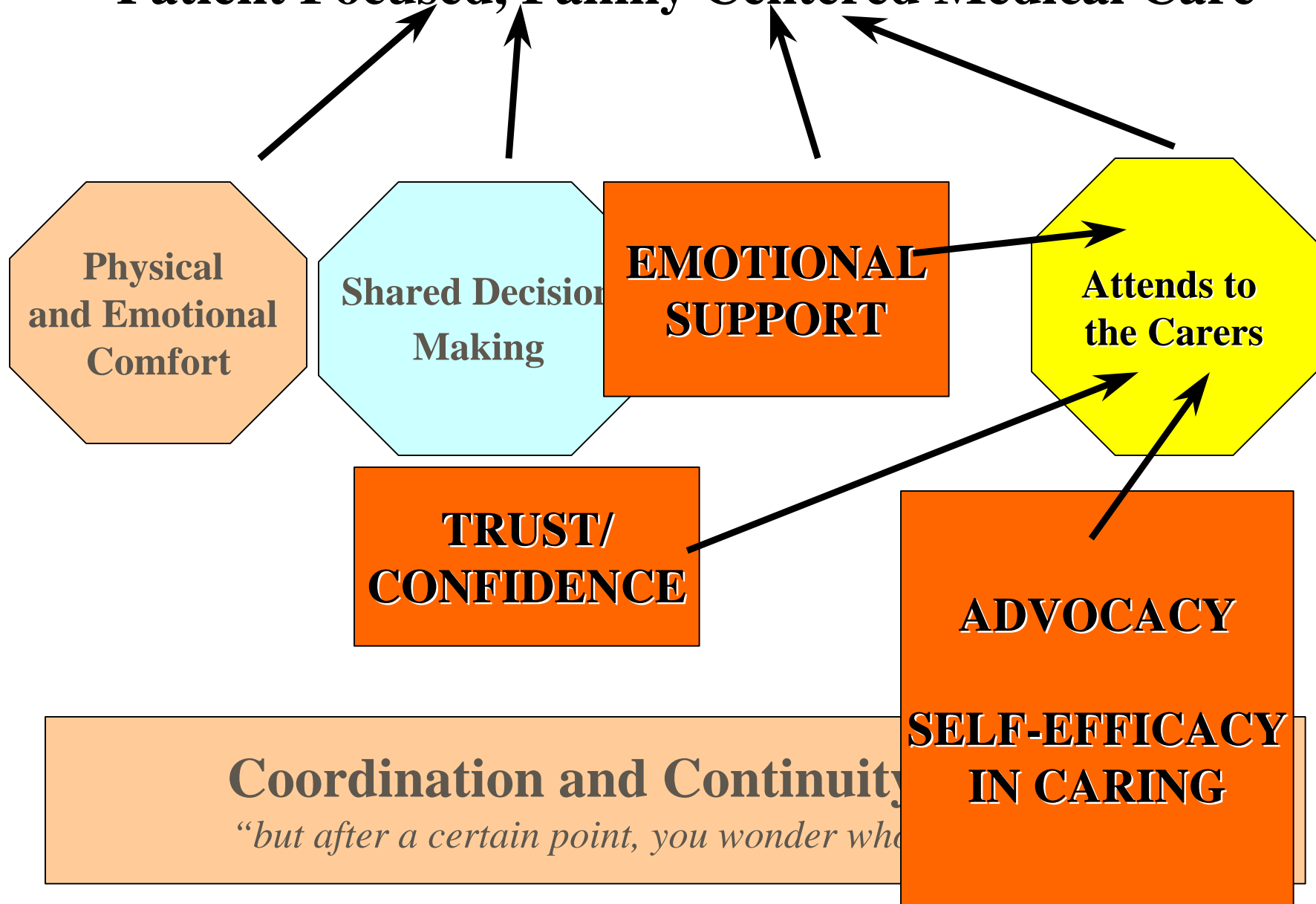
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Patient Focused, Family Centered Medical Care



Patient Focused, Family Centered Medical Care



Proposed Content - -

Physical and Emotional Comfort



- Z Assessment**
- Z Education -- understand medications, use of breakthrough doses, side effects**
- Z Timeliness of response to worsening pain**
- Z desired level of relief**
- Z ongoing monitoring and adjustment**
- Z coordination**
- Z appropriate referral**

Physical Comfort



z Proposed questions --

- y While (PATIENT) was at _____, was there any time when the medical staff did NOT do everything that they could to help control (PATIENT'S) pain?*
- y While (PATIENT) was at _____, did he/she ever have to wait too long for a pain medication to be given to (him/her)?*
- y Did (PATIENT) receive too much, not enough, or the right amount of medicines to control (his/her) pain?*

Proposed Content - - Shared Decision-Making



- y **Communication and education about prognosis, preferences, treatments options in a way the patient could understand**
- y **Understanding and listening to patients concerns**
- y **Desired level of involvement in decision making**
- y **Treatment preferences honored - problem is the surrogate makes peace with these situations**
- y **ACP= communication, formulation of preferences, and development of plans to honor those preferences**
- y **Discussion of existing legal, written advance directives**

Shared Decision-making



z Proposed questions --

- y While (PATIENT) was at _____, did the doctor make a plan that ensured that (his/her) wishes for medical treatment were followed?*
- y At _____, was there any medical procedure or treatment that happened to (PATIENT) that was inconsistent with (his/her) previous wishes?*

Focus on the Individual



- z Achieving a sense of control*

- z Achieving closure*

 - y personal relationships*

 - y spirituality/transcendence*

- z Respect and compassion*

Proposed Content -- Focus on the Individual



z Achieving sense of control

y as independent as wanted

y attend to personal care

y listening to what patient had to say

y respectful of choices about daily routine

Proposed Content - - Focus on the Individual



z Spirituality/Transcendence

- y really listen to your fears, beliefs and concerns*
- y appropriate referral*
- y timeliness of that referral*
- y interfere with the practice of those beliefs*

Proposed Content - - Focus on the Individual



z Achieving Closure

- y Time spent with loved one*
- y Staff helping you communicate with loved one*
- y Facilitate you being with your loved one*
- y Able say important things*
- y Staff not interfering in spending time*
- y Staff not interfering in final goodbye*
- y Comfortably being with persons*

Focus on the Individual



z Proposed questions --

- y How often was the _____ staff respectful of (PATIENT'S) expressed wishes about his/her personal care -- always, often, sometimes, rarely, or never?*
- y Did staff at _____ support (PATIENT) in being as independent at (he/she) wanted?*
- y Was there anything that the staff did that interfered with you saying your "final good-bye?"*

Attend to the needs of those who care for the dying person



- z Advocacy -- feel responsible for good care*
- z Self-efficacy -- need more information*
- z Trust and confidence -- need clear answers*
- z Support -- need help to cope with the loss*

Proposed Content-- Attend to Carers



z *Self-efficacy*

- y** *manage medications*
- y** *physical care*
- y** *what to expect*
- y** *know what to do at the time of death*
- y** *talking to the patient*

Proposed Content-- Attend to Carers



z Self-efficacy

INTRODUCTION: In the next set of questions we will be asking you about how much confidence you had in helping (PATIENT) manage (HIS/HER) health care needs? We will ask you to rate your confidence on a scale of 0 to 10, where 0 is not at all confident and 10 is very confident.

- y* How confident were you in your ability to know what to do if (PATIENT'S) pain got worse?

Attend to the needs of those who care for the dying person



z *Proposed questions --*

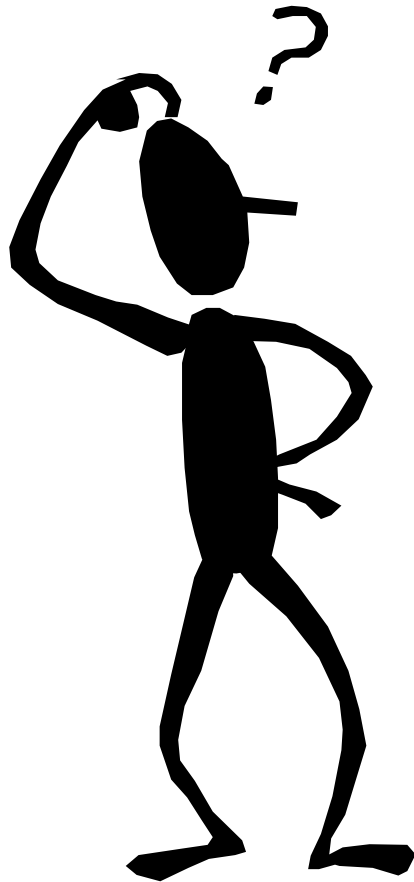
- y** *Would you have liked the staff to be more sensitive to your feelings?*
- y** *Did a member of the staff talk with you about what it would be like for you after (PATIENT'S) death?*
- y** *Would you have liked a member of the staff to call you to see how you were doing after (PATIENT'S) death?*

Individualize Survey to Your Needs



- z Core questions that can be answered about medical care in hospital, hospice, VNA, and NH*

Time Frames



- z Past week for pain and other symptoms*
- z For other domains, time frame is the amount of time under that institution up to one month.*

Proposed use of modules

- z Additional question content in certain domains - complete symptom assessment in the last week of life*
- z site specific questions - self-efficacy for VNA and hospice, family burden*
- z Second survey that looks at care from the perspective of an integrated health care system (follow lead of mortality followback)*

www.chcr.brown.edu/pcoc/toolkit.htm

