Communication with relatives of critically ill patients

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Why is communication with relatives important?

Relatives of ICU patients suffer too…

- Almost 1/2 of all family members of critically ill patients experience symptoms of anxiety & depression.

Families of ICU patients suffer too…

Azoulay AJRCCM 2005

- Risk of PTSD among family members
- 21 ICUs 284 family members
- 90 days after ICU stay of their relatives
- Risk ↑in 33%
- Factors:
  - Information incomplete 48%
  - Sharing decision in ICU 48%
  - Relative died in ICU 50%
  - Relative died after EOL decision 60%
  - Shared EOL decision 82%

Families of ICU patients suffer too…

- Almost 1/2 of all family members of critically ill pt experience symptoms of anxiety & depression.
- Relatives often serve as surrogate decision makers, contributing to decisions about the care of the patient

Strategies of Medical Decision Making

Paternalism	Autonomy	Shared decision making
		

Family member satisfaction with EOL decision making in ICU

- Survey 10 hospitals: quality-improvement intervention to enhance palliative care in ICUs
- Family satisfaction with support during decision making
  - Life-sustaining support withdrawn, spiritual care service involved
  - Withdrawal of support recommended by physician
  - Family wishes in withdraw life support discussed
  - Spiritual needs discussed

Gries CJ. Chest 2008; 133: 704

AMERICAN JOURNAL OF RESPIRATORY AND CRITICAL CARE MEDICINE VOL 163 2001

Meeting the Needs of Intensive Care Unit Patient Families

A Multicenter Study

ELIE AZOULAY, FREDERIC POCHARD, SYLVIE CHEVRET, FRANÇOIS LEMAIRE, MUSTAFA MOKHTARI, JEAN-ROGER LE GALL, JEAN FRANÇOIS DHAINAUT, and BENOIT SCHLEMMER for the French FAMIREA Group

Parameters	Median (Ranges) n (%)
Number of family members	2 (1–3)
Age	45 (34–59)
Sex ratio, % of men	611 (66.4)
Health care professionals	86 (9.3)
Did not speak French	28 (3)
Not of French descent	120 (13)
Relationship with the patient	
Spouse	217 (23.5)
Parent	210 (22.8)
Child	227 (24.7)
Sibling	84 (9.1)
Other family members	99 (10.8)
Not a family member	84 (9.1)
Hospital commuting time, min	30 (20–60)
Desired/allowed information time ratio	1.5 (1–2)
Family feels they received contradictory information	105 (11.7)
Family would like more information about	
Diagnosis	649 (72.5)
Prognosis	692 (77.3)
Treatments	645 (72)
At least one of these components	782 (87.3)
Family does not know the specific role of each caregiver	492 (55)
Family is not helped by their usual doctor	439 (47.7)
Family would like the help of a psychologist	431 (48.1)
Total CCFNI score	2 (2–3)

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TABLE 5

MULTIVARIATE ANALYSIS OF SATISFACTION USING POISSON MODEL

	Adjusted Estimated Relative Ratio of Expected Satisfaction (%)	p Value
Family members of French descent	+25.9	0.0008
Patient to nurse ratio ≤ 3	+12.7	0.0144
Information provided by junior physicians	+30.4	0.0001
Family feels they received contradictory information	−21.1	0.0024
Family does not know the specific role of each caregiver	−13.9	0.0012
Family is helped by their usual doctor	+9.3	0.0012
Desired/allowed time ratio	−3.3	0.0019

Why is communication with relatives important?

- Half the families of ICU patients experience inadequate communication with physicians

Elie Azoulay Crit Care Med 2000 Vol 28, No. 8

Communication Tasks with Relatives

- Breaking bad news
- Discussion on a change in the goals of care for critically ill patient
- Provide appropriate, clear information they need to participate in decision making

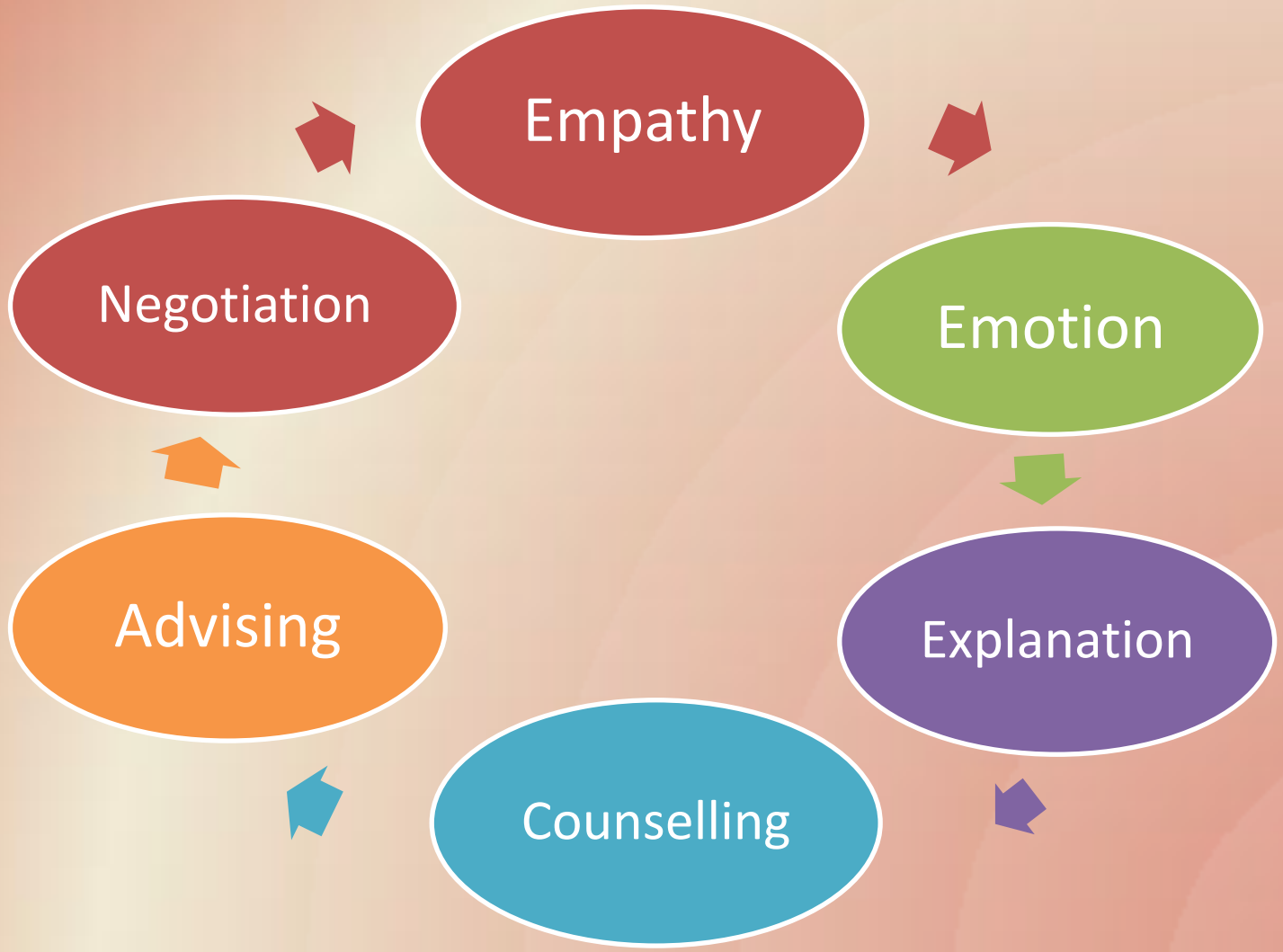
Communication Tasks with Relatives

- Best carried out in the context of a close relationship between the physician and patient, characterized by mutual trust, respect & honesty.



- Often difficult to develop such a relationship in an acute care setting

Communication Principles



Empathy

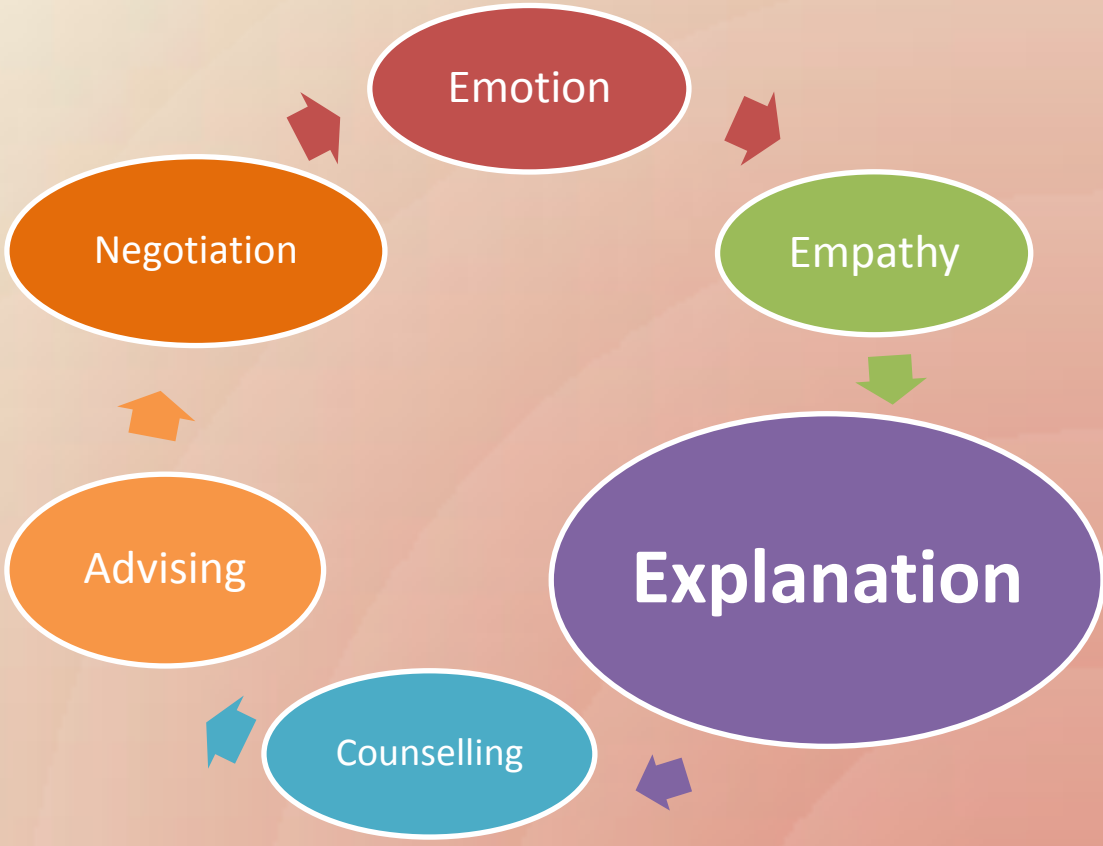
- Involves sharing, comprehending & acknowledging the feelings of relatives
- Telling relatives you realize the situation must be awkful, a decision must be difficult

Emotion

- Permit normal expression of emotion
- Admit to family that the situation is getting to you help to bring you & the family together

Explanation

- Keep clear & simple
- Avoid using jargons



Counselling

- Assist decision making by helping family members consider all the issues
- Refrain from expressing any opinion or supporting any particular action

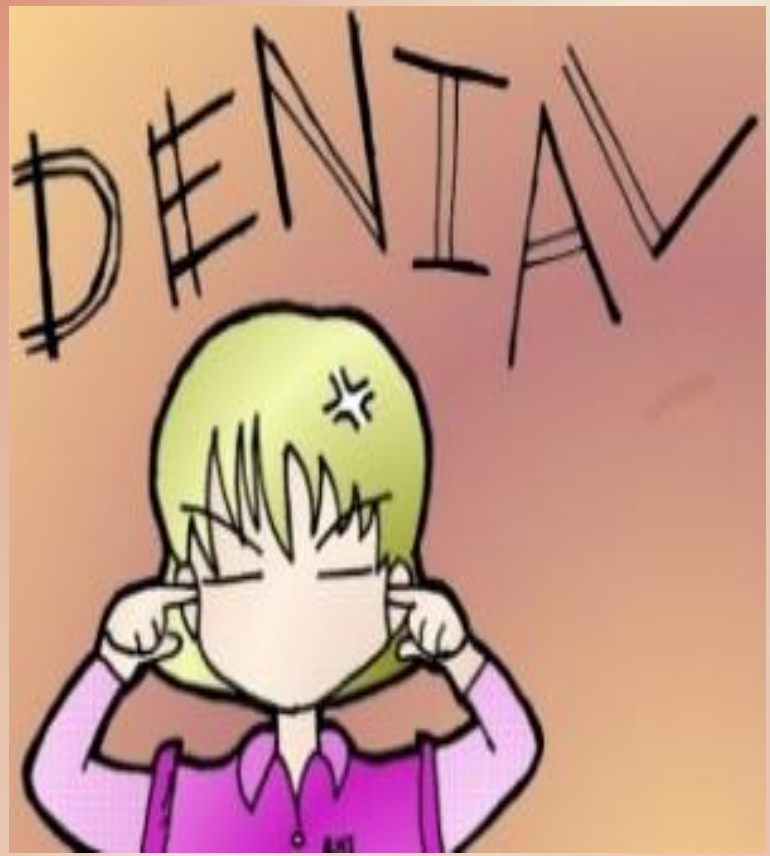
Advising

- On the basis of knowledge of medical situation
- Take into account the views and circumstances of the patient

Negotiation

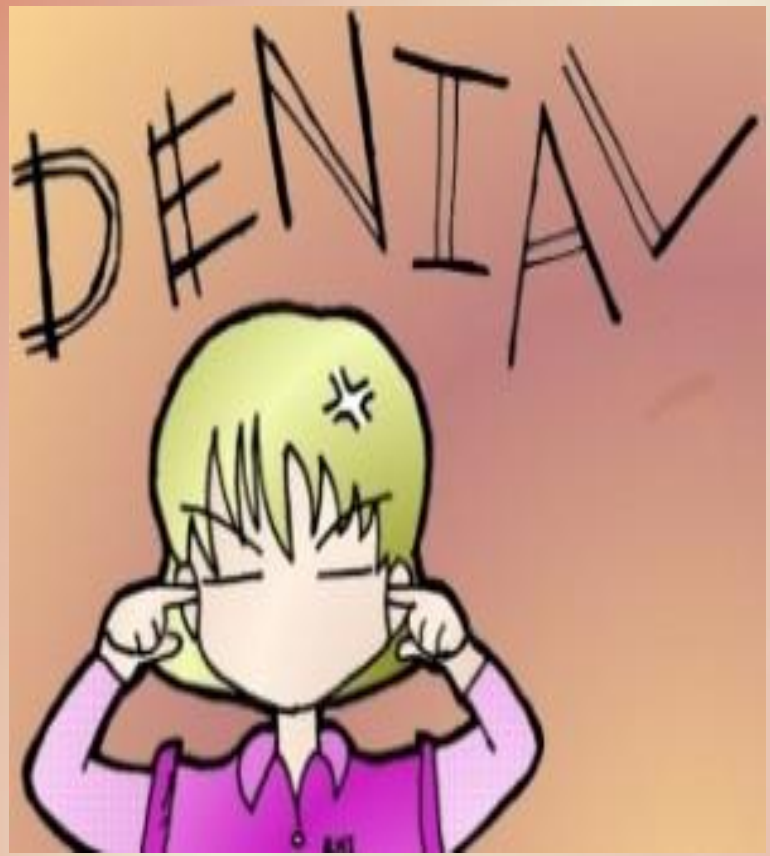
- Include everyone
- Don’t set out to beat the other side
- Seek to understand relatives’ interests, perspective & constraints
- Manage anger
- Defuse anger
- Manage denial

Manage Denial



- Psychological defence mechanism, not being difficult
- Acceptance is associated with overwhleming pain and loss

Manage Denial



- Understand the reasons why acceptance is not possible
- Forcing the issue (“You have to accept”) is unhelpful

Ten most important needs of families of critically dying patients

- To be with the person
- To be helpful to the dying person
- To be informed of the dying person's changing condition
- To understand what is being done to the patient & why
- To be assured of the patient's comfort
- To be comforted
- To ventilate emotions
- To be assured that their decisions were right
- To find meaning in the dying of their loved one
- To be fed, hydrated & rested.

Improving Communication

- Key to communication: TRUST

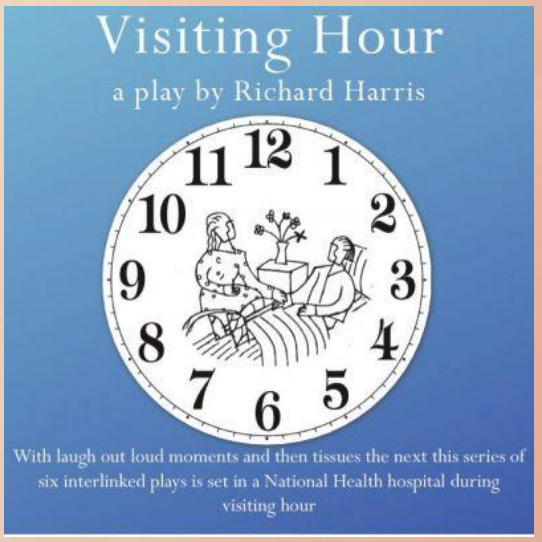
Improving Communication

- Key to communication: TRUST

- **Earned by delivering compassionate, high quality care**
- **Enabled by consistently effective communication**

Trust earned by delivering compassionate, high quality care

- Liberal visiting hours
- Communicating on the care being provided



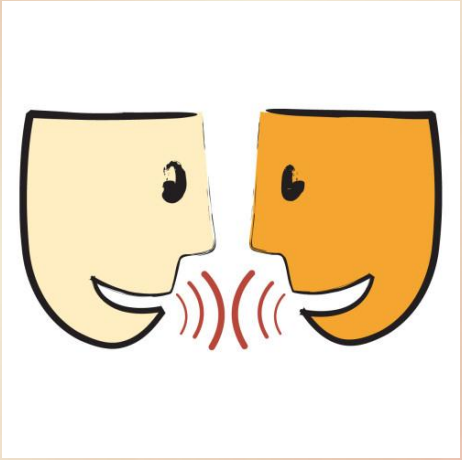
Improving Communication

- Key to communication: TRUST

- **Earned by delivering compassionate, high quality care**
- **Enabled by consistently effective communication**

Trust Enabled by consistently

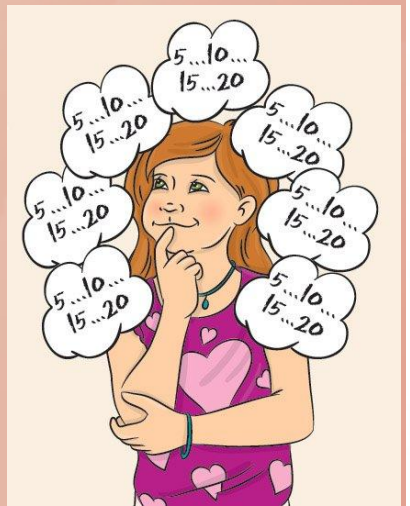
effective verbal communication



1. Understandable, welcoming of questions
2. Frequent & timely
3. Truthful
4. Respectful & culturally informed
5. Attentive and empathetic listening

1. Understandable, Welcoming of questions

- Information presented in language that is at a level of detail appropriate to family members
- Repetition is important
- Employ educational tools
- Families encouraged to ask questions and express feelings



2. **Frequent & Timely**

- Meet family within 24 to 36 hr to review initial events and issues pertinent to patient's admission
- Emphasize hope and determination for achieving recovery; perspective on limits of curative efforts & benchmarks of recovery or decline
- Followed by daily efforts (ideally) to communicate the clinical course

Important Questions Asked by Relatives of ICU Patients

Table 2. List of the 21 most important questions asked by family members of patients in the intensive care unit

Domain	Subdomain	Question
Diagnosis	Neurologic status	Why is he/she not fully conscious?
Diagnosis	Disease	What is wrong with him/her?
Diagnosis	Appearance	I am upset by the way he/she looks. Can you tell me why he/she looks different?
Treatment	What treatments?	What treatments and other care is he/she receiving?
Treatment	Weaning	When will he/she be able to breathe on his/her own?
Treatment	Tubes and machines	What is the purpose of the tubes and machines attached to him/her?
Prognosis	Recovery	Will he/she get better?
Prognosis	Probability	What are the chances that he/she recovers?
Prognosis	How and when families will know	How and when will we know what is going to happen?
Prognosis	Recent events	Is he/she better today?
Comfort	Psychological distress	Is he/she in psychological distress?
Comfort	Supplying comfort items	Is there anything I can do to make him/her more comfortable? (music, newspaper, food)
Comfort	Physical pain	Is he/she in pain?
Interaction	Hearing	Can he/she hear me when I speak to him/her?
Interaction	My participation	What can I do for him/her? (help with care, feeding, washing)
Communication	Being informed	Can I be sure I will be told if something happens?
Communication	News	Will I be informed regularly of changes and, if so, how?
Communication	Phone	Can I call to find out how he/she is doing?
Family	Decision-making	In a decision-making situation, what is expected of me?
Post-ICU	Length of stay	How long will he/she stay in the ICU?
Post-ICU	Sequelae	Will he/she have any after-effects?

2. **Frequent & Timely**

- Meet family within 24 to 36 hr to review initial events and issues pertinent to patient's admission
- Emphasize hope and determination for achieving recovery; perspective on limits of curative efforts & benchmarks of recovery or decline

3. **Truthful**

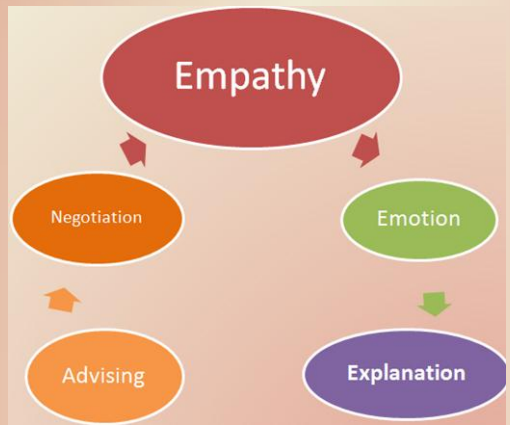
- Provide the best assessment of patient's prognosis while recognizing the uncertainty of such prognostication for individual patient

4. **Respectful and culturally informed**

- Be supportive & respectful of the values and views of patients
- Assess for specific cultural, ethnic or religious issues and needs that might impact care or decision making.

5. Attentive & Empathetic listening

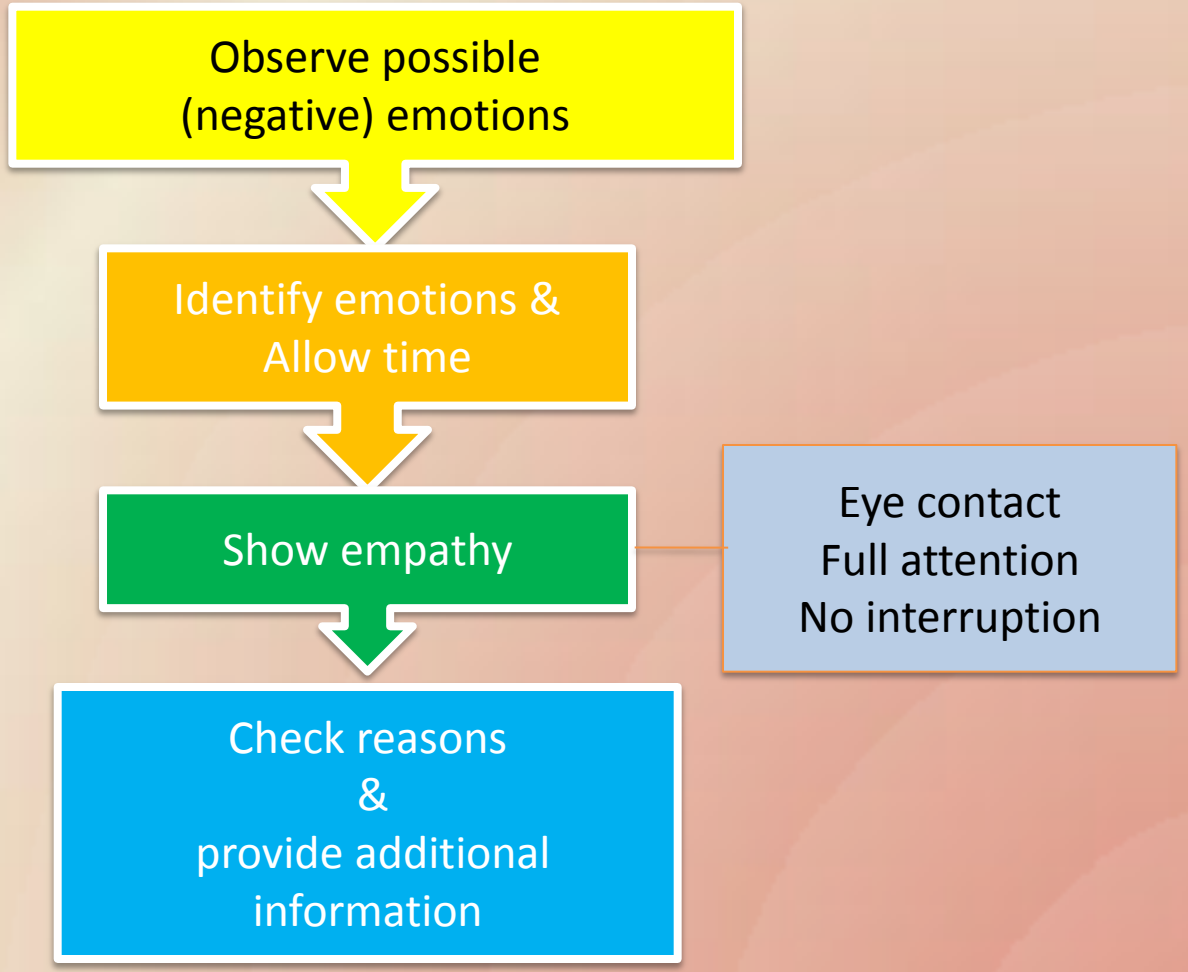
- Intense, potentially overwhelming emotional reactions: anger, fear, loss, guilt, frustration, disappointment
- Be vigilant for opportunities to express empathetic statements.



Active Listening Skills

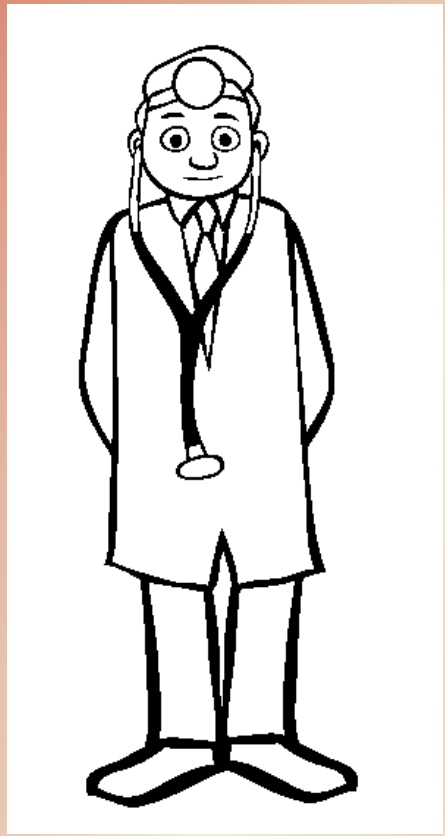
- **S:** face the relative SQUARELY to indicate interest in the exchange
- **O:** adopt an OPEN body posture
- **L:** LEAN towards the relative
- **E:** use EYE CONTACT to show you are paying attention
- **R:** maintain a relaxed body posture to decrease relative's anxiety

Responding to feelings



Empathetic Statements

- *"It must be hard to accept"*
- *"I'm sorry for your loss"*
- *"I know this is very painful for you"*
- *"This is so much harder than most people think"*
- *"Is there anyone I can call for you?"*
- *"How can I be of help?"*

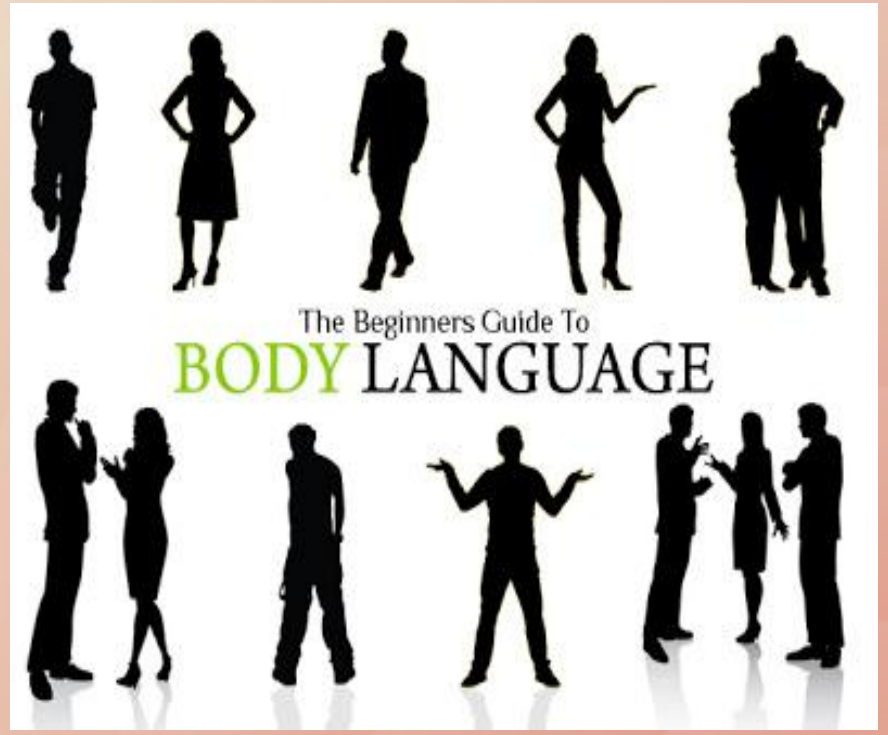


- Thus a primary task for the ICU clinician is to establish, nurture, and sustain trust with patients and their relatives.
- This trust is ultimately earned by delivering compassionate, high-quality care, and enabled by providing effective communication that is timely, truthful, respectful and culturally informed, and entails empathic listening.

- If end of life decisions are required, start a series of meetings sooner rather than later.
- Rapport and trust with family members come as a result of building a relationship over many meetings.
- A consensus is more likely to occur in the setting of trust and when there has been effective communication

Non-verbal communication

- Help to make the artificial situation more human and less hostile, diminish stress & anxiety
- Tone of voice, eye contact, body language, facial expression, touch
- Non-verbal cues not undermining verbal message



VALUE: 5-step Approach to Improving Communication in ICU with Families

- V… Value family statement
- A… Acknowledge family emotions
- L… Listen to the family
- U… Understand patient as a person
- E… Elicit family questions

Curtis, J Crit Care 2002; 17: 147

ORIGINAL ARTICLE

A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

Alexandre Lautrette, M.D., Michael Darmon, M.D., Bruno Megarbane, M.D., Ph.D., Luc Marie Joly, M.D., Sylvie Chevret, M.D., Ph.D., Christophe Adrie, M.D., Ph.D., Didier Barnoud, M.D., Gérard Bleichner, M.D., Cédric Bruel, M.D., Gérald Choukroun, M.D., J. Randall Curtis, M.D., M.P.H., Fabienne Fieux, M.D., Richard Galliot, M.D., Maité Garrouste-Orgeas, M.D., Hugues Georges, M.D., Dany Goldgran-Toledano, M.D., Mercé Jourdain, M.D., Ph.D., Georges Loubert, M.D., Jean Reignier, M.D., Fayçal Saidi, M.D., Bertrand Souweine, M.D., Ph.D., François Vincent, M.D., Nancy Kentish Barnes, Ph.D., Frédéric Pochard, M.D., Ph.D., Benoit Schlemmer, M.D., and Elie Azoulay, M.D., Ph.D.

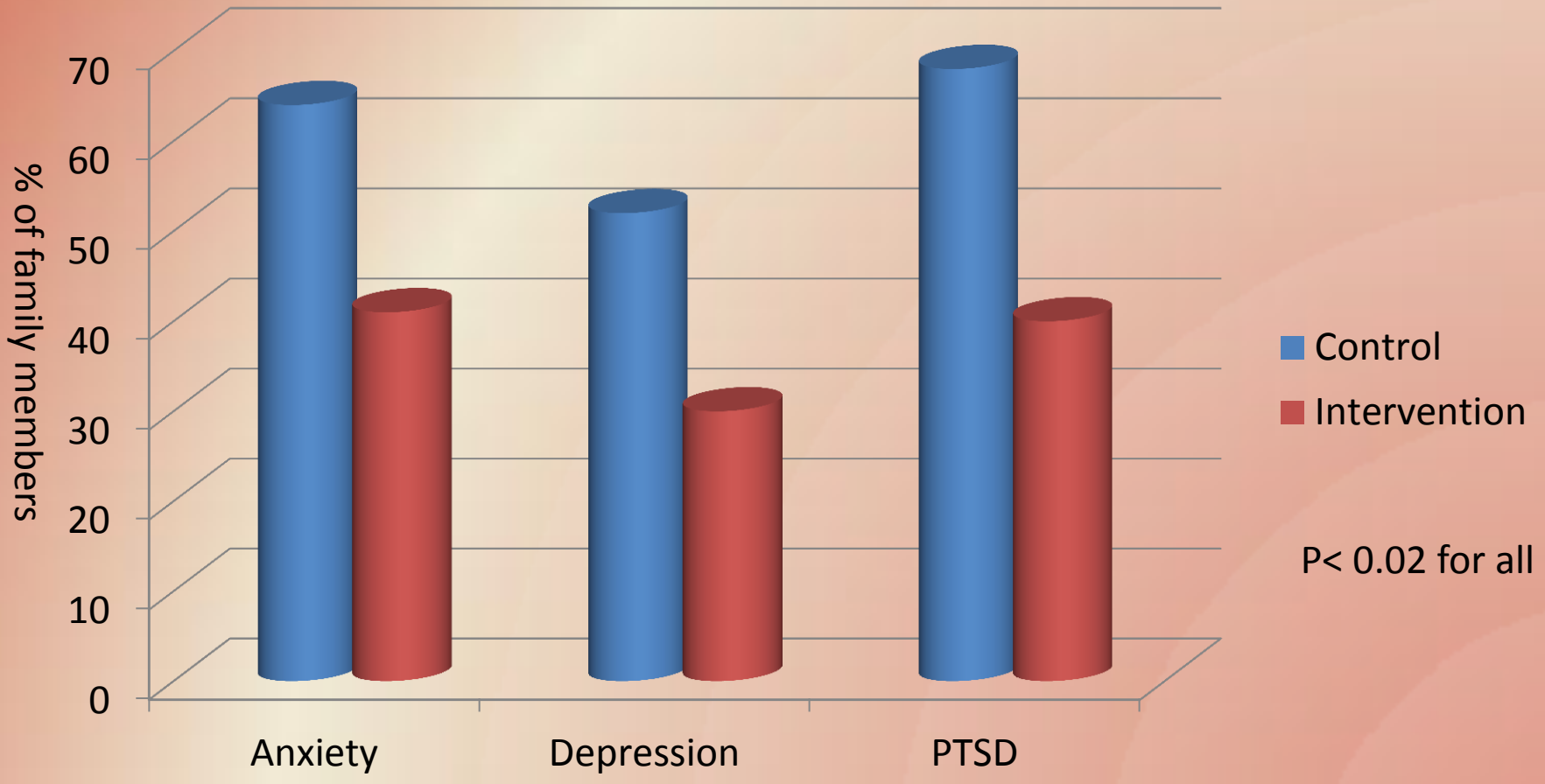
N Engl J Med 2007;356:469-78.

Randomized Trial of Communication Strategy

- Randomized 126 patients
- Eligibility: attending believe “patient will die within a few days”
- Intervention
- Proactive family conference using VALUE strategy
- Bereavement pamphlet for family

Lautrette NEJM 2007: 356

Family Member Outcomes: Psychological Outcome at 3 months



Intrapersonal tensions experienced by surrogate decision makers in ICU

- 30 surrogates, 5 ICUs, 2 hospitals
- Qualitative interview study
- Emotional conflict between the desire to act in accordance with their loved one's values and

1. not wanting to feel responsible for a loved one's death
2. a desire to pursue any chance of recovery

I don't want to be the One Saying "We should Just Let Him Die"

Schenher Y J Gen Intern Med 2012

Ways to overcome surrogate decision maker intrapersonal tensions

- Facilitate discussions between family members
- Not pressurize surrogates to make decision too quickly
- Allow families to reconvene with clinicians soon after hearing bad news to ask questions
- Tailor communication style to family need (compassionate, technical etc)
- Provide someone to listen to their stories, coordinate communication with physicians

Schenher Y J Gen Intern Med 2012

Tools for Communication

- What you think ≠
- What you say ≠
- What you think that you said ≠
- What I hear ≠
- What I understand of what I heard ≠
- What I think that you said

What we think that we are telling is not what the other did understand !

Perception

- Perception is individual
- Depends on HOW < the way > the communication is led more than WHAT < the content >

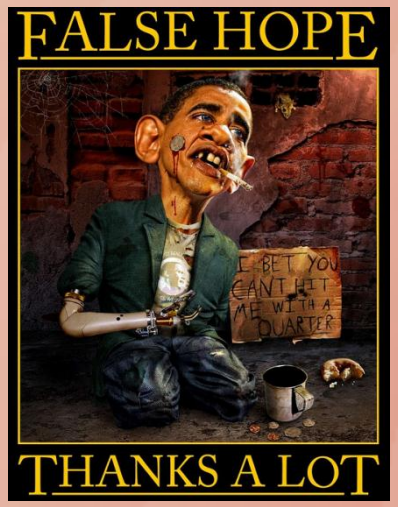
“I ‘ve never been told that!” The importance of words

- Incoherence
- We never use exactly the same words
- Check what they understand: I need to know what you remember of the previous explanations. And not what did you understand?
- “Soft” words
- Severe prognosis, serious situation ?!
- Say the word: he is dying; he may not survive
- Jargon

Sources of Misunderstanding

- The technical explanations:
- Arterial pressures, O2 saturation, names of bacteria, medications

- The false hope: in order to preserve the feelings of family members
- Omission; avoid the strong words
- Death, dying



The respect

- Attitude
- Words

- And act…leave your beeper, telephone at the desk

Other suggestions

- Silence
- No need to fill the emptiness
- Not let the emotion overwhelm you

Remove the mask

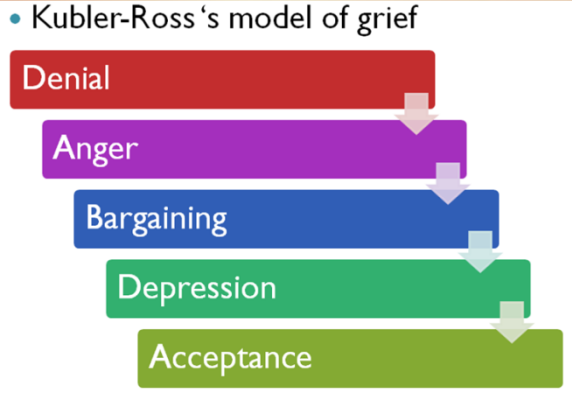
- Welcome their emotion & your emotion

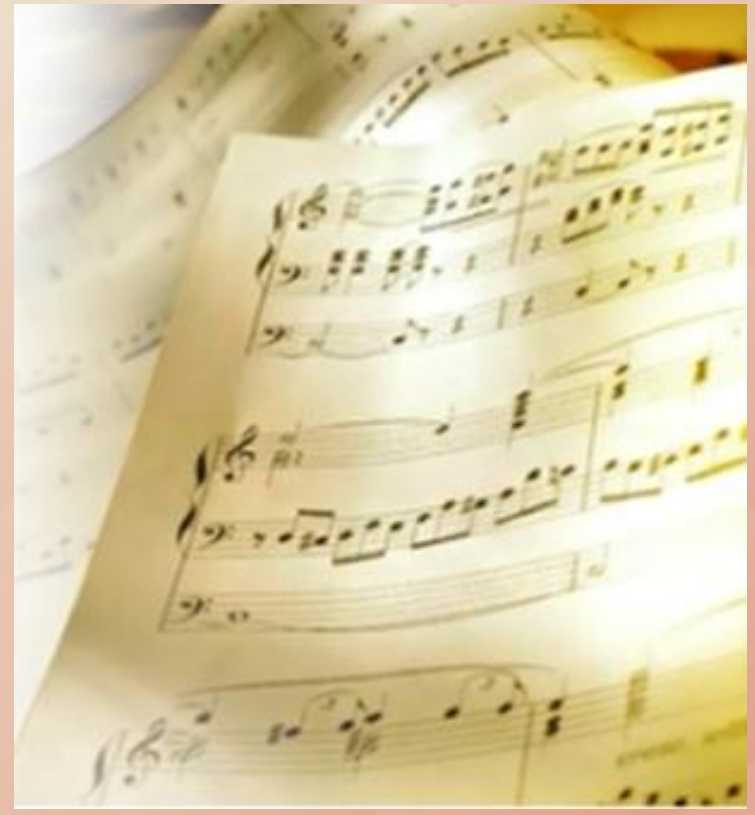
- *I am a physician…or a nurse; I am also a human being*

- Touching can help when we don't know what to tell any more

The rhythm

- Follow the rhythm of understanding and emotion
- Time to accept what is inacceptable & the unavoidable
- Stages of Kubler-Ross:





Familiar Requests

- *"We want everything done for our loved one!"*
- *"Is there a miracle therapy that this patient is entitled to?"*
- *"Doctor, just do everything, regardless the price!"*

Family Features

- Relatives may make decisions with which the healthcare team disagrees
  - •Grief
  - •Guilt
  - •Secondary gain
  - •A gap between the physicians' values & those of patients or their families
  - •Uncertainty about the desired goals & outcomes

SD Goold JAMA 2000; 283: 909

Continuing life support is not in patient's best interest

- Some relatives can never agree to any plan to withdraw life-prolonging treatment.
- Change the approach from the traditional one of seeking family's consent (shared approach) to one where you take a clear leadership (paternalistic approach)
- ***Get all involved medical colleagues to document their opinion in support of limitation***
- Explain the situation, clearly inform them that further interventions are not clearly appropriate.
- With a subsequent deterioration, inform the relatives and simply state the 'patient is dying'

Conclusions

- Relatives of ICU patients found themselves in frightening and demanding situations
- They need our empathy & understanding
- Effective communication improves psychological well-being of relatives, clinical decision making and family satisfaction

Conclusions

- Enough time should be spent for communication
- Understandable language with clear statements should be used
- ICU physician should be direct, straightforward & compassionate
- Contradictory information should be avoided
- Printed information can improve family comprehension