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

<table>
<thead>
<tr>
<th>Paternalism</th>
<th>Autonomy</th>
<th>Shared decision making</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td><img src="image2.png" alt="Image" /></td>
<td><img src="image3.png" alt="Image" /></td>
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</tbody>
</table>
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  • Life-sustaining support withdrawn, spiritual care service involved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
### Meeting the Needs of Intensive Care Unit Patient Families
A Multicenter Study

ELIE AZOULAY, FRÉDÉRIC POCHARD, SYLVIE CHEVRET, FRANÇOIS LEMAIRE, MUSTAFA MOHTAR, JEAN-ROGER LE GALL, JEAN FRANÇOIS DHAINAUT, and BENOIT SCHENEMER for the French FAMIRICA Group

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Median (Ranges)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of family members</td>
<td>2 (1–3)</td>
</tr>
<tr>
<td>Age</td>
<td>45 (34–59)</td>
</tr>
<tr>
<td>Sex ratio, % of men</td>
<td>611 (66.4)</td>
</tr>
<tr>
<td>Health care professionals</td>
<td>86 (9.3)</td>
</tr>
<tr>
<td>Did not speak French</td>
<td>28 (3)</td>
</tr>
<tr>
<td>Not of French descent</td>
<td>120 (13)</td>
</tr>
<tr>
<td>Relationship with the patient</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>217 (23.5)</td>
</tr>
<tr>
<td>Parent</td>
<td>210 (22.8)</td>
</tr>
<tr>
<td>Child</td>
<td>227 (24.7)</td>
</tr>
<tr>
<td>Sibling</td>
<td>84 (9.1)</td>
</tr>
<tr>
<td>Other family members</td>
<td>99 (10.8)</td>
</tr>
<tr>
<td>Not a family member</td>
<td>84 (9.1)</td>
</tr>
<tr>
<td>Hospital commuting time, min</td>
<td>30 (20–60)</td>
</tr>
<tr>
<td>Desired/allowed information time ratio</td>
<td>1.5 (1–2)</td>
</tr>
<tr>
<td>Family feels they received contradictory information</td>
<td>105 (11.7)</td>
</tr>
<tr>
<td>Family would like more information about</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>649 (72.5)</td>
</tr>
<tr>
<td>Prognosis</td>
<td>692 (77.3)</td>
</tr>
<tr>
<td>Treatments</td>
<td>645 (72)</td>
</tr>
<tr>
<td>At least one of these components</td>
<td>782 (87.3)</td>
</tr>
<tr>
<td>Family does not know the specific role of each caregiver</td>
<td>492 (55)</td>
</tr>
<tr>
<td>Family is not helped by their usual doctor</td>
<td>439 (47.7)</td>
</tr>
<tr>
<td>Family would like the help of a psychologist</td>
<td>431 (48.1)</td>
</tr>
<tr>
<td>Total CCFNI score</td>
<td>2 (2–3)</td>
</tr>
</tbody>
</table>
### TABLE 5
MULTIVARIATE ANALYSIS OF SATISFACTION USING POISSON MODEL

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

- Involves sharing, comprehending & acknowledging the feelings of relatives
- Telling relatives you realize the situation must be awful, 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 overwhelming 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
### Table 2. List of the 21 most important questions asked by family members of patients in the intensive care unit

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

1. Observe possible (negative) emotions
2. Identify emotions & Allow time
3. Show empathy
4. Check reasons & provide additional information

Eye contact
Full attention
No interruption
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
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., Benoît Schlemmer, M.D., and Elie Azoulay, M.D., Ph.D.

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

P< 0.02 for all

% of family members

Control
Intervention

P< 0.02 for all

Anxiety
Depression
PTSD
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 unacceptable & the unavoidable

• Stages of Kubler-Ross:

  1. Denial
  2. Anger
  3. Bargaining
  4. Depression
  5. Acceptance

Kubler-Ross’s model of grief
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