

# End-of-life care and ethical decision-making: learning from best practices.

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No conflict of interest to declare

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**Decision-making  
in ICU:  
Who decides?**

*Any decision must be multi-disciplinary*

Really? Who says this?

Really? Do we practice what we preach?



Any decision must be multi-disciplinary

**Who says this?**

## Who says this? Experts in the field

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# Interprofessional Shared Decision-Making in the ICU: A Systematic Review and Recommendations From an Expert Panel\*

*Crit Care Med* 2019; 47:1258–1266

Andrej Michalsen, MD, MPH<sup>1</sup>; Ann C. Long, MD, MS<sup>2,3</sup>; Freda DeKeyser Ganz, PhD, RN<sup>4</sup>; Douglas B. White, MD, MAS<sup>5</sup>; Hanne I. Jensen, PhD, RN<sup>6,7</sup>; Victoria Metaxa, MD, PhD<sup>8</sup>; Christiane S. Hartog, MD, PhD<sup>9,10</sup>; Jos M. Latour, PhD, RN<sup>11</sup>; Robert D. Truog, MD<sup>12</sup>; Jozef Kesecioglu, MD, PhD<sup>13</sup>; Anna R. Mahn, RN<sup>10</sup>; J. Randall Curtis, MD, MPH<sup>2,3</sup>

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*Unfortunately, successful teamwork in ICUs is often hampered by discord concerning prognostication, disagreement about indication for treatments, insufficient knowledge of patients' goals of care, and a lack of adequate communication, collaboration, and decision-making among team members.*

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## Five recommendations

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1. IP-SDM defined as a **collaborative process among clinicians** that allows for team involvement in important clinical decisions
2. Regarding important clinical decisions, **ICU clinicians** consider **engaging** in an **IP-SDM process** in order to promote the most appropriate decisions
3. Clinicians and hospitals must **implement strategies** to accept and foster an **ICU climate oriented** toward interprofessional and interdisciplinary collaboration and **IP-SDM**

# Five recommendations

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4. Clinicians **implementing** interprofessional shared decision-making should consider incorporating a **structured approach**
5. Further studies are needed to **evaluate** and **improve** the quality of **IP-SDM**



# Shared decision-making

Curtis JR, White DB: Practical guidance for evidence-based ICU family conferences. *Chest* 2008; 134:835–843

Lautrette et al: A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007; 356:469–478

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**TABLE 3. The VALUE TEAM-Template**

V	Value the input from all of the members of the interprofessional team, including, among others, physicians, nurses, physiotherapists, clergy, psychologists, and ethicists;
A	Acknowledge emotions;
L	Listen to each other;
U	Understand the team-members as integral persons, including their commitments to patients and high-quality patient care;
E	Elicit the expert suggestions of team-members and make use of their specific expertise;
T	Tie the decision to the best evidence available;
E	Elaborate on the patient's values, goals, and preferences;
A	Address diverse opinions and seek consensus among team members; and
M	Make the best decision weighing reasonable medical options with the patient's goals and the quality of life he/she would want to achieve after their stay in the ICU

**Making Medical Treatment Decisions for Unrepresented Patients in the ICU**

Am J Resp Crit Care Med 2020;201(10):1182-1192

An Official American Thoracic Society/American Geriatrics Society Policy Statement

Thaddeus M. Pope, Joshua Bennett, Shannon S. Carson, Lynette Cederquist, Andrew B. Cohen, Erin S. DeMartino, David M. Godfrey, Paula Goodman-Crews, Marshall B. Kapp, Bernard Lo, David C. Magnus, Lynn F. Reinke, Jamie L. Shirley, Mark D. Siegel, Renee D. Stapleton, Rebecca L. Sudore, Anita J. Tarzian, J. Daryl Thornton, Mark R. Wicclair, Eric W. Widera, and Douglas B. White; on behalf of the American Thoracic Society and American Geriatrics Society

**Who says this also?  
ATS & AGS**

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**Unrepresented patients:**

*Adult patient lacks decision-making capacity, an applicable advance directive, and any available surrogate decision-maker.*

*For these patients, there is no one with whom the clinician can engage in shared decision-making, which is recommended...*

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Recommendation 1 Institutions should promote **advance care planning**

Recommendation 2 Institutions should **implement strategies...**

**Recommendation 3** *Institutions should manage decision-making...*

Recommendation 4 Institutions should use... **patient's values...**

Recommendation 5 Institutions should manage decision-making... **fair process...**

Recommendation 6 Institutions should **employ** this fair process...

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### Recommendation 3 Institutions should manage decision-making...

Whenever possible, the interprofessional, multidisciplinary committee should include three to five members, including a **physician**, a **nurse**, and one **person** who is neither (e.g., a chaplain or social worker).

A white computer keyboard is positioned in the upper right corner of the frame. A black stethoscope is draped across the center and lower right, with its chest piece resting on the surface. The background is a plain, light-colored surface.

**Any decision must be multi-disciplinary**

**Do we practice what we preach?**

# Do we practice what we preach?

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Some do, some don't

Perhaps check yourself using the 32-item

Ethical Decision-Making Climate Questionnaire (EDMCQ)

## Ethical decision-making climate in the ICU: theoretical framework and validation of a self-assessment tool

BMJ Qual Saf 2018;27:781–789

Bo Van den Bulcke,<sup>1</sup> Ruth Piers,<sup>2</sup> Hanne Irene Jensen,<sup>3,4</sup>  
Johan Malmgren,<sup>5</sup> Victoria Metaxa,<sup>6</sup> Anna K Reyners,<sup>7</sup> Michael Darmon,<sup>8</sup>  
Katerina Rusinova,<sup>9</sup> Daniel Talmor,<sup>10</sup> Anne-Pascale Meert,<sup>11</sup>  
Laura Cancelliere,<sup>12</sup> László Zubek,<sup>13</sup> Paolo Maia,<sup>14</sup> Andrej Michalsen,<sup>15</sup>  
Johan Decruyenaere,<sup>1</sup> Erwin J O Kompanje,<sup>16</sup> Elie Azoulay,<sup>17</sup>  
Reitske Meganck,<sup>18</sup> Ariëlla Van de Sompel,<sup>19</sup> Stijn Vansteelandt,<sup>19</sup>  
Peter Vlerick,<sup>20</sup> Stijn Vanheule,<sup>21</sup> Dominique D Benoit<sup>1</sup>

# Do we practice what we preach?

## Ethical Decision-Making Climate Questionnaire (EDMCQ)

To cite: Van den Bulcke B, Piers R, Jensen HI, et al. *BMJ Qual Saf* 2018;27:781–789.

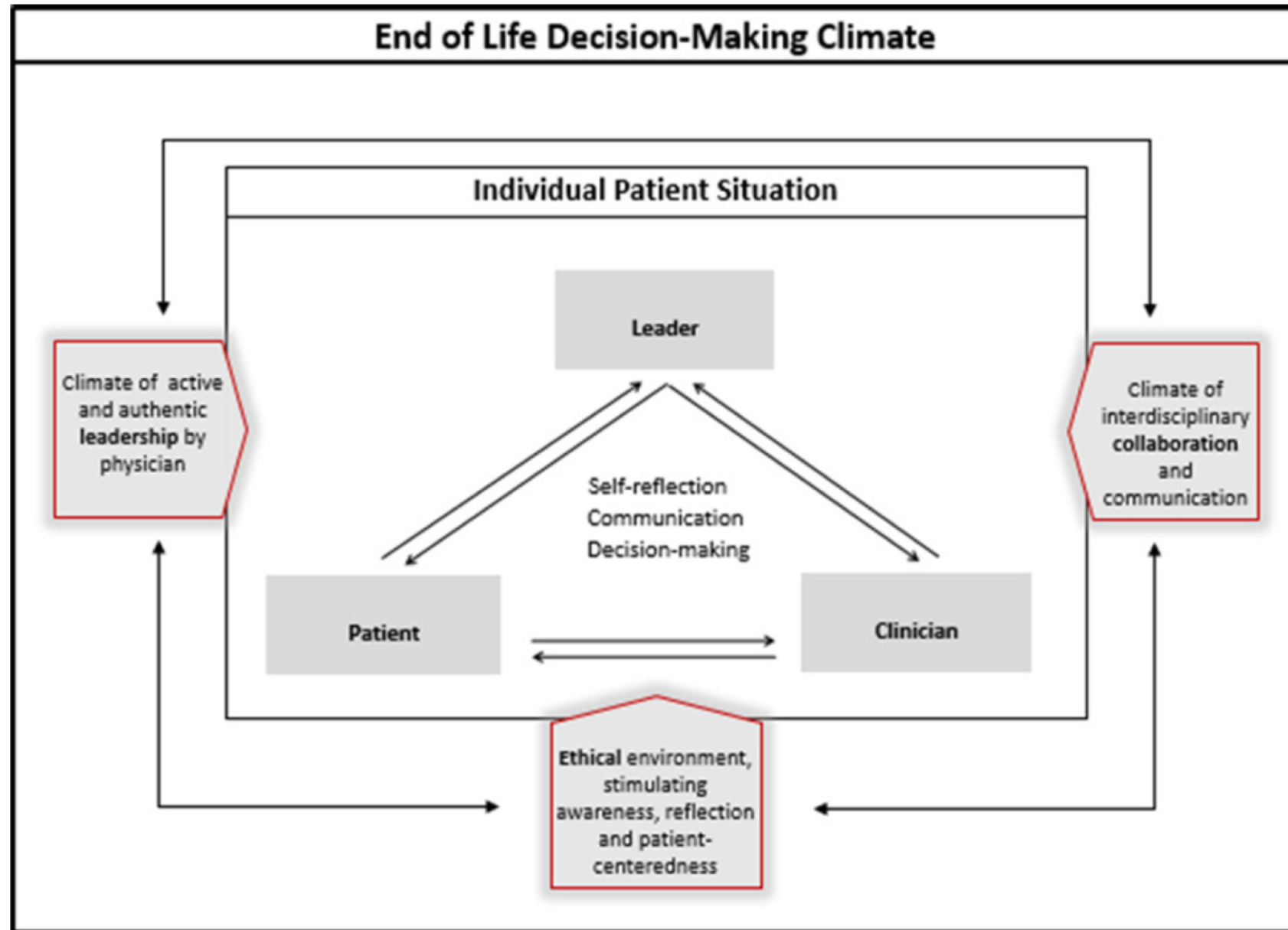


Figure 1 Theoretical framework.

# Do we practice what we preach?

## The next chapter

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Did COVID-19 change the dynamics of decision-making in ICU?

UK Government issued an **ethical framework** (revised 2017) to help people think through strategic aspects of decision-making during a pandemic, as well as providing an **ethical compass for clinicians**

<https://www.gov.uk/guidance/pandemic-flu#ethical-framework>



# Do we practice what we preach?

## The next chapter

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### **Equal concern and respect is the fundamental principle**

- everyone matters
- everyone matters equally but this does not mean that everyone is treated the same
- interests of each person are the concern of all of us, and of society
- harm that might be suffered by every person matters and so minimising the harm that a pandemic might cause is a central concern

<https://www.gov.uk/guidance/pandemic-flu#ethical-framework>



**Thus...**

**Who decides?**

# VENICE studies

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Latour et al. EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care. *Nurs Crit Care* 2009;14:110-21

Langley et al. South African critical care nurses' views on end-of-life decision-making and practices. *Nurs Crit Care* 2014;19:9-17

Badir et al. Turkish critical care nurses' views on end-of-life decision making and practices. *Nurs Crit Care* 2016;21:334-342

# VENICE studies

Latour et al. Nurs Crit Care 2009;14:110-21

**Table 4** Nurses' experiences and involvement in EOL decisions

	<i>n</i>	Strongly agree or agree [ <i>n</i> (%)]	Do not know [ <i>n</i> (%)]	Strongly disagree or disagree [ <i>n</i> (%)]
Timing of EOL discussion often too early	156	11 (7)	4 (2.6)	141 (90.4)
Timing of EOL discussion just right	154	56 (36.4)	16 (10.4)	82 (53.2)
Timing of EOL discussion often too late	155	91 (58.7)	18 (11.6)	46 (29.7)
Asked by medical colleagues to participate in EOL decisions	157			
Always actively involved in EOL discussions with physicians	157			
Often initiated EOL discussion with doctors	154			
Patient and/or family is always involved in EOL discussions	155			
Patient and/or family always need to be consulted before EOL decision is made	159			
Involvement in EOL decisions positively influences job satisfaction	156			

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Timing of EOL discussion often too early	156			
Timing of EOL discussion just right	154			
Timing of EOL discussion often too late	155			
Asked by medical colleagues to participate in EOL decisions	157	60 (38.2)	12 (7.6)	85 (54.1)
Always actively involved in EOL discussions with physicians	157	69 (44)	7 (4.5)	81 (51.6)
Often initiated EOL discussion with doctors	154			
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Asked by medical colleagues to participate in EOL decisions	157			
Always actively involved in EOL discussions with physicians	157			
Often initiated EOL discussion with doctors	154			
Patient and/or family is always involved in EOL discussions	155	92 (59.3)	8 (5.2)	55 (35.5)
Patient and/or family always need to be consulted before EOL decision is made	159	125 (78.6)	2 (1.3)	32 (20.1)
Involvement in EOL decisions positively influences job satisfaction	156	112 (71.8)	18 (11.5)	26 (16.7)



# VENICE studies

Langley et al. Nurs Crit Care 2014;19:9-17

Badir et al. Nurs Crit Care 2016;21:334-342

## South Africa

- 24% ICU nurses stated that they were always actively involved in EOL discussions with physicians
- 13% ICU nurses reported that they were always asked to participate in decision-making process by medical colleagues

## Turkey

- 76% ICU nurses had not had any active involvement in decision making regarding withholding or withdrawing treatment for patients
- 56% ICU nurses reported that medical colleagues did not ask them to participate in decision-making process regarding EOL care

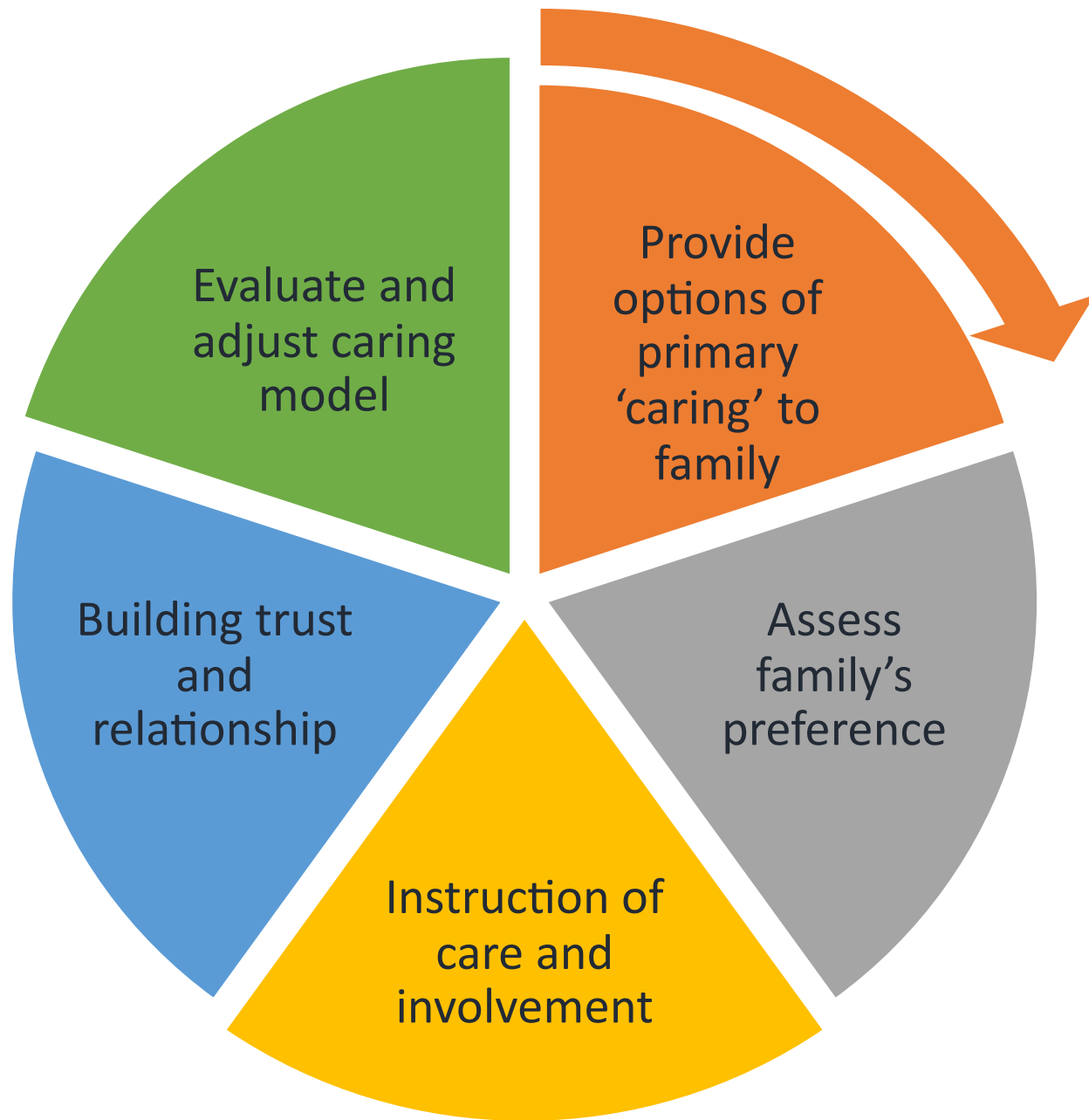
# Final Thoughts

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Doctors have the ultimate legal responsibility (in many countries)

Nurses have the professional responsibility (in all countries)

Sharing responsibilities increase the quality of ethical practice in ICU  
...including the responsibility to care for the well-being of our colleagues



Pathway to collaborative working with relatives during the end of life and palliative care of an ICU patient

My advice:

Take the TEAM approach

**T=Trust**

Building trust among **all** team members

**E=Engage**

Engaging **all** stakeholders in palliative care

**A=Assess**

Assess experiences and improve practice

**M=Must**

The sky is the limit

## **In Summary**

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Individual patient and family care based on their needs

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Not every family wants to take part in end-of-life decision of their beloved

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Training not only 'intellectual intelligence' but also 'emotional intelligence'

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Dignity, humanity, and compassion

# Thank you

**Jos M. Latour**

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