

CONGRESSO NAZIONALE IRC 2023



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LA RIVOLUZIONE DEI SISTEMI



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Fine vita e comunicazione

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Qual è il nostro dovere?

LG ILCOR 2020: <<Clinician(s) must take care to ensure that **any decision is in the individual's best interest**>>.



Se vi piacciono le certezze assolute, siete nel posto sbagliato

Guidelines for Neuroprognostication in Comatose Adult Survivors of Cardiac Arrest

Neurocrit Care (2023) 38:533–563

<https://doi.org/10.1007/s12028-023-01688-3>

EI SISTEMI

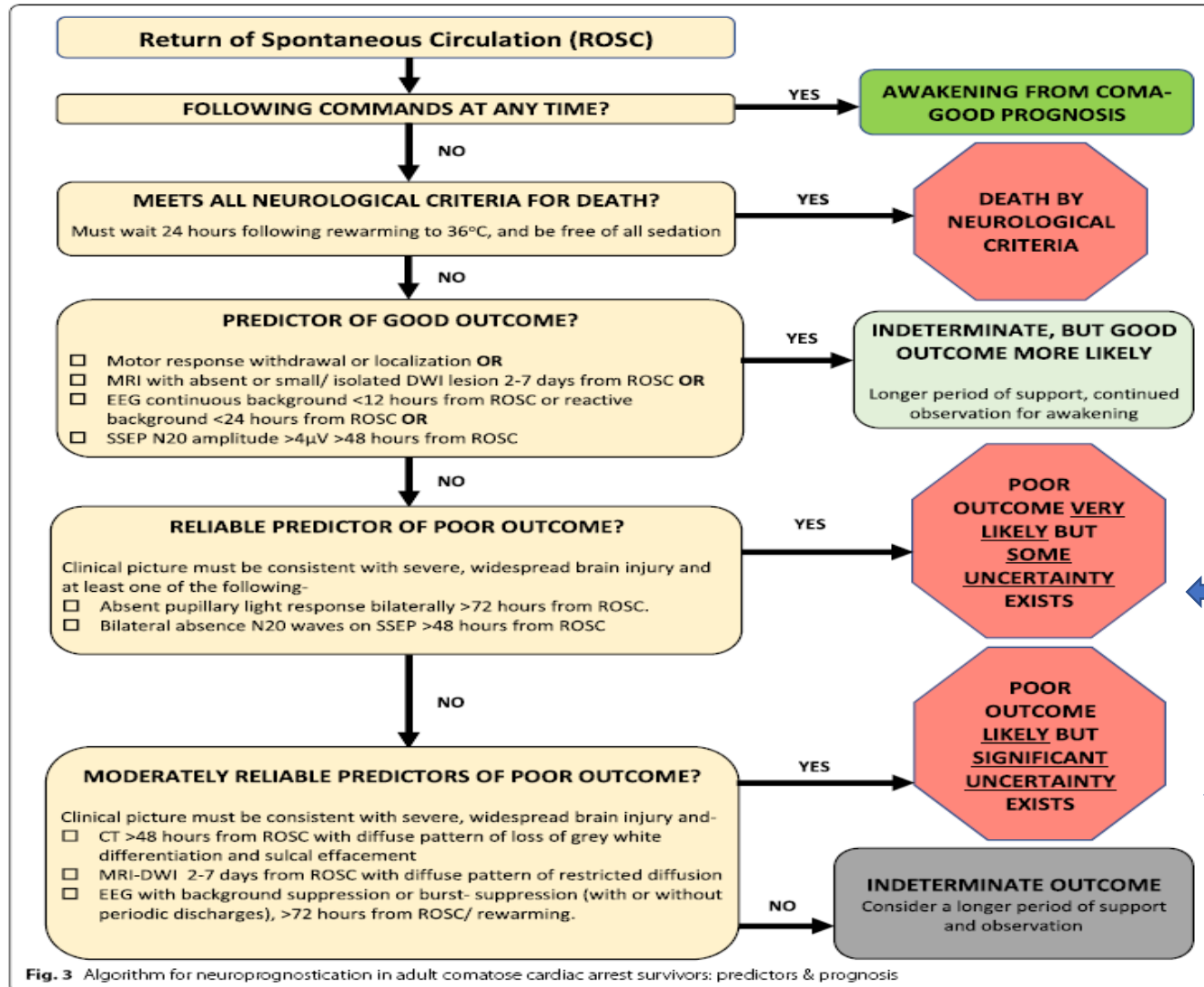


Fig. 3 Algorithm for neuroprognostication in adult comatose cardiac arrest survivors: predictors & prognosis

Come possiamo conoscere il best interest di quel paziente specifico?

- LG ILCOR 2020 (Ethics of resuscitation and end of life decisions):

<<defining an unfavourable outcome is challenging. The cut-off of a CPC 2 may translate to a spectrum of functional outcomes. Moreover, **the value of an outcome to an individual will likely be specific to that person.**>>



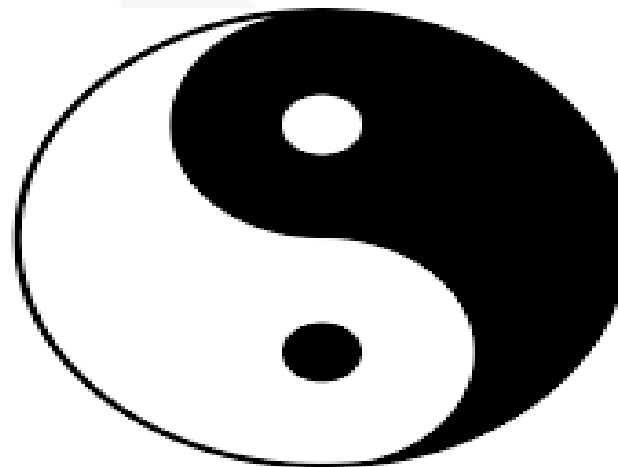
Ricordiamoci che...

- Capire se l'outcome più probabile sarebbe accettabile per quel singolo paziente è **difficile**.
- **Dobbiamo parlare** con il paziente o, più spesso, con la famiglia per capirlo.
- (No, lo scopo non è evitare guai medico-legali. Lo scopo è fare il meglio per paziente e se possibile anche per la sua famiglia e per noi)



Iniziamo:

- Due momenti per la comunicazione:
 - nel processo decisionale (ogni volta che è possibile)
 - a valle del processo decisionale (quando un contatto precedente non è stato possibile)



Come comunicare nel fine-vita?

Interventions for interpersonal communication about end of life care between health practitioners and affected people

Cochrane Database of Systematic Reviews 2022, Issue 7. Art. No.: CD013116.

- End of life care: "includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days)

Taken together, the above definitions show that the EoL period may be one of prognostic uncertainty and highly variable in duration.

Implications for practice

There is currently no high-certainty evidence to inform practice decisions about how healthcare practitioners can best communicate with patients, carers, and family members about end of life (EoL) and EoL care.



La limitazione delle cure è comune in tutto il mondo, ma con differenze importanti

Variations in end-of-life practices in intensive care units worldwide (Ethicus-2): a prospective observational study

Worldwide limitations of life-sustaining therapies in ICU patients are common and occur with considerable regional variability. Withholding life-sustaining treatment is the most prominent limitation followed by withdrawal of treatment. Active shortening of the dying process is uncommon. One in five patients survived treatment limitations. Future research should elucidate

- In Italia: circa 20% decessi in ICU per limitazione delle cure (3% sopravvive)

Lancet Respir Med 2021;
9: 1101-10

Obiettivo: la dignità

Dying with Dignity in the Intensive Care Unit

Deborah Cook, M.D., and Graeme Rucker, D.M.

When the organ dysfunction of critical illness defies treatment, when the goals of care can no longer be met, or when life support is likely to result in outcomes that are incongruent with patients' values, ICU clinicians must ensure that patients die with dignity. The definition of "dying with dignity" recognizes the intrinsic, unconditional quality of human worth but also external qualities of physical comfort, autonomy, meaningfulness, preparedness, and interpersonal connection.³ Respect should be



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Table 1. Examples of the ABCDs of Dignity-Conserving Care.*

Attitudes and assumptions can affect practice.

Reflect on how your own life experiences affect the way in which you provide care.

Be aware that other clinicians' attitudes and assumptions can affect their approach to patients.

Teach learners to be mindful of how their perspectives and presumptions can shape behaviors.

Behaviors should always enhance patient dignity.

Demonstrate with nonverbal methods how patients and their families are important to you.

Do not rush; sit down and make eye contact when talking with patients and their families.

Turn off digital devices and avoid jargon when talking with patients and their families.

Compassion is sensitivity to the suffering of another and the desire to relieve it.

Elicit the personal stories that accompany your patient's illness.

Acknowledge the effect of sickness on your patient's broader life experience.

Recognize and relieve suffering.

Dialogue should acknowledge personhood beyond the illness.

Explore the values that are most important to your patients.

Ask who else should be involved to help your patients through difficult times.

Encourage patients and their families to reflect and reminisce.

* This approach is adapted from Chochinov.⁴



Shared decision making, utopia o opportunità reale?



“a collaborative process that allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences.”⁸⁴ Several SDM

- Semplicemente un dovere a cui non sottrarsi.
- un processo che dipende molto dalle relazione nello staff e con i famigliari.
- Un dovere faticoso. Un dovere magnifico. Un’arte.

Il processo di decisione condivisa

CARE AT THE END OF LIFE:

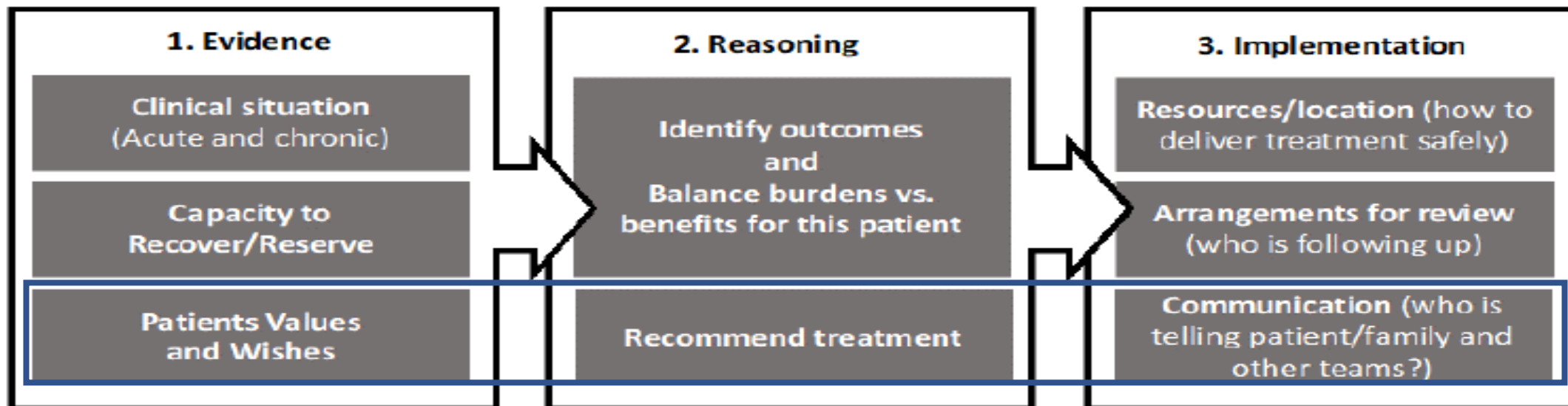
A guide to best practice, discussion and decision-making in and around critical care

This report was produced as part of the Critical Futures initiative, looking to the future for critical care services. www.ficm.ac.uk/criticalfutures

ENDORISING ORGANISATIONS

ICUsteps
Royal College of Anaesthetists
Royal College of Emergency Medicine
Royal College of Physicians, London
UK Critical Care Nursing Alliance

Decision-making for escalation of treatment: Warwick model



Apertura, flessibilità, umiltà

Shared decision-making models: involvement of families and patients

Approaching decisions relating to end of life transitions and care, a shared decision-making model is regarded as best practice, where collaborative decisions involve all parties: health care teams, families and patients (Kon et al., 2016; White et al., 2018). [Shared decision-making](#) underpins NHS values. Individual values, goals and preferences must be considered, with overall planning of treatment goals through information exchange, deliberation and decision-making. Excellent communication skills are critical to the success of shared decision-making (SDM), and outcomes of

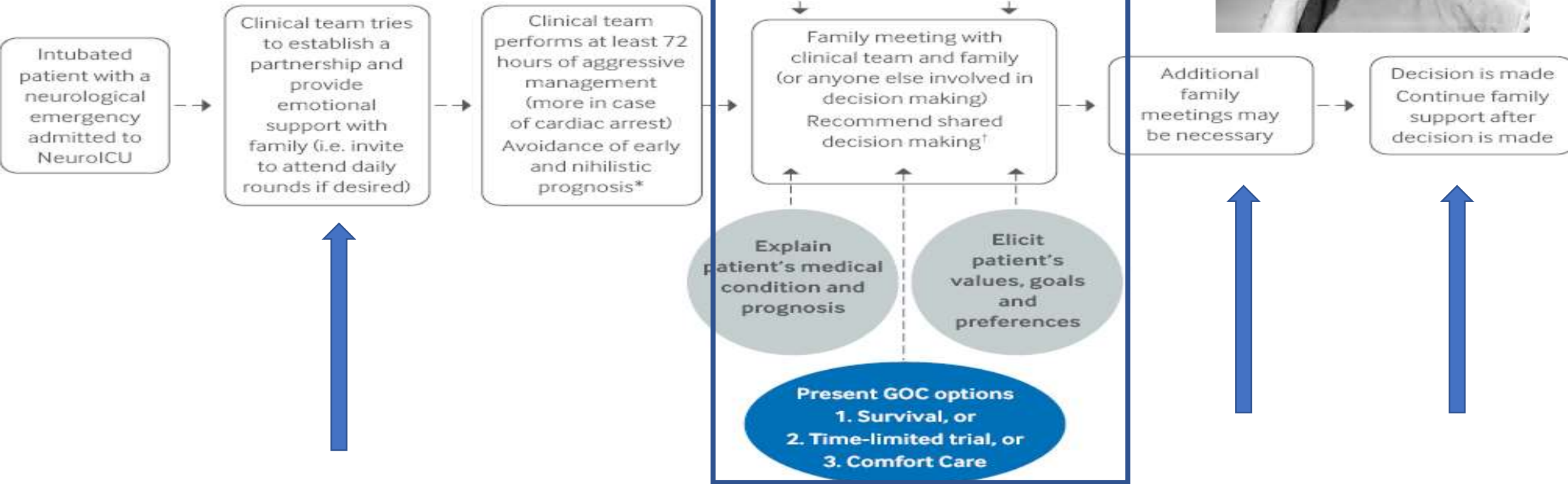
Whatever decisions are made there should always be an openness to review, particularly if new information may change the outcome. This requires ongoing conversations with patients and families where there should be clear articulation of the evolving nature of some decision-making processes, including how sometimes a prognosis will only become clearer after days of critical care e.g. return of spontaneous circulation after cardiac arrest.

Il modello migliore (per me)

Prognostication and shared decision making in neurocritical care

Kelsey Goostrey,¹ Susanne Muehlschlegel^{1,2,3}

BMJ 2022;377:e060154



Concretamente: ascoltare



Communication at the End-of-Life in the Intensive Care Unit: A Review of Evidence-Based Best Practices

SARAH RHOADS, MD; TIM AMASS, MD, ScM

V.A.L.U.E.

families, the clinician should be mindful of the amount of time spent sharing information, as compared to families being allowed to express concerns and hopes. A demonstrable decrease in stress symptoms and an increase in family satisfaction has been shown to be directly proportional to the amount of time a family is able to speak during family meetings, as compared to time spent in which the clinician is directing communications.^{4,7}

Due aspetti particolari

- Alcune famiglie sono molto articolate. Larghe, conflittuali, problematiche. Richiedono un surplus di pazienza, rispetto, competenza, e un surplus di cautela (ad esempio: coerenza nelle comunicazioni).
- Alcuni familiari o alcune famiglie non hanno valori chiari, riferimenti solidi o simili. Tendono a formare le proprie convinzioni durante i colloqui. Anche in questo caso serve competenza, pazienza, attenzione, rispetto.

Nella realtà, cosa succede?

Global Comparison of Communication of End-of-Life Decisions in the ICU

CHEST 2022; 162(5):1074-1085

RESULTS: Of 87,951 patients admitted, 12,850 died or experienced a limitation of therapy (14.6%). Of these, 1,199 patients (9.3%) were known to have an advance directive, and wishes were elicited from 6,456 patients (50.2%). Limitations of life-sustaining therapy were implemented for 10,401 patients (80.9%), 1,970 (19.1%) of whom had mental capacity at the time, and were discussed with 1,507 patients (14.5%) and 8,461 families (81.3%). Where no discussions with patients occurred (n = 8,710), this primarily was because of a lack of mental capacity in 8,114 patients (93.2%), and where none occurred with families (n = 1,622), this primarily was because of unavailability (n =

CON CHI PARLIAMO?

TABLE 1] Clinician Knowledge of Patient Preferences Regarding Life-Sustaining Treatments and Sources Thereof by Region^{a,b}

Variable	Africa	America Latin	America North	Asia	Australia and New Zealand	Europe Central	Europe Northern	Europe Southern	Total
No. of ICUs (no. of patients)	2 (162)	10 (571)	9 (918)	30 (1,838)	9 (541)	45 (3,893)	37 (2,305)	57 (2,622)	199 (12,850)
Source of information regarding patient preferences									
Advance directive	0/66 (0.0)	17/389 (3.0)	453/908 (49.3)	72/1,454 (3.9)	20/523 (3.7)	511/3,624 (13.1)	59/2,097 (2.6)	67/2,369 (2.6)	1,199/11,430 (9.3)
Patient	1 (25.0)	3 (3.4)	63 (7.7)	18 (1.8)	36 (9.5)	218 (10.2)	119 (10.4)	11 (1.2)	469 (7.3)
Family	3 (75.0)	67 (76.1)	492 (60.1)	885 (88.6)	223 (59.0)	1,303 (61.1)	773 (67.6)	775 (86.9)	4,521 (70.0)
Multiple sources	0 (0.0)	18 (20.5)	257 (31.4)	95 (9.5)	116 (30.7)	543 (25.5)	236 (20.6)	103 (11.5)	1,368 (21.2)
Other	0 (0.0)	0 (0.0)	6 (0.7)	1 (0.1)	3 (0.8)	68 (3.2)	15 (1.3)	3 (0.3)	96 (1.5)



CON QUANTI NON PARLIAMO?



Perché non parliamo?

TABLE 4] Reasons for Not Discussing Limitation of Life-Sustaining Therapies With the Patients or Families by Region^a

Variable	Africa	Latin America	North America	Asia	Australia and New Zealand	Europe Central	Europe Northern	Europe Southern	Total, All Patients
Patient									
Unconscious, lacked mental capacity, or both	51 (98.1)	345 (96.4)	539 (94.9)	1,198 (89.5)	292 (86.6)	2,483 (93.7)	1,613 (93.7)	1,593 (94.4)	8,114 (93.2)
Will not understand	1 (1.9)	10 (2.8)	19 (3.3)	106 (7.9)	37 (11.0)	146 (5.5)	67 (3.9)	71 (4.2)	457 (5.2)
Other	0 (0.0)	3 (0.8)	10 (1.8)	34 (2.5)	8 (2.4)	20 (0.8)	41 (2.4)	23 (1.4)	139 (1.6)
Family									
No family	0 (0.0)	1 (1.1)	3 (5.6)	9 (34.6)	7 (15.2)	132 (21.3)	27 (15.7)	24 (3.9)	203 (12.5)
Family unavailable	4 (100)	10 (11.4)	47 (87.0)	5 (19.2)	26 (56.5)	270 (43.6)	84 (48.8)	71 (11.6)	517 (31.9)
Family will not understand	0 (0.0)	1 (1.1)	0 (0.0)	4 (15.4)	7 (15.2)	39 (6.3)	3 (1.7)	79 (12.9)	133 (8.2)
Patient unresponsive to maximum therapy	0 (0.0)	74 (84.1)	2 (3.7)	7 (26.9)	5 (10.9)	156 (25.2)	25 (14.5)	429 (70.0)	698 (43.0)
Other	0 (0.0)	2 (2.3)	2 (3.7)	1 (3.8)	1 (2.2)	22 (3.6)	33 (19.2)	10 (1.6)	71 (4.4)

Data are presented as No. (%).

^aThe denominator included all the patients who were subject to a limitation of life-sustaining therapies (n = 10,401), except for the 1,691 patients (16.3%) and 8,779 families (84.4%) for whom the reasons were not recorded.



Come parliamo?



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Argumentation in end-of-life conversations with families in Dutch intensive care units: a qualitative observational study

Intensive Care Med (2023) 49:421–433

the conversation. Only in a minority of conversations, a true exchange of arguments (i.e., doctors and families responding to each other's arguments by complementing or contradicting the other's arguments) took place. This was mainly the case within the N-ICU. The exchange of arguments was generally quite brief in the sense that not all possible types of arguments were presented and then discussed together.



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Argumentation in end-of-life conversations with families in Dutch intensive care units: a qualitative observational study



We frequently observed a lack of concrete explanation and deepening of arguments and of summarizing all exchanged arguments. This raises the question whether doctors and families really understood each other's arguments, especially since both parties seldom asked clarifying questions. This may add to mutual misunderstandings reveal that adequately discussing uncertainties improves both the decision-making process and the wellbeing of patients and their families [33–42]. Based on these findings, we recommend including uncertainty as a topic for discussion in professional guidelines concerning end-of-life decision-making in the ICU. This will not reduce the



BEFORE CONSULTATION

Consider which types of arguments are suitable/appropriate for the decision options and how you can substantiate those arguments:

- generally accepted healthcare standards
- uncertainty
- medical (in)effectiveness
- proportionality
- comparison
- patient's quality of life
- patient's former wishes and family's substituted judgment
- psychological wellbeing of families
- family's moral responsibility
- professional authority

Let the family prepare for the argument exchange as well, especially by considering:

- patient's quality of life
- patient's former wishes and family's substituted judgment
- psychological wellbeing of families
- family's moral responsibility

DURING CONSULTATION

Walk through the suitable/appropriate arguments (*see: Before*) with the family

Substantiate, elaborate on, and explain your arguments. It may help to ask (yourself) the question *why?*

Ask families to share their arguments, especially regarding:

- patient's quality of life
- patient's former wishes and family's substituted judgment
- psychological wellbeing of families
- family's moral responsibility

In case of a decision in the gray zone, discuss both standpoints (to continue and to discontinue life-sustaining treatment) and substantiate these with arguments

Take the time to weigh up all the arguments together with the family of the patient

Try to avoid discussing arguments regarding a certain decision and taking that particular decision in the same conversation

Summarize arguments and decisions

Make a plan for the immediate future

AFTER CONSULTATION

Debrief with the other intensive care staff members participating in the consultation

Analyze the position presented by the family and the way to meet them

Take the time to weigh up all the arguments

Make a program for the next consultation

Share the program within the doctors and nurses

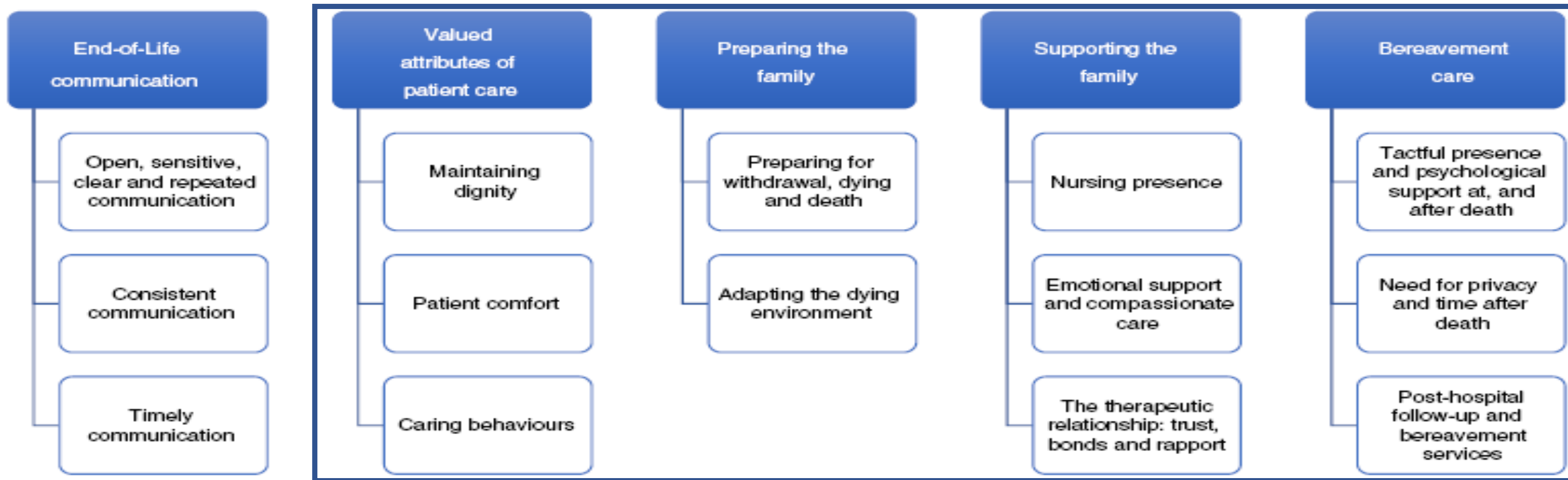
Fig. 3 Recommendations for doctors

Argumentation in end-of-life conversations with families in Dutch intensive care units: a qualitative observational study

Comunicare, ma non solo a parole

A qualitative meta-synthesis investigating the experiences of the patient's family when treatment is withdrawn in the intensive care unit

J Adv Nurs. 2020;76:2222-2234.



Altre situazioni delicate

- Culture diverse (in particolare orientale)
- Il caso pediatrico
- Famiglie conflittuali con lo staff
- Proposta di donazione a cuore fermo
- (staff diviso o non informato)



E se c'è un conflitto?

Understanding conflict, confusion and communication

Confusion and limited communications about withdrawal or withholding treatments is one of the main causes of both perceived and actual conflict (Azoulay et al., 2009). This can be between ICU teams and families, between different clinical teams or within the same clinical team. **Clear, honest communication from the point of admission onwards can help minimise disputes.** In most circumstances conflict can be resolved by sensitive negotiations, good listening, timely second opinions and other expert opinions. Religious and other external support can also be invaluable if the conflict is between families and clinical teams. It is essential that teams move away from a paternalistic approach and take into consideration the opinions of what families consider the best interests / wishes of the patient would be (Macfarlane et al., 2018).

If difficulties persist a more structured approach becomes necessary with the likely involvement of hospital legal and management teams (Turnbull et al., 2019). Discussions should focus on attempts to lay out plans that families and clinical teams can agree on. Meetings should be clearly documented in case notes and minuted (recording of verbatim comments rather than interpretations of what has been said). Copies should be available to all.

E la relazione con lo staff?

- Non è diversa. Sono diversi solo alcuni accenti



Dying with Dignity in the Intensive Care Unit

Robert Cook, MD, and George Bedke, DM

CONCLUSIONS

Palliative care in the ICU has come of age. Its guiding principles are more important than ever in increasingly pluralistic societies. Ensuring that patients are helped to die with dignity begs for reflection, time, and space to create connections that are remembered by survivors long after a patient's death. It calls for humanism from all clinicians in the ICU to promote peace during the final hours or days of a patient's life and to support the bereaved family members. Ensuring death with dignity in the ICU epitomizes the art of medicine and reflects the heart of medicine. It demands the best of us.







Italian Resuscitation Council