ESM 1. Web appendix 1.

This electronic supplement consists of:

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    - Pg 3-7: ICU center characteristics
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CRFs

Overview of different questionnaires			
5 pages	ICU center characteristics	local investigator	Once before 28 days study period
8 pages	Clinician personal characteristics, working conditions and Ethical Decision-Making Climate	clinicians	Once before 28 days study period
1 page	Clinician patient-related questionnaire on perception of disproportionate care	clinicians	daily for every patient
7 pages	Patient characteristics on admission	local investigator	Once for every patient
1 page	Patient characteristics during admission	local investigator	Daily for every patient
1 page	Patient characteristics at discharge	local investigator	Once for every patient
2 pages	Patient characteristics one year after ICU admission	local investigator	Once for every patient

ICU – CENTER CHARACTERISTICS

ICU number:	…..

Your hospital

	a1.University	a2.University -affiliated	a3.Public	a4.Private
YH1. What is the type of your hospital?	☐	☐	☐	☐
		1.Public	2.Private non profit	3.For profit
YH 2. For US only: What is the ownership status of your hospital?		☐	☐	☐
			1.Medicare	2.Medicaid
YH 3. For US only: What is the % of patients			.... %	.... %
	1.< 250	2. 250 - 500	3. 500 - 750	4. > 750
YH 4. What is the total number of hospital beds?	☐	☐	☐	☐

Your ICU

YI1. What types of patients are admitted to your ICU? (<u>more than 1 answer possible</u>) a. Medical b. Surgical c. Cardio-surgical d. Trauma e. Cardiac f. Burns g. Transplantation Medical = a+e Surgical=b+c+d+d+f+g Mixed	☐ ☐ ☐ ☐ ☐ ☐ ☐
YI 2. Who makes ICU-admission decisions? (<u>more than 1 answer possible</u>) a. ICU physician b. Referring physician c. Patients and relatives	☐ ☐ ☐
YI 3. Are admission requests ever refused? <u>(only one of the following)</u> a. Never b. Rarely (every few months) c. Occasionally (once a month) d. Sometimes (every few weeks) e. Often (every few days)	☐ ☐ ☐ ☐ ☐

YI 4. What is the number of beds in your ICU? YI 4b. (only if more than 14 beds:) Will all the beds in your ICU be used for <u>patient</u> data collection? YI 4c. If no: how many positions will be included for patient data collection? YI 5. What is the number of patients admitted in 2013 in your ICU? YI 6. What was the ICU mortality rate in your ICU in 2013? YI 7. What was the mean length of stay in your ICU in 2013? (in days)	….. YES / NO .... ….. ….%. …..

	1. Open	2. Mixed	3. Closed
YI 8. What is the type of your ICU? (open= primary role by physicians outside the ICU; closed=primary role by ICU physician; mixed=overlap of the above models)	☐	☐	☐

	1. Yes	2. No
YI 9. Can physicians outside the ICU order tests and prescribe medications?	☐	☐

Your ICU team		
1. ICU nurses YIT1. What is the number of nurses in your ICU? YIT 2. What is the number of full-time positions nurses in your ICU? YIT 3. In total, how many nursing staff are there working during 24 hours? a. of whom … nurse assistants (only FOR FRANCE) b. of whom … nurses (registered nurses) YIT 4. What is the average 24 hours patient-to-nurse ratio? **2. ICU physicians** YIT 5. What is the number of physicians working full time in your ICU in general (≥ 50% of activities in the ICU)? a. of whom … junior physicians (in training) b. of whom … senior physicians (not in training, head of ICU included) YIT 5b. What is the number of physicians working part time in your ICU (less than 50% of activities in the ICU? c. of whom … junior physicians in training) d. of whom … senior physicians (not in training, head of ICU included) YIT 6. In total, how many physicians on ICU call <u>in the hospital</u> are there working during 24 hours? a. of whom … junior physicians (in training) b. of whom … senior physicians (not in training, head of ICU included) YIT 7. Only if junior physicians present : What is the average 24 hours patient-to-junior physician ratio? YIT 8. What is the average 24 hours patient-to-senior physician ratio?	1 nurse per …. patients 1 junior physician per … patients 1 senior physicians per … patients	
	1. Yes	2. No
YIT 9. Is there at least one junior physician (in training) 24 hours a day a. Present in your ICU? b. Present in your hospital and on ICU call? YIT 10. Is there at least one senior physician (not in training) 24 hours a day a. Present in your ICU? b. Present in your hospital and on ICU call?	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐
YIT 11. Is a psychologist or psychosocial worker available in your ICU? YIT 12. If yes, Is this psychologist or psychosocial worker full-time dedicated to your ICU?	☐ ☐	☐ ☐

End-of-life care in your ICU

			1.Physician	2.Nurses	3.Both
EOL 1. Who decides about symptom control during end-of-life care?			☐	☐	☐
	1.Never	2.Rarely	3.Frequently	4.Routinely	5.Always
EOL 2.1 Are there meetings between nurses and physicians for each end-of-life decision?	☐	☐	☐	☐	☐
EOL 2.2 Are nurses actively involved in end-of-life decisions?	☐	☐	☐	☐	☐
EOL 2.3 Are nurses present during the communication of end-of-life information to family members?	☐	☐	☐	☐	☐
EOL 2.4 Does your unit perform terminal sedation? *defined as sedation with continuous IV narcotics and/or sedatives until the patient becomes unconscious* *(this is not euthanasia since death ensues from the underlying illness)*	☐	☐	☐	☐	☐
EOL 2.5 Does your unit perform terminal extubation *defined as the removal of the endotracheal tube at the end-of-life, usually after the administration of boluses of sedatives and/or analgesics*	☐	☐	☐	☐	☐
EOL 2.6 Can intubated patients be discharged to the wards?	☐	☐	☐	☐	☐
EOL 2.7 Can dying patients be discharged to the wards?	☐	☐	☐	☐	☐
EOL 2.8 Can a dying patient be discharged home?	☐	☐	☐	☐	☐
				1.Yes	2.No
EOL3. Is there a guideline or provider order entry set for end-of-life care in your ICU?				☐	☐

Practical IT related questions important for datacollection

1. How are patients identified in your ICU? **Please give an example of a patient ID**	.....	
	Yes	No
2. Are there computers available in the respective units?	☐	☐
3. Do physicians AND nurses easily get access to these computers?	☐	☐
4. Does your internet browser allow Internet Explorer 7, Firefox 10 or Google Chrome?	☐	☐
5. Is it possible to go on-line and fill-out web-based questionnaires in your ICU? *(Will ICT in your hospital accept our webbased survey in your proxy server?)*	☐	☐
6. Do you have a SAPS II score available on the day of admission?	☐	☐
7. Does your system automatically provide a TISS score?	☐	☐

The DISPROPRICUS Study: Questionnaire related to the HEALTHCARE PROVIDER

Goal of the study

Clinicians perceive the care they provide as inappropriate when they feel that it clashes with their personal beliefs and/or professional knowledge. **Moral distress occurs when one feels what is the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action.** ICU workers who experience acute moral distress are at increased risk for burnout.

This study focuses on disproportionate care defined as care which is perceived as disproportionate (too much or too little) in relation to the expected prognosis of the patient in terms of expected survival or quality of life or patient or family wishes.

The goal of this study is (1) to evaluate how frequently ICU healthcare providers feel that patient care is disproportionate and (2) to identify workenvironmental factors that promote ICU workers' well-being.

Practical considerations

This survey deals with your personal characteristics and your work environment. We ask you to fill it out once at the start of the study. This questionnaire takes maximum 20 minutes to complete.

In the near future, you will be asked to shortly report about your perceptions about the appropriateness of care given to each patient who is under your care during a month span.

This is an anonymous questionnaire survey, meaning that the results will be revealed in a way that precludes identification of the participating ICUs and healthcare providers.

If you have any questions, please contact the local investigator.

Thank you for participating in this study!

Personal characteristics and working conditions

ICU number:	…..
ICU healthcare provider number:	…..

Personal characteristics

PC1. What is your age?			…. years	
PC2. What is your gender?			☐ Female	☐ Male
			1.Yes	2.No
PC3. Are you living with a partner?			☐	☐
PC4. Do you have any children?			☐	☐
PC5. What is your religion? a. Roman Catholic b. Protestant c. Greek-orthodox d. Muslim e. Jewish f. Buddhist g. Non-religious h. I do not wish to answer this question				
	1.Not important	2.Not very important	3.Important	4.Very Important
PC6. How important is your religion for your professional attitude towards end-of-life decisions?	☐	☐	☐	☐

Working conditions

WC1. What is your role in the ICU? (choose 1) a. Nurse (and/or nurse assistant >> only in the French questionnaires) b. Head nurse c. Junior physician (in training) d. Senior physician e. Head of ICU	☐ ☐ ☐ ☐ ☐	
	1. Yes, more than 50% of activities WITHIN the ICU	2. No, More than 50% of activities OUTSIDE the ICU
WC1b. Is more than 50% of your clinical activities within the ICU?	☐	☐
WC2. If you are a physician, what is your <u>main basic</u> medical specialty? (choose 1) a. Surgery b. Anesthesiology c. Pulmonology d. Emergency Medicine e. Internal Medicine f. Hospitalist g. ICU specialist	☐ ☐ ☐ ☐ ☐ ☐ ☐	
WC3. How many years have you had regular activities in the ICU?	…..	
WC4. How many hours on average do you work per week?	…..	
WC5. How many night shifts on average do you work per month (including during weekends)?	…..	
WC6. How many daytime shifts during weekends on average do you work per month?	…..	
	1. Yes	2. No
WC7. Are you doing ICU research or participating in an ICU working group within your ICU?	☐	☐
WC8. Have you ever been involved in a medico-legal claim against you, regardless of the outcome?	☐	☐

Job strain (demand, control, support) and intentional jobleave

To what extent do you agree with the following statements?	A1.Stronlgy disagree	A2. Mainly disagree	A3. Agree	A4. Strongly agree
JS_D 1. I have to work very hard.	☐	☐	☐	☐
JS_D 2. I am asked to do an excessive amount of work.	☐	☐	☐	☐
JS_D 3. I don't have enough time to get my work done.	☐	☐	☐	☐
JS_C 4. I don't have to do a lot of repetitive work.	☐	☐	☐	☐
JS_C 5. I have (a job which requires me) to be creative.	☐	☐	☐	☐
JS_C 6. I have (a job which requires me) to learn new things.	☐	☐	☐	☐
JS_C 7. I have a lot of say about what happens on my job/at my work.	☐	☐	☐	☐
JS_C 8. I have a lot of freedom to decide how I do my work.	☐	☐	☐	☐
JS_S 9. I work with helpful people.	☐	☐	☐	☐
JS_S 10. I work with people who take a personal interest in me.	☐	☐	☐	☐
JS_S 11. My supervisor is helpful.	☐	☐	☐	☐
JS_S 12. My supervisor is concerned about my welfare.	☐	☐	☐	☐
JL 13. I have thoughts about leaving my current position/job.	☐	☐	☐	☐

Interdisciplinary and safety culture

To what extent do you agree with the following statements?	1. Strongly disagree 2. Disagree 3. Neither 4. Agree 5. Strongly agree
I1. In my ICU, there are regular opportunities for open and informal dialogue between healthcare providers	
I2. In my ICU, there is regular structured and formal dialogue between the various disciplines within the team to discuss patient care.	
I3. In my ICU, we regularly reflect on the quality of care provided from the various points of view of the staff.	
I4. In my ICU, the teams are well coordinated/managed.	
I5. In my ICU, there is an open and constructive culture in the department such that criticism can be easily expressed.	
I6. In my ICU, discussions about patients lead to greater understanding and agreements.	
I7. In my ICU, I am always regarded and addressed by everyone in the team as a fully-fledged team member.	
I8. In my ICU, team members from another discipline respect my work.	
I9. In my ICU, I have confidence in the professional competence of my team members.	
I10. In my ICU, it is difficult to speak up if I perceive a problem with patient care	
I11. The culture in my ICU makes it easy to learn from the errors of others	

Leadership culture
Leadershipskills of the senior physicians in charge of daily patient care

To what extent do you agree with the following statements?	1. Never 2. Seldom 3. Occasionally 4. Often 5. Always
LC1. In my ICU, the physicians in charge let the team members know what is expected of them.	
LC 2. In my ICU, the physicians in charge make accurate and timely decisions.	
LC 3. In my ICU, the physicians in charge take full charge when emergencies arise.	
LC 4. In my ICU, the physicians in charge are hesitant about taking initiative in the group.	
LC 5. In my ICU, the physicians in charge help team members settle their differences.	
LC 6. In my ICU, my physicians in charge trust the team members to exercise good judgment.	
LC 7. In my ICU, the physicians in charge permit the team members to use their own judgment in solving problems.	
LC 8. In my ICU, the physicians in charge encourage initiative in the team members.	
LC 9. In my ICU, the physicians in charge treat all team members as their equals.	
LC 10. In my ICU, the physicians in charge abstain from explaining their actions.	
LC 11. In my ICU, the physicians in charge are well aware of their own emotions and attitudes.	
LC 12. In my ICU, the physicians in charge are well aware of their role model function.	
LC 13. In my ICU, the physicians in charge dare to show their vulnerability	

End-of-life care Climate

To what extent do you agree with the following statements?	1.Stronlgy disagree	2. Mainly disagree	3. Agree	4. Strongly agree
EC1. My colleagues understand my thoughts/feelings about difficult end-of-life decisions.	☐	☐	☐	☐
EC 2. In my ICU, different opinions and values concerning end-of-life are tolerated.	☐	☐	☐	☐
EC 3. In my ICU, we talk about moral problems.	☐	☐	☐	☐
EC 4. In my ICU, there is a structured, formal debriefing after a difficult patient care situation.	☐	☐	☐	☐
EC 5. In my ICU, nurses are present during the communication of end-of-life information to the family.	☐	☐	☐	☐
EC 6. In my ICU, nurses are involved in end-of-life decision-making.	☐	☐	☐	☐
EC 7. In my ICU, nurses and physicians collaborate well with one another during end-of-life situations.	☐	☐	☐	☐
EC 8. In my ICU, death is perceived as a treatment failure, so decisions to withdraw or withhold therapy are seldom taken.	☐	☐	☐	☐
EC 9. In my ICU, EOL decisions are frequently postponed.	☐	☐	☐	☐
EC 10. In my ICU, patients with little chance of recovery are frequently admitted.	☐	☐	☐	☐
EC 11. In my ICU, patients with little chance of recovery frequently occupy an ICU bed which other patients would benefit more from.	☐	☐	☐	☐

Personal opinions concerning ethical issues in the ICU:
Healthcare costs and end-of-life care

To what extent do you agree with the following statements?	1.Stronlgy disagree	2. Mainly disagree	3. Agree	4. Strongly agree
PO_HCC1. As a clinician, I have a responsibility to help control healthcare costs.	☐	☐	☐	☐
PO_HCC2. If a medical intervention has any chance (no matter how small) of helping the patient, it is the physician's duty to offer it.	☐	☐	☐	☐
PO_HCC3. Physicians should know the overall cost of the care they provide.	☐	☐	☐	☐

	1. Yes, ICU inappropriate for this type of patients	2. No, ICU appropriate for this type of patients
PO_EOL4. Are there situations when admission to ICU is inappropriate for a patient ACCORDING TO YOU (more than 1 answer possible)?		
1. The patient requires monitoring only	☐	☐
2. Patient with advanced dementia	☐	☐
3. Patient with advanced co-morbidities	☐	☐
4. Patient in persistent vegetative state.	☐	☐
5. Other (please specify in English) _____	☐	☐
_____		

The Dispropricus Study: Patient-related Questionnaire

Perceived disproportionate care?	
PT number These data are confidential and will be invisible for persons outside your ICU	……

	Yes	No
P1. Do you feel that this patient is getting disproportionate care?	☐	☐
	A1. Too much care	A2. Too little care
P2. If yes: **What is the direction of disproportional care?**	☐	☐
P3. If yes: **2. Why do you feel that the care is disproportionate? (MORE than 1 possible)**	1. Agree	O. Not agree
SQ001. In my opinion, the amount of care is **inconsistent with the expected survival**	☐	☐
SQ002.In my opinion, the amount of care is **inconsistent with the expected quality of life**	☐	☐
SQ003.In my opinion, the amount of care is **inconsistent with patient's wishes**	☐	☐
SQ004.In my opinion, the amount of care is **inconsistent with family's wishes**	☐	☐

If yes: Moral distress occurs when one feels what is the right thing to do, but institutional or other constraints make it difficult to pursue the desired course of action	0. NOT distressing at all	1. A little distressing	2. Quite distressing	3. Very distressing	4. Extremely distressing
P4. To what extent do you find that the perception of disproportionate care <u>in this patient</u> is distressing for you personally?					

Patient Characteristics – data on ICU admission (day 1)

ICU number:	……
PT number:	……
Study date: (dd/mm/yy - please fill out manually)	

	Yes	No
IC1. Is your patient a minor (under 18 years of age) OR admitted for monitoring only If yes >> webapplication will indicate that patient is not included in the study	☐	☐

	1.Yes	2.not required	3.No
IC2. Informed consent obtained by competent patient or family of incompetent patient	☐	☐	☐
If no >> questionnaire stops here !!! If yes or not required >> collect patient characteristics			

Pre-admission characteristics

PAC1. Patient's age		.. years	
PAC2. Patient's gender		☐ Female	☐ Male
		Yes	No
PAC3. Seriousness of chronic underlying diseases (More than 1 possible): **a. Moderate to severe heart failure (NYHA III, IV)** **b. Moderate to severe COPD/asthma (GOLD III, IV)** **c. Moderate to severe dementia (GDS 6,7)** *GDS 6: largely unaware of recent experiences and events in their lives, require assistance with basic ADL's, behavioural and psychological symptoms of dementia are common* *GDS 7: verbal abilities will be lost over the course of this stage, incontinent, needs assistance with feeding, lose ability to walk.* **d. Diagnosis of solid tumour/cancer**			
PAC3dc. If yes to diagnosis of a solid tumor: cancer status	**1.Controlled / Remission**	**2.Uncontrolled / new diagnosis**	**3.Uncontrolled / recurrence or progression**
PAC3dd.If yes to diagnosis of a solid tumor: cancer type: 1. Lung cancer 2. Breast cancer 3. Head and neck cancer 4. Oesophagus or stomach cancer 5. Pancreatic cancer **6.** Colon cancer **7.** other			
PAC 3. Seriousness of chronic underlying diseases (More than 1 possible): **e. Diagnosis of haematological malignancy**			

PAC3ec. If yes to diagnosis of a haematologic malignancy: cancer status	1.Controlled / Remission	2.Uncontrolled / new diagnosis	3.Uncontrolled / recurrence or progression
PAC3ed. If yes to diagnosis of a haematologic malignancy: type 1. Acute leukemia 2. High grade lymphoma 3. other			
PAC 3. Seriousness of chronic underlying diseases (More than 1 possible): **f. Moderate to severe liver cirrhosis (Child-Pugh B, C)** **g. Chronic renal failure requiring dialysis** **h. Moderate to severe HIV (AIDS stage)** i. **Moderate to severe neurological disease** PAC 3ia. If moderate to severe neurologic disease, please specify in English……			
PAC4. Other conditions (More than 1 possible) a. Problematic alcohol abuse (more than 4 drinks a day for male, more than 3 drinks a day for female) b. Active drug abuse c. Active smoking d. Social isolation e. Self neglect f. Nursing home resident g. Mental retardation			

PAC 5. Functional status <u>2 weeks before</u> ICU-admission (ECOG/WHO score) (choose 1)

a. Totally bedridden
b. Capable of only limited self-care, confined to bed or chair 50% or more of waking hours
c. Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours
d. Symptomatic but completely ambulatory and able to carry out work of a light or sedentary nature
e. Fully active, able to carry on all predisease activities without restriction

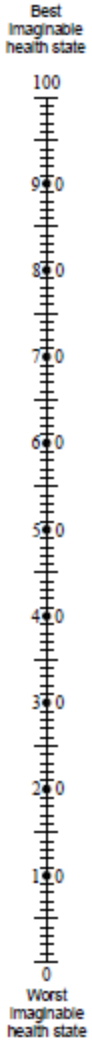
f. Don't know

QOL <u>2 weeks before</u> ICU-admission			
Practical guidelines: - **to be asked preferentially to the patient, if not possible to the next of kin / closest relative** - **ask for their condition 2 to 3 weeks before admission in the ICU** **For more information: see practical manual**			
QOL 1. How was the interview taken? 1. Face to face 2. By phone 3. By e-mail 4. By postal mail			
QOL2. Who answered the questions? 1. Patient 2. Family			
QOL 3. If family answered the questions: How is this person related to the patient?			1. Partner 2. Brother or sister 3. Parent 4. Child 5. Other
	1.No problems	2.Some problems	3.Unable
QOL4. a.Mobility (walking about)	☐	☐	☐
b.Self-care (washing/dressing)	☐	☐	☐
c.Usual activities (e.g. work, housework, family or leisure activities)	☐	☐	☐
	1.No	2.Moderate	3.Extreme
QOL 5. f. Pain / Discomfort	☐	☐	☐
g. Anxiety / Depression	☐	☐	☐
h. VAS score (on a scale from 0 to 100) **can also be asked by phone interview,** **or by asking the proxy to rate how he or she, (i.e. the proxy), would rate the subject's health)**			….

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Admission and Advance care planning data

RP1. What are the main clinical reasons for admission? More than one possible**!**

a. Head trauma
b. Multiple trauma
c. Neurologic (stroke/intracranial bleeding)
d. Infectious: Sepsis / Severe sepsis / Septic shock
e. Cardiovascular (heart failure/coronary artery disease/aneurysm/cardiogenic shock)
f. Gastro-intestinal or liver (bleeding or hepatic failure)
g. Respiratory failure
h. Metabolic (renal failure/elektrolyt disturbance)
i. scheduled surgery

RP1a. j. Other (please specify in english)

	Yes	No
RP2. Is the patient admitted after surgery within 48 hours?	☐	☐

Advance directives

	1.Yes	2.No	3.Don't know
RP 3.1. Is the patient competent to participate in discussions about treatment options and prognosis at admission?	☐	☐	☐
RP 3.2. Are the patient's wishes concerning end-of-life care known?	☐	☐	☐
RP 3.3. Is there an advance directive available?	☐	☐	☐

RP 4. Is there a decision to withdraw/withhold therapy made <u>before ICU admission?</u>

a. No restriction in therapy ☐
b. No CPR only ☐
c. Withholding of therapy ☐
d. Don't know ☐

Seriousness of illness and decision to limit therapy

	1.Yes	0.No
SI 1. Seriousness of acute illness at admission in the ICU: 1. Invasive mechanical ventilation 2. Non-invasive mechanical ventilation 3. Vasopressor therapy: 4. Dialysis:	☐ ☐ ☐ ☐	☐ ☐ ☐ ☐
SI 2. If yes to mechanical ventilation SI 3. Fi02 PEEP	…….. ……. cm H_20	
SI4. If yes to vasopressors SI 4a. Dosage noradrenaline in µg/kg/min (1 θ=1000 ng) SI 4a. Dosage adrenaline in µg/kg/min (1 θ=1000 ng) SI 4a. Dosage dobutamine in µg/kg/min (1 θ=1000 ng) SI 4a. Dosage dopamine in µg/kg/min (1 θ=1000 ng) SI 4a. Dosage vasopressine (in unit/hours) SI 5. Other vasopressor SI5a SI 5b	…..(name) .....(unit) …….(dosage in unit/hours)	
SI 6. If available in your centre: SAPS II score		
SI 7. If available in your centre: TISS score		
SI 7b. If available in your centre: APACHEII score		
SI 8. Is there a decision to limit therapy made at admission <u>in the ICU</u>? 1. No limitation of therapy 2. No CPR only 3. Withholding of therapy 4. Withdrawal of therapy	☐ ☐ ☐ ☐	

Patient Characteristics during admission	
ICU number:	……
PT number:	……
Study date: (dd/mm/yy - please fill out manually)	.. / .. / ..

Seriousness of illness and decision to limit therapy		
	1.Yes	0.No
SI1. Seriousness of acute illness: 1. Invasive mechanical ventilation 2. Non-invasive mechanical ventilation) 3. Vasopressor therapy: 4. Dialysis:	 ☐ ☐ ☐ ☐	 ☐ ☐ ☐ ☐
SI2. If yes to mechanical ventilation a. Fi02 b. PEEP	 …….. ……. cm H_20	
SI3. If yes to vasopressors a.Dosage noradrenaline in µg/kg/min (1 θ=1000 ng) b.Dosage adrenaline in µg/kg/min (1 θ=1000 ng) c.Dosage dobutamine in µg/kg/min (1 θ=1000 ng) d.Dosage dopamine in µg/kg/min (1 θ=1000 ng) Dosage vasopressine (in unit/hours) e.Other vasopressor g. f.	 ….. (name) ..... (unit) …….(dosage in unit/hours)	
SI4. If available in your centre: TISS score	……..	
SI5. Is there a decision to limit therapy at this moment? 1. No limitation of therapy 2. No CPR only 3. Withholding of therapy 4. Withdrawal of therapy	 ☐ ☐ ☐ ☐	

Patient Characteristics at discharge

ICU number:	……
PT number:	……
Study date: (dd/mm/yy - please fill out manually)	.. / .. / ..

Date of discharge (dd/mm/yy)	.. / .. / ..

	Yes	No
Did the patient die in the ICU ?	☐	☐

Patient Characteristics 1 year after ICU admittance	
ICU number:	……
PT number:	……

Survival 1 year after ICU admittance?			
	Yes	No	**Loss to follow-up**
Is the patient alive 1 year after **ICU admittance** ?	☐	☐	☐
If no: is the time of death known? If yes: what was the time of death? If yes, proceed to the following question	☐ dd/mm/yy	☐	

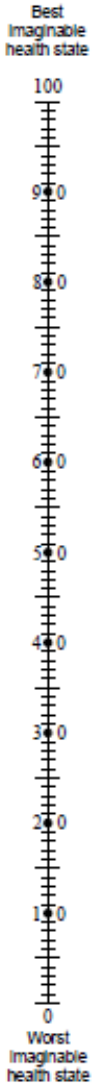
If the patient survived, what is the QOL 1 year after ICU admittance?			
Practical guidelines: Preferably to be answered by the patient, if this is not possible then by the next of kin / closest relative For more information: see practical manual			
	Yes	No	Not required
Informed consent? Only if 'yes' or 'not required by law', proceed to the following question	☐	☐	☐
		Yes	**No**
Were you able to contact the patient or relatives to assess the quality of life?		☐	☐
If yes:			
1. How was the interview taken? Face to face By phone By e-mail By postal mail		 ☐ ☐ ☐ ☐	 ☐ ☐ ☐ ☐
2. Who answered the questions? Patient Family		 ☐ ☐	 ☐ ☐
2b. If family answered the questions: How is this person related to the patient?		- Partner - Brother or sister - Parent - Child - Other	
3. Place of residence: Where has the patient spent the most time during the last month: *An institutional setting where care – on site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care – is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time. (Sometimes referred to as: skilled nursing facility, nursing home) ** other example is the palliative care unit		- At home - In the hospital - In a*Longterm care facility - In a **Hospice or other palliative care instution	
EuroQOL 5 D			

	No problems	Some problems	Unable
1. Mobility (walking about)	☐	☐	☐
2. Self-care (washing/dressing)	☐	☐	☐
3. Usual activities (e.g. work, housework, family or leisure activities)	☐	☐	☐
	No	Moderate	Extreme
4. Pain / Discomfort	☐	☐	☐
5. Anxiety / Depression	☐	☐	☐
6. VAS score (on a scale from 0 to 100) **(can also be asked by phone interview, or asking the proxy to rate how he or she, (i.e. the proxy), would rate the subject's health)**			….

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



The DISPROPRICUS study

Disproportionate care in the ICU's : a multicenter international longitudinal study

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INDRODUCTION

Intensive care medicine treats patients suffering from life threatening conditions resulting from acute dysfunction or failure of one or more of the vital organs. However, increased use of advanced life sustaining treatment in patients with poor long term expectations secondary to more chronic organ dysfunctions and/or a poor quality of live has become a worrying trend over the last decade (1-5). 73% of European intensivists and 87% of Canadian intensivists declare that they frequently admit patients with unrealistic perspectives (6,7). Up to date, the only study which has analyzed the perception of disproportionate care by health care providers in relation to individual patients' situations on the floor was conducted by our research group and was published in *JAMA* (8). In this European study 27% of a total of 1,651 interviewed doctors and nurses declared that they had to treat at least 1 patient who received disproportionate care on the day of the study. Further, 60% indicated that similar situations were common in their units. In addition, nowadays, natural or spontaneous death has become rare in the ICU due to technical innovations, and most patients die only when the intensivist, in consultation with all parties concerned, takes the decision to withhold or withdrawn therapy (9-13). Thus, ICU teams are increasingly confronted with difficult decisions concerning end of life. Furthermore, the decisions must be related to the different legal, ethical and cultural frameworks which prevail in different countries. This, together with more in depth individual psychological factors in doctors and nurses (14), often leads to postponed end of life decision-making (15-16). The results include unnecessary suffering by patients and their relatives (17,18), conflicts (19), burnout (20, 21) or high staff turnover among health care providers (8). In view of the high cost of ICU medicine (0.5 to 1% of the GDP) this also entails enormous financial implications for society (22, 23).

DEFINITION OF DISPROPORTIONATE CARE

In the current project disproportionate care is defined as care which is perceived by health care providers as disproportionate in relation to the expected prognosis of the patient in terms of expected survival or quality of life. Contrary to earlier publications the current project opts for the term disproportionate care rather than futile care, analogous to our landmark study published in *JAMA* (8). This approach has several advantages:

- First, contrary to the term "futile care", disproportionate care entails a potential bidirectional discrepancy between the administered care and the prognosis: this may be "too much" or "not enough". Although the latter situation is rare in practice (8) it is necessary to consider this aspect as well, since both situations may arise with different health care providers, but with relation to one and the same patient.

- Secondly, futile care presupposes a high degree of certainty regarding the final fatal prognosis, as the term implies that the patient will die, despite this care. However, this term does not take real life situations into account, viz. the difficulty to predict an individual patient's survival. This is a common situation in the ICU, where technical innovations virtually exclude patients' spontaneous death (9-11).

- Thirdly, this term does not take account of the physician's evolving opinion in daily practice concerning a patient's prognosis. In other words, the physician needs some time before he can perceive the administered care as futile, depending on the patient's evolution, among other things. In this respect, our terminology recognizes another phase prior to futile care: this is the period during which the physician or nurse starts to doubt whether the level of care which they administer is still appropriate.

- Fourthly, every health care provider views a specific situation as a reflection of his emotional past, norms and values (24-28). As a result, different health care providers will have different views on the same patient situation. In practice the term futile care applies only as an absolute term when different expert health care providers agree that the "too much" care is administered. Thus the chance of futile care increases with increasing agreement among health care providers of perceived disproportional care.

- Finally, the term futile care contains a negative and intentional connotation, as if physicians purposely administer futile care. This is, of course, not the case; possible explanations include an unconscious strategy of self-protection against confrontation with death (14), anxiety in decision making (29, 30), or the fear that one's actions are considered as failure in the eyes of colleagues, relatives or society (30, 31). Lack of leadership, which is a more common general denominator for the factors listed above, has also been found to be an important factor in delaying end-of-life decisions in the ICU (8,15,16,19). Analysis of the ethical work climate in general and the quality of communication within and outside of the team will therefore be important to take into account in this study.

OBJECTIVES

The only study up to date of doctors and nurses' perception of disproportionate care in relation to actual individual patient situations on the floor was conducted by our research unit (8). The relation between perception of disproportionate care and the final outcome of the patient was not analyzed in that study. This limitation is related to the cross-sectional design of the study.

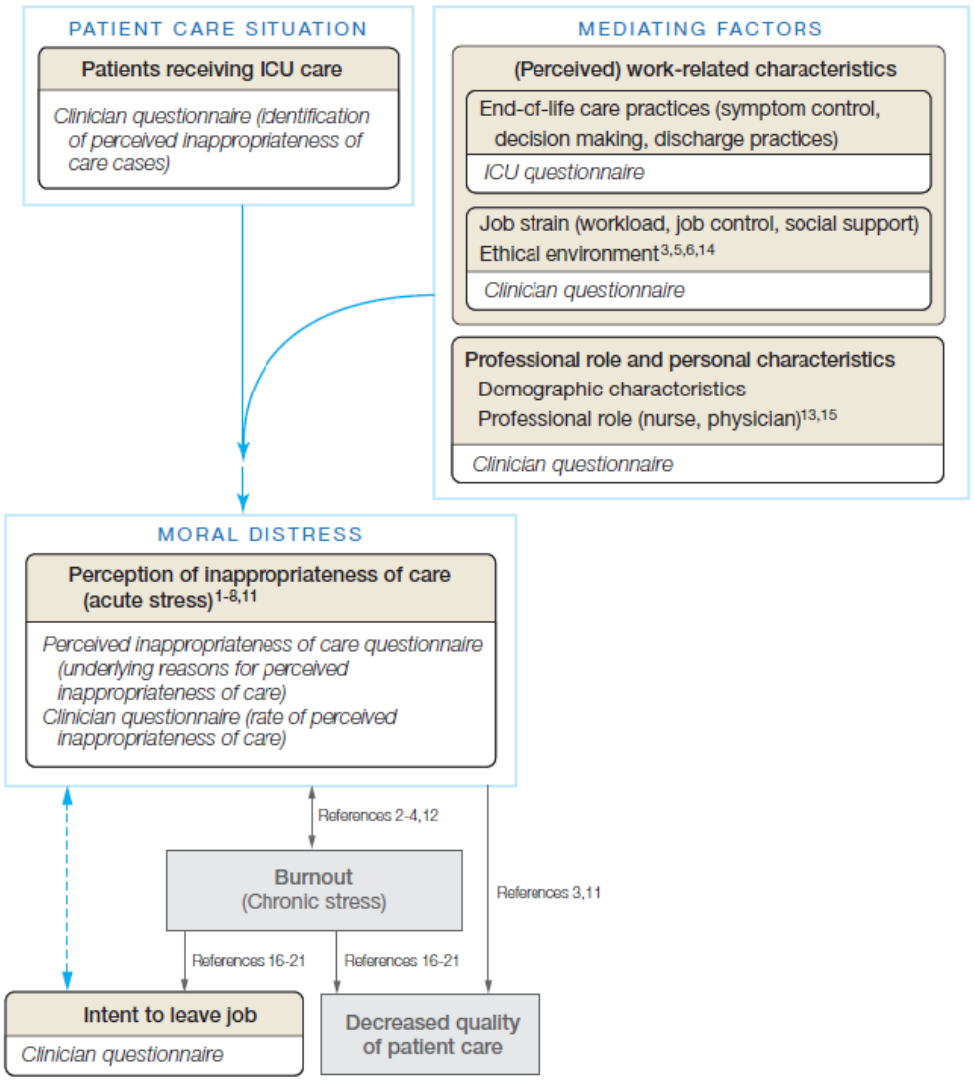
The objective of the current project is to examine the (cumulative) incidence, time of onset and duration of dis-, partial and full agreement of perception of disproportionate care and the accompanying degree of moral distress among doctors and nurses on the basis of a multicentric prospective longitudinal approach. Contrary to our previous study these findings will be related to survival and the patient's quality of life in the short-term as well as mid-term. As such, by comparing intervals between onset of dis-, partial and full agreement of perception of disproportionate care within the team and relating these to decisions to forego life sustaining treatment and time of death we will gain insight in the development of futile care while taking into account the ethical climate of the participating ICUs and the patient's severity of illness.

METHODOLOGY

General methodology

This project consists of a multicentric international (Europe and the US) quantitative, prospective study of a 1 month duration. For this study we will use the same theoretical framework and questionnaires as in the APPROPRICUS study (8).

Figure 1. Theoretical Framework for the Perception of Inappropriateness of Care and Study Instruments



ICU indicates intensive care unit. A patient care situation that is perceived as inappropriate according to the clinician's personal and work-related background may cause moral distress. When moral distress is repetitive, cannot be avoided, or is not acknowledged by the clinical team or superiors who might potentially affect the distress-causing situation, moral distress may accumulate and subsequently lead to job leave, burnout, decreased quality of patient care, or a combination of these outcomes. The relationship between perception of inappropriateness of care and intent to leave job was investigated in this research (dashed arrow); and the directionality of any association cannot be determined by the study design. Components of the theoretical framework shown in gray were not measured in this study.

As mentioned above, we will not limit this study to collecting essential objective information about the patient's critical illness and the daily evolution of this, but we will also collect information about doctors' and nurses' perceptions of the situation. As such we will be able to assess whether the subjective information of a particular or several health care providers is informative about a patient's outcome. If there is disproportional care according to these health care providers, then the severity of experienced moral distress will be asked. The reasons for disproportional care will also be assessed on the basis of a greatly abridged version of the "perceived inappropriateness of care questionnaire" that will take less than 2 minute per day per patient to fill in. In addition, we will also take the personal characteristics of the health care provider into account as well as the ethical work climate in the units trough the "clinician questionnaire" and the "ICU questionnaire".

DATA COLLECTION

All the data will be collected through the use of a website especially designed for this study. Normal web applications use HTTP (Hypertext Transfer Protocol) to transfer web pages between the web server and the web browser. In order to guarantee data safety a HTTPS website signed by a trusted certificate authority will be used for this project. All the transferred data is encrypted in these circumstances and can only be read by the web browser and the web server. Hospitals that join this project will have to make sure that their browsers accept the HTTPS certificate. Hospitals that join this project also have to allow internet access to the study web site. If any proxy server and/or firewall is available it should allow access to the web site.

Our web application will be tested on Microsoft Windows and Linux. The minimum requirements for the browsers are listed below.

- Microsoft Windows
  - Internet Explorer 7+
  - Firefox 10+
  - Google Chrome
- Linux
  - Firefox 10+
  - Google Chrome
- (Mac OS X)
  - Safari

The ICU questionnaires (see appendix 1) will be filled in by the local investigator of each center 2 months prior to the start of the study. It takes 20 minutes to be filled in. The health care providers questionnaires (see appendix 2) will be filled in by each doctor and nurse who will be in charge of the patients during the one month observation period and who agree to participate with the study 2 weeks prior to the start of the observation period. It takes 30 minutes to be filled in. All the health care providers will receive a unique login and password for this purpose. During the one month observation period each health care providers have to

fill in the perception of disproportionate care questionnaire on a daily base for every patient they take care of. After having logged in, the health care provider will be asked to fill in the local patient number and to answers where according to him / her this patient receives disproportionate care. If so, the health care provider will be asked in which direction he/she feels disproportionate care is provided ("too much" or " not enough") and for which item(s) ("amount of care is inconsistent with the expected prognosis", "amount of care is inconsistent with the expected quality of life", "amount of care is inconsistent with the patient's wishes" or "amount of care is inconsistent with the family's wishes"). Finally, the health care provider will be asked to fill in the amount of distress that this patient's situation provokes on a four point Likert scale. This questionnaire requires less that 2 minutes per patient per day to be filled in (see appendix 3) in case of disproportionate care and less 15 seconds otherwise.

Meanwhile and independently from the health care providers classical severity of illness data of all new patients admitted during the one month observation period for reasons other than monitoring and routine post-operative care will be collected by the local investigator (and or local study nurse) (see appendix 4). Data collection requires less than 10 minutes per new patients and less than 5 minutes per patient per day for the longitudinal data. On the basis of the data from our first study (8), an observation period of 1 month in 48 centers (14 countries already agreed to participate and to include at least 4 centers) will allow us to include approximately 2,400 patients (average of 50 new patients per month per center) in the current project and to observe 360 deaths in the ICU (average mortality of 15%). We expect with an additional excess in mortality of 15% within the first year after discharge and by taking into account dropouts that each center will have to collect outcome and quality of life data at 1 year for an average 30-35 patients. For this purpose, we will make use of the EQ-5D questionnaire (32). The EQ-5D is a questionnaire which measures health in five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression [31]. Each domain has three levels: no problems, moderate problems or severe problems. This questionnaires requires less than 5 minutes to be filled in (see appendix 5). These questionnaires will be send by regular mail. If the questionnaires are not returned within one month, patients or relatives will be contacted by phone to assess QOL after 1 year. If there is no contact by phone, the family practitioner needs to be contacted to assess if the patient had died meanwhile.

DATA ANALYSIS

The study will generate an extensive data collection. The analysis of these data is complex, partly as a result of the longitudinal character of the data. Our research unit has extensive experience with this complex longitudinal data analysis (11, 34-36) as a result of the existing close collaboration with experienced statisticians (Prof. S. Vansteelant and Prof. E. Goetghebeur, Department of Applied Mathematics and Computer Science, Ghent University). We will use *classic hierarchic logistic regression models* to take country and center effects into account (8), but we will also use more complex statistical techniques, such as *marginal structural models in combination with competing risk analysis* (34-36). This allows us to take the evolution of the severity of the patient's illness into account during the entire ICU stay (34, 36) until a do-not-resuscitate order and death or discharge.

ROLE OF NATIONAL COORDINATORS

The national coordinator is responsible 1) for recruiting at least 4 motivated centers per country, 2) to provide assistance to the local investigators during data collection together with the principal investigators 3) for the translation of questionnaires (Brisling method, see appendix) and 4) the IRB approval. The questionnaires of the current study are largely based (90%) on the APPROPRICUS study. Questionnaires are already available in English, French, Dutch, Italian, Polish and Portuguese and will require only minor modification for the current study. Full translation of the questionnaires is required for all other languages.

The national coordinators who have been contacted* or who already agreed to participate are

Belgium : Dominique Benoit (Flemish part), An-Pascale Meert (Wallonia part and Brussels)

Denmark : Hane Irene Jensen

England : Francesca Rubullota

France : Michael Darmon

Germany : Andrej Michalsen

Greece : Metaxa Victoria

Hungary : Laszlo Zubek

Italy : Francesca Rubullota

Poland : Barbara Tamowicz

The Netherlands : An Reyners

Tsjech Republic : Katarina Rusinova

Portugal : Paolo Azevedo

US : Dany Talmor

ROLE OF LOCAL INVESTIGATORS

The local investigators are responsible for the recruitment of patients according the inclusion criteria, informed consent and the (website based) data collection.

AUTHORSHIP

All the national coordinators will be coauthor of at least one of the principal publications. We will first try to publish the main results in high ranked journals. If the journal accepts a high number of co-authors (most high ranked journals do), than there will be no problem at all. However, if the journal does not allow a high number of co-authors, we will have to divide the authorship among multiple publications. The coauthors who could not be listed because of journal policy will have the priority in subsequent publications. In order to determine the

order, we will make a ranking depending on the personal involvement in the project and the quantity and quality of data – we will try to keep this as transparent as possible and for this we will use the international guidelines. After the main publications, the coauthors might become first authors for presenting substudies on the main database or first author together with the local investigators on the data coming from their respective country. Local investigators will be cited in Pubmed, such as in our previous publication JAMA, not as coauthors but as participant of the Dispropricus study group of the ESICM. An anonymous benchmarking report will also be send to the local investigators. As such the local investigators will be able to compare the cumulative incidence of perception of disproportionate care, the associated moral distress and the ethical climate in their ICU with ICU's within and outside their country.

WORKPLAN

April 2013	Basic English questionnaire and protocol
May-August 2013	Feedback of the questionnaires by the national coordinators
May-December 2013	Recruitment of centers in each country by the national coordinators
May-December 2013	Translation of questionnaires by the national coordinators and submission of protocol to local or national ethical committees
October 2013	Update and debriefing at the ESICM in Paris.
December 2013	Pilot study at the Ghent university Hospital only
January 2014	Uploading of the translated questionnaires on the website and final check by national coordinators
March 2014	Final update and debriefing at the ISICEM in Brussels
March 2014	Data collection of ICU characteristics
March-April 2014	Data collection of health care providers characteristic
May 2014	Data collection at bedside (30 days in total)
Until May 2015	Collection of outcome data (ICU, 28 days, hospital mortality and QOL at 1 year.

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