

This Provisional PDF corresponds to the article as it appeared upon acceptance. Fully formatted PDF and full text (HTML) versions will be made available soon.

**Physician-related barriers to communication and patient and family-centred decision making towards the end of life in intensive care: a systematic review**

*Critical Care* 2014, **18**:604 doi:10.1186/s13054-014-0604-z

Mieke Visser (mievis@xs4all.nl)  
Luc Deliens (Luc.deliens@vub.ac.be)  
Dirk Houttekier (Dirk.houttekier@vub.ac.be)

Published online: 18 November 2014

**ISSN** 1364-8535  
**Article type** Research  
**Submission date** 25 June 2014  
**Acceptance date** 20 October 2014  
**Article URL** <http://ccforum.com/content/18/6/604>

Like all articles in BMC journals, this peer-reviewed article can be downloaded, printed and distributed freely for any purposes (see copyright notice below).

Articles in BMC journals are listed in PubMed and archived at PubMed Central.

For information about publishing your research in BMC journals or any BioMed Central journal, go to <http://www.biomedcentral.com/info/authors/>

# Physician-related barriers to communication and patient and family-centred decision making towards the end of life in intensive care: a systematic review

Mieke Visser<sup>1</sup>  
Email: mievis@xs4all.nl

Luc Deliens<sup>1,2</sup>  
Email: Luc.deliens@vub.ac.be

Dirk Houttekier<sup>1\*</sup>  
\* Corresponding author  
Email: Dirk.houttekier@vub.ac.be

<sup>1</sup> End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) and Ghent University, Laarbeeklaan 103, B-1090 Brussels, Belgium

<sup>2</sup> Department of Medical Oncology, Ghent University, De Pintelaan 185, B-9000 Ghent, Belgium

## Abstract

### Introduction

Although many terminally ill people are admitted to an intensive care unit (ICU) at the end of life, their care is often inadequate due to poor physician communication and lack of patient and family-centred care. The aim of this systematic literature review was to describe physician-related barriers to adequate communication within the team and with patients and families, and to patient and family-centred decision making, towards the end of life in ICU, according to the quality indicators for end-of-life care in ICU developed by the Robert Wood Johnson Foundation's critical care end-of-life peer workgroup.

### Method

Four electronic databases (Medline, EMBASE, CINAHL, PsycINFO) were searched for potentially relevant records published between 2003 and 2013 in English or Dutch, using controlled vocabulary and free text words. Studies were included if they reported on physician-related and physician-reported barriers to adequate communication and decision making. Barriers were categorized as related to physicians' knowledge, physicians' attitudes or physicians' practice. Study quality was assessed using design-specific tools. Evidence for barriers was graded according to the quantity and quality of studies in which they were reported.

## **Results**

Of 2191 potentially relevant records, 36 studies were withheld for data synthesis. We determined 90 barriers, of which 46 related to physician attitudes, 24 to physician knowledge and 20 to physician practice. Stronger evidence was found for physicians' lack of communication training and skills, their attitudes towards death in the ICU and their focus on clinical parameters, and their lack of confidence in their own judgment of the patient's true condition.

## **Conclusion**

We conclude that many physician-related barriers hinder adequate communication and shared decision making in ICUs. Better physician education and palliative care guidelines are needed to enhance knowledge, attitudes and practice regarding end-of-life care. Patient, family and health care system related barriers need to be examined.

## **Introduction**

Almost 30% of the Medicare beneficiaries in the United States are admitted to an intensive care unit (ICU) in the last phase of life [1]. The conclusion of the SUPPORT study in 1995 was that many patients in ICUs receive unwanted life-sustaining treatments and insufficient palliative care at the end of life [2]. In a survey of 82 adult ICUs in nine European countries plus Israel, shortcomings were perceived in ICU care by one in three physicians for at least one patient on the day of the survey in 2011 [3]. Perceived disproportionate care was the most common shortcoming indicated by physicians and 'too much treatment' was reported in 89% of those cases. Decisions about end-of-life care were mostly reported as being made too late or too infrequently and nurses as well as physicians were strongly distressed by the perception of inappropriate care.

Death in an ICU is often described as a devastating experience for patients and their families, with patients remaining dependent on intensive life-supporting care, neither dying nor recovering. Expectations are still unrealistically high among patients and their families but also among physicians [4,5]. Continuing life-sustaining treatments without clinical improvement causes suffering to patients and deprives them and their families of palliative care including honest prognostic information and time to prepare for dying and bereavement [4,6].

End-of-life care in ICUs is often inadequate due to factors such as lack of communication between patients and health care providers, lack of patient and family-centred care and lack of emotional and psychosocial support and it is apparent that some of these things are the result of physician-related barriers, many of which have been reported in scientific literature [6,7]. When the goals of care and treatment preferences of patients are not clear and treatment decisions are not shared with patients and families, ICU physicians will not be able to treat patients according to their wishes and the patient's quality of life might be harmed. This is why patients and families are expressing their wishes for better communication and a larger role in the decision making process and asking ICU clinicians to respond to their palliative care needs [8].

The Robert Wood Johnson Foundation's critical care end-of-life peer workgroup identified seven specific domains of ICU palliative care quality including adequate communication within the team and with patients and families and patient and family-centred decision making [9]. In a multicenter study, ICU patients and families expressed strong agreement about the importance of communication and patient- and family-centred decision making in ICU end-of-life care and defined adequate communication by clinicians as timely, ongoing, clear, complete, compassionate and addressing condition, prognosis and treatment and adequate patient-focused medical decision making as aligned with patient values, care goals, treatment and preferences [6,10]. For these two domains, 23 quality indicators were developed (10 for communication within the team and with patients and family and 13 for patient- and family-centred decision making), through literature review and expert consensus [11]:

### **Quality indicators for communication within the team and with patients and families**

1. Meet as interdisciplinary team to discuss the patient's condition, clarify goals of treatment, and identify the patient's and family's needs and preferences.
2. Address conflicts among the clinical team before meeting with the patient and/or family.
3. Utilize expert clinical, ethical, and spiritual consultants when appropriate.
4. Recognize the adaptations in communication strategy required for patients and families according to the chronic vs. acute nature of illness, cultural and spiritual differences, and other influences.
5. Meet with the patient and/or family on a regular basis to review patient's status and to answer questions.
6. Communicate all information to the patient and family, including distressing news, in a clear, sensitive, unhurried manner, and in an appropriate setting.
7. Clarify the patient's and family's understanding of the patients' condition and goals of care at the beginning and end of each meeting.
8. Designate primary clinical liaison(s) who will communicate with the family daily.
9. Identify a family member who will serve as the contact person for the family.
10. Prepare the patient and family for the dying process.

### **Quality indicators for patient and family-centred decision making**

11. Recognize the patient and family as the unit of care.
12. Assess the patient's and family's decision-making style and preferences.
13. Address conflicts in decision making within the family.
14. Assess, together with appropriate clinical consultants, the patient's capacity to participate in decision making about treatment and document assessment.
15. Initiate advance care planning with the patient and family.
16. Clarify and document the status of the patient's advance directive.
17. Identify the healthcare proxy or surrogate decision maker.
18. Clarify and document resuscitation orders.
19. Assure patients and families that decision making by the healthcare team will incorporate their preferences.
20. Follow ethical and legal guidelines for patients who lack both capacity and a surrogate decision maker.
21. Establish and document clear, realistic, and appropriate goals of care in consultation with

the patient and family.

22. Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient's condition changes.
23. Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected.

The objective of this systematic review is to describe physician-related and physician-reported barriers to the quality indicators for adequate communication within the team and with patients and families, and adequate patient and family-centred decision making towards the end of life in the ICU as developed by the end-of-life peer workgroup of the Robert Wood Johnson Foundation.

The specific research questions for this systematic literature review are: What are the physician-related and physician-reported barriers to communication within the team and with patients and families in end-of-life care in ICU according to the 10 quality indicators for communication within the team and with patients and families in end-of-life care in ICU as developed by the RWJF? What are the physician-related and physician-reported barriers to patient- and family-centred decision making in end-of-life care in ICU according to the 13 quality indicators for patient- and family-centred decision making in end-of-life care in ICU as developed by the RWJF?

Establishing scientific evidence about the barriers that hinder ICU physicians in communication and shared end-of-life decision making is important to improve the quality of end-of-life care of terminally ill ICU patients.

## **Methods**

### **Search strategy**

The electronic databases Medline, EMBASE, CINAHL, and PsycINFO were searched for study reports published between 2003 and August 2013, in Dutch or English language.

We used controlled vocabulary and free text words including: "physicians", "palliative care", "advance care planning", "terminal care", "terminally ill", "critical care", "intensive care units" (Additional file 1).

### **Criteria for eligibility of studies**

Study inclusion criteria were:

- Addressing a clear research question or objective and using primary collected qualitative or quantitative data;
- Reporting on ICU physicians treating adult patients. Intensive care physicians were defined as: attending physicians, critical care fellows, resident physicians or consultants. If a study reported on various types of intensive care clinicians, separate results for physicians had to be reported;
- Reporting on physician communication within the team and with patients and families, or on patient and family-centred decision making towards the end of life of patients in an ICU;

- Reporting on physician-related barriers to communication and patient and family-centred decision making reported by the physicians themselves (physician-reported) and not by other caregivers of the ICU-team (e.g. nurses), by patients, or by proxies or relatives. The focus was on barriers that can be changed, therefore age, sex and background of the physicians were not included as barriers.

Study exclusion criteria were:

- Reporting on medical students, nurses or patients and family;
- Reporting on physicians in non-adult ICUs (e.g. neonatal ICU);
- Having a quality assessment score of 5 or lower.

## **Study selection**

Duplicates of the retrieved records were removed. MV and DH independently examined titles and abstracts of retrieved records, using a piloted form, to exclude obviously irrelevant records. Disagreement was resolved by consensus, when necessary the third reviewer (LD) was involved for arbitration.

In the next step of the study selection procedure, eligibility of retrieved studies was examined independently by MV and DH using a piloted form. When necessary a third reviewer (LD) was involved for arbitration.

## **Data collection**

Characteristics of the included studies were extracted to a piloted data-extraction form. Physician-related and physician-reported barriers for each of the 23 quality indicators for communication within the ICU-team and with patients and their families, and patient and family-centred decision making in end-of-life care in ICU [11], were extracted independently by MV and DH. Barriers were categorized as to whether they related to the physician's knowledge, attitudes or practice, according to a model developed by Cabana and colleagues [12]. In cases of disagreement a third reviewer (LD) was involved for arbitration.

## **Quality assessment and grading evidence**

The quality of studies with a qualitative research design was assessed using the dedicated tool from the Critical Appraisal Skills Programme (CASP) [13]. For appraisal of the quantitative studies (all identified eligible quantitative studies were surveys) a survey-specific appraisal tool developed by the centre for evidence-based management was used [14]. Both appraisal tools address the appropriateness of the research method in relation to the study objectives, ethical issues, and the quality of the data collection and analysis. Quality assessment scores were assigned independently by MV and DH. In cases of disagreement a third reviewer (LD) was involved for arbitration. For both qualitative and quantitative studies the total quality assessment scores are presented as scores on a scale from 0 to 10. Studies with assessment scores from 8 to 10 were qualified as high-quality studies, with scores 6 to 7 as medium-quality studies and with scores equal to or lower than 5 as low-quality studies. Low-quality rated studies were excluded from data synthesis. Barriers reported in two or more high-quality studies qualified as stronger evidence. Barriers reported in one high-quality study and one medium-quality study, or in one high-quality study or in two or more medium-quality

studies were graded as medium evidence. Barriers reported in one medium-quality study were graded as weaker evidence (Figure 1).

---

**Figure 1 Quality assessment and grading of evidence.**

---

Because of the nature of this study, systematic literature review, ethical approval was not required.

## **Results**

### **Study selection**

From the electronic database searches 2191 records were retrieved, 465 from Medline, 1285 from Embase, 120 from PsychINFO and 321 from Cinahl (Figure 2). After removal of duplicates (n = 667) and obviously irrelevant records (n = 1459), 65 full-text articles were assessed for eligibility. Of those 65, one study did not meet the quality requirements, nine did not report on physician communication within the team or with patients and families, or on patient and family-centred decision making towards the end of life of patients in the ICU, and 19 did not report on physician-related barriers reported by the physicians themselves. Thirty-six studies met all the inclusion criteria and were included for data synthesis.

---

**Figure 2 Study selection.**

---

### **Characteristics and quality assessment of included studies**

Of the 36 included studies, 18 were qualitative studies and 18 were surveys (Table 1). Fourteen were conducted in the USA, five in Canada, four combined results from several European countries, three were done in Germany, two in the UK and one each in Australia, Poland, China, Greece, Austria, Ireland, Hungary and West Indies. Quality assessment scores varied between 6.5 and 9.5 for qualitative studies and 6 or 7 for quantitative studies.

**Table 1 Characteristics and quality assessment of included studies**

Authors (Year)	Country	Objective	Study design	Participants	Quality assessment
<b>Qualitative studies</b>					
Pattison N, Carr SM, Turnock C, Dolan S. (2013) [15]	UK	To explore the meaning of end-of-life care for critically ill cancer patients, families, oncologists, palliative care specialists, critical care consultants and nurses.	Qualitative, phenomenological in-depth interviews.	13 physicians.	9
Gutierrez KM. (2012) [16]	US	To explore the experiences of critical care nurses and physicians with advance directives in an Intensive Care Unit (ICU) to identify the benefits and limitations of advance directives and recommendations for improvement.	Descriptive ethnographic study with interviews in a 22-bed medical/surgical ICU in a large community hospital.	Seven attending, three fellow physicians.	6 ½
Barnato AE, Tate JA, Rodriguez KL, Zickmund SL, Arnold RM. (2012) [17]	US	To explore norms of decision making regarding life-sustaining treatments at two academic medical centres that contribute to their opposite extremes of end-of-life ICU use.	Mixed-methods study: family meetings, informal and formal interviews, and artefacts.	Attending physicians of two academic medical centres, patients and family.	8
Schenker Y, Tiver GA, Hong SY, White DB. (2012) [18]	US	Describe whether and how comfort care was presented as an option in family conferences about treatment options, and assess whether the strength of the physicians' belief that life support should be withdrawn was associated with the presentation of comfort care.	Mixed-methods study of 72 audio-recorded family conferences about end-of-life treatment decisions.	Physicians and family.	8
Jox RJ, Schaider A, Marckmann G, Borasio GD. (2012) [19]	Germany	To explore how clinicians themselves define medical futility, who they think should assess this, how they justify performing futile treatment and how they communicate futility situations to patients and caregivers.	Qualitative mixed-method approach at a large tertiary referral centre, analysing protocols of ethics consultations and semi-structured interviews.	Seven physicians.	8 ½
Baggs JG, Schmitt MH, Prendergast TJ, Norton SA, Sellers CR, Quinn JR, Press N. (2012) [20]	US	To examine the role of the "attending physician" in four adult ICUs and the consequences of role complexities for clinicians, patients and families, particularly in the context of end-of-life decision making.	Ethnographic study in a large academic hospital with surgical, medical, cardiovascular and burn/trauma ICU, observations of end-of-life discussions and interviews.	30 physicians.	8 ½
Coombs MA, Addington-Hall J, Long-Sutehall T. (2012) [21]	UK	To identify the challenges for health care professionals when moving from a recovery trajectory to an end-of-life trajectory in intensive care.	Semi-structured interviews in two ICUs in a large university-affiliated hospital in England.	13 doctors.	9



Ahern SP, Doyle TK, Marquis F, Lesk C, Skrobik Y. (2012) [22]	Canada	An interview-based qualitative study was conducted to identify what is important to physician trainees in ICU and infer from this positive educational experiences for physician trainees.	Qualitative approach of hermeneutic phenomenology, semi-structured interviews.	19 critical care physician trainees in their postgraduate years (R4-R6).	8 ½
Gehlbach TG, Shinkunas LA, Forman-Hoffman VL, Thomas KW, Schmidt GA, Kaldjian LC. (2011) [23]	US	Assess the concordance between patients' code status preferences and their actual code status orders; compare patients/surrogates and their physicians regarding their respective assessments of most important goals of care.	Survey, interviews with closed-ended and open-ended questions in a medical ICU of a large academic medical centre.	15 physician participants.	7 ½
Schwarze ML, Bradley CT, Brasel KJ. (2010) [24]	US	To examine the culture and practice of surgeons in order to assess attitudes and concerns regarding advance directives for their patients who have high-risk surgical procedures.	Qualitative study in trauma and surgical critical care.	10 physicians.	7 ½
Corke C, Milnes S, Orford N, Henry MJ, Foss C, Porter D. (2009) [25]	Australia	To examine attitudes of intensive care doctors to advance care planning and medical enduring power of attorney.	Survey, followed by open-ended question.	275 trainees and fellows.	7
Sibbald R, Downar J, Hawryluck L. (2007) [26]	Canada	To explore how frontline ICU staff defines medically futile care, to discover why they provide it and to identify strategies that might promote a more effective use of ICU resources.	Qualitative interviews in 16 ICUs of academic and community hospitals.	16 medical directors.	8
Beck S, van de Loo A, Reiter-Theil S. (2008) [27]	Germany	To identify difficulties and uncertainties in making decisions of withholding and withdrawing mechanical ventilation among intensive care physicians.	Problem-centred interviews.	28 interviewees, four consultants, 11 senior registrars, 13 senior house officers (20 out of 28 were specialists).	9
Baggs JG, Norton SA, Schmitt MH, Dombeck MT, Sellers CR, Quinn JR. (2007) [28]	US	To clarify unit cultures surrounding end-of-life decision making in four US adult medical and surgical ICUs.	Prospective ethnographic study of four adult ICUs. A six-member research team used participant observation, field notes, and semi-structured interviews of providers, patients, and families.	13 physicians.	8
White DB, Braddock CH 3rd, Berecknye S, Curtis JR. (2007) [29]	US	To determine the nature and extent of shared decision making about end-of-life treatment in ICUs, what factors predict higher levels of shared decision making.	Mixed-method study: ICU family conferences in a county hospital, a university hospital and two community hospitals and questionnaires to physicians.	35 physicians leading conferences.	8 ½
Hsieh HF, Shannon SE, Curtis JR. (2006) [30]	US	To identify inherent tensions that arose during family conferences in the intensive care unit, and the communication strategies clinicians used in response.	Qualitative content analysis; communication between family members and physicians is analysed using a dialectic perspective in 51 family-clinicians conferences in four hospitals.	36 physicians who led the conferences.	8 ½

Palda VA, Bowman KW, McLean RF, Chapman MG. (2005) [31]	Canada	To explore the process of the provision of futile care in Canadian intensive care units.	Survey with closed and open-ended questions.	114 physicians.	6 ½
West HF, Engelberg RA, Wenrich MD, Curtis JR. (2005) [32]	US	To identify categories of expressions of non-abandonment in the setting of ICU family conferences concerning withdrawing life-sustaining therapy or the delivery of bad news, and develop a conceptual model in which non-abandonment is expressed.	Qualitative analysis of statements of abandonment during family conferences discussing withholding/withdrawing of treatment.	35 physicians leading the conferences.	7 ½
<b>Quantitative studies</b>					
Bülow HH, Sprung CL, Baras M, Carmel S, Svantesson M, Benbenishty J, Maia PA, Beishuizen A, Cohen S, Nalos D. (2012) [33]	European countries (6 countries)	To examine whether religion and religiosity are important to end-of-life decisions and patient autonomy in the ICU?	Structured questionnaires in six European countries, 143 ICUs.	304 physicians.	6
Schimmer C, Gorski A, Ozkur M, Sommer SP, Hamouda K, Hain J, Aleksic I, Leyh R. (2012) [34]	Germany	To determine the decision-making process of withholding and/or withdrawal of life-sustaining treatment in cardiac intensive care units in Germany.	Questionnaire among all heart surgery ICUs (79) in Germany.	35 clinical directors, 25 senior ICU physicians.	6
Kübler A, Adamik B, Lipinska-Gediga M, Kedziora J, Strozec L. (2011) [35]	Poland	To analyse the attitudes of ICU physicians regarding decisions to forgo life-sustaining treatment for adult ICU patients.	Survey.	217 intensive care physicians working in ICUs in Poland.	6
Weng L, Joynt GM, Lee A, Du B, Leung P, Peng J, Gomersall CD, Hu X, Yap HY. (2011) [36]	China	To document current attitudes and practices of ICU doctors in China when dealing with issues that have strong ethical and moral dimensions; to make comparisons with those reported by ICU doctors in Hong Kong and Europe.	Anonymous, written, structured questionnaire survey.	315 participants, representing 54 ICUs in 30 cities in 21 of the 31 regions of China.	7
Kranidiotis G, Gerovasili V, Tasoulis A, Tripodaki E, Vasileiadis I, Magira E, Markaki V, Routsis C, Prekates A, Kyprianou T, Clouva-Molyvdas PM, Georgiadis G, Floros I, Karabinis A, Nanas S. (2010) [37]	Greece	To study the frequency, type and rationale for limiting life support in Greek multidisciplinary ICUs, the clinical and demographic parameters associated with it, and the participation of relatives in the decision-making process.	Prospective observational study, with an anonymous questionnaire in eight multidisciplinary, general hospital-affiliated ICUs	304 patients and their physicians.	7
Schaden E, Herczeg P, Hacker S, Schopper A, Krenn CG. (2010) [38]	Austria	To explore Austrian intensive care physicians' experiences with and their acceptance of the new advance directives legislation two years after enactment.	Survey among all intensive care units in Austria.	139 participants.	6
Westphal DM, McKee SA. (2009) [39]	US	To examine differences between physicians and nurses on knowledge about advance directives and do-not-resuscitate orders, and the personal factors that underlie beliefs and practices related to the use of advance directives and do-not-resuscitate orders discussion and designation.	Survey.	53 physicians.	6

Sprung CL, Woodcock T, Sjkovist P, Ricou B, Bulow HH, Lippert A, Maia P, Cohen S, Baras M, Hovilehto S, Ledoux D, Phelan D, Wennberg E, Schobersberger W. (2008) [40]	European countries (17 countries)	To evaluate physician documentation and reasons, considerations and difficulties in end-of-life decision making in ICUs.	Prospective study of end-of-life practices and decisions in consecutive patients who died or were subject to any limitation of life-saving interventions in 37 ICUs in 17 European countries.	ICU physicians.	6
Collins N, Phelan D, Marsh B, Sprung CL. (2006) [41]	Ireland	To study the frequency, rationale and process for withholding and withdrawing life-sustaining treatment in intensive care patients in Ireland.	Prospective observational study of all consecutive patients admitted to ICU who died or had life-sustaining treatment limited.	Data of 122 patients, documented by physicians.	7
Nelson JE, Angus DC, Weissfeld LA, Puntillo KA, Danis M, Deal D, Levy MM, Cook D. (2006) [42]	US	To improve the understanding of educational needs among residents caring for the critically ill	Survey.	184 physicians.	7
White DB, Curtis JR, Lo B, Luce JM. (2006) [43]	US	To determine how decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision makers are made.	Prospective longitudinal cohort study.	47 physicians of patients without decision-making capacity and without a surrogate.	6
Moss AH, Demanelis AR, Murray J, Jack J. (2005) [44]	US	To assess the knowledge, skills and attitudes that physicians and nurses who practice in West Virginia's ICUs have concerning end-of-life care.	Survey.	153 physicians.	6
Cohen S, Sprung C, Sjkovist P, Lippert A, Ricou B, Baras M, Hovilehto S, Maia P, Phelan D, Reinhart K, Werdan K, Bulow HH, Woodcock T. (2005) [45]	European Countries (17 countries)	To examine the communication of end-of-life decisions in Europe.	Prospective observational study of 4248 patients with any limitation of life-sustaining treatment or dying in 37 ICUs in 17 countries.	Physicians collected data on 4248 patients.	7
Elo G, Dioszeghy C, Dobos M, Andorka M. (2005) [46]	Hungary	The study the factors associated with limiting resuscitation in Hungary.	Survey.	72 doctors.	7
Sinuff T, Cook DJ, Rocker GM, Griffith LE, Walter SD, Fisher MM, Dodek PM, Sjkovist P, McDonald E, Marshall JC, Kraus PA, Levy MM, Lazar NM, Guyatt GH. (2004) [47]	Canada, US, Sweden, Australia	To study the rate of establishing do-not-resuscitate directives, determinants, and outcomes of those directives for mechanically ventilated patients.	Multicentre observational study.	3099 critically ill patients admitted to 15 ICUs, documentation attending physicians clinical judgements.	7
Yap HY, Joynt GM, Gomersall CD. (2004) [48]	Hong Kong	To examine ethical attitudes of intensive care physicians in Hong Kong.	Survey	65 physicians.	7
Hariharan S, Moseley HS, Kumar AY, Walrond ER, Jonnalagadda R. (2003) [49]	West Indies	To analyse the characteristics of moribund patients in a surgical ICU and highlight the dilemmas inherent in treating such patients.	Prospective collection of data from patient records.	Data of patients recorded by physicians of surgical ICU.	6
Garland A, Connors A. (2007) [50]	Canada	To quantify the influence that ICU staff physicians have on decisions to limit life support made for critically ill patients	Data prospectively collected in the 13-bed medical ICU of a 520-bed urban university-affiliated teaching hospital.	9 staff physicians.	7

## Barriers

All the barriers reported by ICU physicians were categorized per quality indicator as developed by Clarke and colleagues [11] as barriers related to the knowledge, attitude and practice of physicians [12]. Ninety different barriers were identified, of which 24 related to physician knowledge (Table 2), 46 to physician attitudes (Table 3) and 20 to physician practice (Table 4). Stronger evidence was found for eight specific barriers (all related to physician's attitudes), medium evidence for 39 and weak evidence for 43.

**Table 2 Barriers with regard to physicians' knowledge**

Quality indicators <sup>a</sup>	Barriers with regard to physicians' knowledge
General	<ul style="list-style-type: none"> <li>• Insufficient physician training in communication about end-of-life issues.*[42]</li> <li>• Clinician's reluctance to use opioids or sedatives because of concern about side effects.*[42]</li> <li>• Lack of education in palliative medicine.*[44]</li> </ul>
1	<ul style="list-style-type: none"> <li>• Involvement of surgeons slows down decision making, because they don't understand patients' situation.**[21]</li> </ul>
2	<ul style="list-style-type: none"> <li>• Lack of communication skills of senior medical residents with colleagues.**[22]</li> </ul>
5	<ul style="list-style-type: none"> <li>• No familiarity with skilled and timely communication.**[26]</li> </ul>
10	<ul style="list-style-type: none"> <li>• Not taught how to make a diagnosis of dying, no awareness of process of dying.**[21]</li> <li>• Unrealistic expectations by clinicians about patient prognosis or effectiveness of ICU treatment.*[42]</li> </ul>
16	<ul style="list-style-type: none"> <li>• Physicians' uncertainty about the legal situation of advance directives.*[38]</li> <li>• Lack of physicians' experience with advance directives.*[38]</li> </ul>
21	<ul style="list-style-type: none"> <li>• Lack of familiarity to make a prognosis.**[15]</li> <li>• Not knowing how to deal with 'feeling helpless' with families pressuring ICU teams to uphold treatment or when family members are upset about the aggressiveness of care provided to their unwilling loved one.**[22]</li> <li>• Uncertainty concerning the services provided by local hospice programs and who to refer to hospices.*[44]</li> <li>• No awareness of professional or local guidelines that related to the provision of futile care.*[31]</li> <li>• Insufficient training in communication with patients/families.*[31]</li> <li>• Lack of discussions on ethical issues in medical programmes: lack of knowledge on ethical issues concerning end-of-life decisions.*[48]</li> </ul>
22	<ul style="list-style-type: none"> <li>• No familiarity with defining futility and how to communicate futility to patient and family.**[19]</li> <li>• No knowledge of management of critical illness by referring specialists: confounding factors in decision making.**[21]</li> </ul>
23	<ul style="list-style-type: none"> <li>• Conditioned that doing nothing or withdrawing treatment is not helping the patient.**[19]</li> <li>• No familiarity with legal framework regarding end-of-life decisions, wrong conception that law prohibits withdrawal of mechanical ventilation.**[27,36]</li> <li>• No awareness of end-of-life care guidelines.**[27]</li> <li>• Not being at ease talking to patients/families about limitation of therapy.*[36]</li> <li>• No familiarity with end-of-life decision making ("Good prognosis" and "give it a go" is often said because of no familiarity with end-of-life decision making).*[25]</li> <li>• Insufficient clinician training in techniques for forgoing life-sustaining treatment without patient suffering.*[42]</li> </ul>

<sup>a</sup> Quality indicators for adequate communication and decision making in ICU as developed by Clarke and colleagues [11].

\* Barriers for which weaker evidence was found.

\*\* Barriers for which medium evidence was found.

**Table 3 Barriers with regard to physicians' attitudes**

Quality indicators <sup>a</sup>	Barriers with regard to physicians' attitudes
1	<ul style="list-style-type: none"> <li>• Lack of consensus among the treating team in end-of-life decisions, surgeons in ICU do not want to give responsibility to others members of the clinical team, looking at the small percentage of patients who survive only, and one physician could push for futile treatment looking at a small aspect of patients overall condition only.***[20,26]</li> <li>• Perception by the critical care attending that the consulting specialist controls life-sustaining treatment decision making.**[17]</li> <li>• Physicians are overly sure of making the right decision themselves; they do not include patients in care decisions and consensus development. **[21,37]</li> </ul>
2	<ul style="list-style-type: none"> <li>• Conflicting opinions of prognosis and treatment and recognition that death is a potential reality by different attending physicians.***[15,20]</li> <li>• Surgeon's disagreement with other consultants to accept futility treatment.*[49]</li> </ul>
5	<ul style="list-style-type: none"> <li>• Negative attitude towards relatives who want limitation of treatment.*[37]</li> </ul>
6	<ul style="list-style-type: none"> <li>• Family is thought not to understand end-of-life practice, family was considered not available, or physicians found discussion with relatives not necessary.*[37]</li> </ul>
10	<ul style="list-style-type: none"> <li>• Palliative care input was limited to the very end of life and 'death is not usually expected' and narrow interpretation when a patient is dying, i.e.: a patient whose vital signs cannot be maintained despite maximal life-sustaining treatment is dying.***[15,17]</li> <li>• Physicians sometimes use language that seems to imply abandonment of the patient during the end-of-life decision making process, as if withdrawal is the sole responsibility of the family, without mentioning another mode of care.*[32]</li> </ul>
11	<ul style="list-style-type: none"> <li>• Uneasiness in dealing with surrogate decision maker.**[22]</li> <li>• Family is thought not to understand, family was not available, or physicians found discussion not necessary.**[37,45]</li> </ul>
15	<ul style="list-style-type: none"> <li>• Negative opinion of advance directives: perceived as often not preventing unwanted aggressive treatment (because of lack of communication with relatives) and lacking a level of specificity necessary to facilitate decision making.*[16]</li> <li>• Physicians' own ethical values regarding advance directives.*[38]</li> </ul>
18	<ul style="list-style-type: none"> <li>• Physicians find do-not-resuscitate orders paper work, slow, and not applicable to situations of dying at the ICU.**[28]</li> <li>• Physicians are not aware of patients' preferences regarding do not resuscitation orders.*[23]</li> <li>• Physicians believe that do-not-resuscitate orders should not be applied.*[36]</li> <li>• Most physicians only discuss do-not-resuscitation order when the prognosis is poor or when condition deteriorates.** [39,47]</li> <li>• Family dynamics and legal concerns were the most important concerns affecting physicians' decision to write or obtain a do-not-resuscitate order.*[39]</li> <li>• The most important factor influencing do-not-resuscitate decision was the opinion of the head of department or doctor in charge of the patient, not the wishes of patient/family.*[46]</li> </ul>
21	<ul style="list-style-type: none"> <li>• No acceptance that the patient is dying; opinion that life should be the foremost concern in end-of-life decision making and that patient's goal of care is to survive (surgeons); physicians cannot let patients die: "They regard life at any cost to be a success"(comment physician).***[21,28,31,35]</li> </ul>

- 
- Conflicting opinion of prognosis, medical uncertainty and focus on narrow physiologic objectives without recognition that the condition of the patient becomes terminal, reaching a point of futility with prolongation of dying, are barriers for time left to appropriate decision making.\*\*\*[15-17]
  - Surgeons in the team want to continue life-sustaining treatment, don't accept that they cannot go any further, don't consider end-of-life discussions in surgical ICU, which take place later in patients' illness trajectory, often in crisis atmosphere.\*\*\*[19,20]
  - Physicians are sure of making the right decisions themselves and do not include patients in care decisions and consensus development.\*\*[21,37]
  - Considering that families don't understand end-of-life practices, that families are not available, or that discussions about goals of care are not necessary.\*\*[37,45]
  - Considering time spent with family as wasted time and energy when families want continuation of aggressive treatment or when there is disagreement or extended hesitation over a decision.\*\*[22]
  - No appropriate communication strategy, no information seeking but arguing or avoiding discussions with patient/family as decision-centred strategy.\*\*[30]
  - Not eliciting family's wishes, or assessment of family's understanding of information, the family is often more told than asked about nature and context of end-of-life decisions.\*\*[29,45]
  - Feeling of loss of control of referred patients, not believing in giving up on patients are reasons not to refer patients to hospice.\*[44]
  - No recognition of patients' goals of care.\*[23]
- 22
- Physicians find it easier to carry on with treatment than to discuss alternative goals of care.\*\*[21]
  - Surgeons consider informed consent documentation as a contract for potentially burdensome postoperative therapy after a difficult operation (e.g. transplant, neurosurgery).\*[24]
- 23
- Concerns of omission life-sustaining treatment are larger (missing something treatable, fear of doing something wrong or limiting life-sustaining treatment for a patient who might survive) than concerns about harm of commission life-sustaining treatment (such as iatrogenic harms, prolonging dying, and treating a patient against their preferences).\*\*\*[17,19]
  - Only when physicians believe that life support should be withdrawn, having end-of-life care discussions or shared decision making with the patient/family is considered.\*\*\*[18,29]
  - Physicians' concerns of legal action imposed by families for forgoing life-sustaining treatment. Therefore they follow families' wishes, even after reading patients' advance directives, and even when the medical staff uniformly felt that it was not medically appropriate because of futile treatment.\*\*[16,26,36,39,42]
  - Physicians prefer their own ideas about best interest of the patient, are more focused on medical technical parameters concerning withholding/withdrawing therapy, and continue treatment, not respecting patient's/family's wishes or patient's living will to stop.\*\*[27,33,34,40]
  - Diagnostic uncertainty or potential for reversibility of illness is justification for continuation of treatment against the medical enduring power of attorney's or patient's wishes for palliation.\*\*[25,37]
  - Unresponsiveness to treatment already offered is the main factor influencing the physician's decision to withholding/withdrawing therapy, not patient/family request.\*\*[37,40,41]
  - Doubts about the validity of the patient's wish expressed beforehand.\*\*[25,27]
  - Less respect for patients' wishes by surgeons compared to other ICU physicians.\*\*[28]
-

- Feeling of betrayal, unhappiness, disappointment and even culpability when family member confronts physician with advance directives in the setting of prolonged life-sustaining treatment.\*[24]
- To consider death in ICU as a personal failure.\*[24]
- Distrust of the motivation of the health care proxy wanting to forgo life-sustaining treatment and the underlying family preferences.\*[25]
- Distrust concerning the timeliness of the advance directive.\*[25]
- Physicians' conception that medical enduring power of attorney and advance directives provide an indication or guideline, rather than a decision that has to be respected.\*[25]
- Legal concerns or disagreements with other physicians about whether it is appropriate to write do-not-resuscitate order or withdraw treatment from patients who lack decision making capacity and without a substitute decision maker\*[43]
- Personal values and beliefs of intensivists are barrier to forgoing life-sustaining treatment, more than comorbidities or the type of acute illness.\*[50]

<sup>a</sup> Quality indicators for adequate communication and decision making in ICU as developed by Clarke and colleagues [11].

\* Barriers for which weaker evidence was found.

\*\* Barriers for which medium evidence was found.

\*\*\* Barriers for which stronger evidence was found

**Table 4 Barriers with respect to physicians' practice**

Quality indicators <sup>a</sup>	Barriers with respect to physicians practice
General	• Competing demands for clinicians' time.*[42]
1	• Unavailability of attending physicians due to rotation systems.**[22]
2	• Hierarchy under physicians is barrier to solve problems in the team before talking to the patient.**[22]
7	• Individual physicians' lack of holistic view.**[26]
10	• Physicians do not routinely check that family members understand the information they are given and discuss family's role in decision making.**[29]
15	• Low confidence to take responsibility, physicians do not refer to hospice care, because patient or family does not accept that patient is dying.*[44]
21	• Not actively recommending the creation of an advance directive.*[38]
	• Low confidence to take responsibility: physician does not take the responsibility for decision making with the dying patient: leaves the patient to die as if patient decides when to die.**[15]
	• Low confidence to take responsibility, considering family requests for continued futile treatment as a mandate and not as a normal communication and decision-making process.**[17,31]
	• Low confidence to take responsibility, externalizing control for decision making to patients, families and specialists who they believe expect aggressive treatment.**[17]
	• Postponing decision making until all treatment options are exhausted, until the last moment (surgeons).**[28]
	• No usage of professional or local guidelines that related to the provision of futile care.*[31]
23	• Lack of time and information is reason to initiate life support, resulting in futile treatment.**[26]
	• Continuation of aggressive treatment is justified, because of lot of money is already invested in the patient, and availability of resources.**[17]
	• Aggressive care deemed to be appropriate because of no awareness of providers of existence of advance directive or living will.*[16]

- 
- Low confidence to take responsibility: the rate of withholding and withdrawing therapy was also reduced upon family's wishes.\*[35]
  - Considering withholding and withdrawing decisions inappropriately delayed.\*[37]
  - No support of an internal multidisciplinary committee or professional policies in case of patients who miss decision-making capacity and without a surrogate.\*[43]
  - Low confidence to take responsibility, when family insists that everything should be done for patients with poor prognosis, physicians are less inclined to withdraw treatment, than when family insists to limit therapy.\*[48]
  - Low confidence to take responsibility, high hopes of the family and consistent requests to the surgeons contributed to the continuation of therapy which was considered futile by at least two consultants.\*[49]
- 

<sup>a</sup> Quality indicators for adequate communication and decision making in ICU as developed by Clarke and colleagues [11].

\* Barriers for which weaker evidence was found.

\*\* Barriers for which medium evidence was found.

### ***Barriers with regard to physician knowledge***

Barriers were identified for eight of the 23 quality indicators. Because not many barriers were identified per quality indicator, almost identical barriers with low or medium evidence were compared and combined across the quality indicators.

Across quality indicators, stronger evidence was found for the barrier lack of communication training and skills in end-of-life discussions in general [42], and for quality indicators (QIs) 2, 5, 21, 22 and 23 [19,22,26,31,36], including how to communicate to patient and family the futility of further treatment.

*Meet as interdisciplinary team to discuss the patient's condition, clarify goals of treatment, and identify the patient's and family's needs and preferences (QI 1)*

Medium evidence was found for the barrier that, due to the hierarchy of the system, surgeons who are not fully aware of the patient's actual condition (i.e. that further treatment may be futile) can slow down the decision-making process by the team [21].

*Preparing the patient and family for the dying process (QI 10)*

One barrier found was that physicians are not taught how to make a diagnosis of dying (medium evidence) [21], and have unrealistically high expectations about the prognosis and effectiveness of ICU treatment (weaker evidence) [42].

*Clarify and document the status of the patient's advance directive (QI 16)*

Physicians are uncertain about the legal standing of, and have no experience with, advance directives (weaker evidence) [38].

*Establish and document clear, realistic, and appropriate goals of care in consultation with the patient and family (QI 21)*



Lack of familiarity with how to make a prognosis (medium evidence) [15], and not knowing how to relate to families who pressurize them to continue treatment or are upset by the aggressiveness of treatment given against their wishes were identified as barriers (medium evidence) [22].

*Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient's condition changes (QI 22)*

Referring specialists are not familiar with the management of the critical illnesses of ICU patients, which can lead to difficulties when changes in management have to be made (medium evidence) [21].

*Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected (QI 23)*

Not being aware of the laws applying to do-not-resuscitate status and the limitation of life-sustaining treatment or withdrawal of treatment (medium evidence) [27,36], not being aware of end-of-life guidelines (medium evidence) [27] and being conditioned to treat for recovery rather than to do nothing (medium evidence)[19], were identified as barriers.

### ***Barriers with regard to physician attitudes***

Barriers were identified for 11 of the 23 quality indicators. Stronger evidence was found for eight specific barriers.

*Meet as interdisciplinary team to discuss the patient's condition, clarify goals of treatment, and identify the patient's and family's needs and preferences (QI 1)*

There is a danger of lack of consensus among the treating team when the focus of the surgeon is on the small percentage of patients who will survive because of their treatment and not on the greater percentage who will not, and when ICU physicians focus on the particular aspect of the patient's condition which comes under their remit rather than on their overall condition and thus do not want to pass responsibility to other members of the clinical team who may have a more holistic perception of the patient's condition (stronger evidence) [20,26]. Medium-strength evidence was found for the barriers that physicians are overly sure of making the right decision themselves and that they do not include nurses' opinions and patients' needs in care decisions and consensus development [21,37].

*Address conflicts among the clinical team before meeting with the patient and/or family (QI 2)*

Disagreement and conflicting opinions of prognosis, treatment and imminence of death by different attending physicians was found as a barrier (stronger evidence) [15,20].

*Prepare the patient and family for the dying process (QI 10)*

A narrow interpretation of when a patient is dying, i.e. when vital signs cannot be maintained despite maximal life-sustaining treatment, and the consideration of palliative care as being only for the very end of life were both identified as barriers (stronger evidence) [15,17].

*Recognize the patient and family as the unit of care (QI 11)*

Medium evidence was found for the barriers that physicians feel uneasy dealing with surrogate decision makers [22], that they think that the family will not understand, and that they find end-of-life discussions with relatives unnecessary [37,45].

*Initiate advance care planning with the patient and family (QI 15)*

Identified as barriers, were the physicians' personal ethical values and their negative opinion of advance directives, considering them inapplicable in emergency situations and lacking a level of specificity (weaker evidence) [16,38].

*Clarify and document resuscitation orders (QI 18)*

We found medium evidence for the barrier that physicians discuss do-not-resuscitate orders only when the prognosis is poor [39,47], and the most important factor influencing the decision to write a do-not-resuscitate order is the physician's opinion and not the wishes of patient or family to stop treatment (weaker evidence) [46]. The family's wish that a do-not-resuscitate order is not written and concerns about their legality are important in influencing a physician's decision (weaker evidence) [39]. A physician's belief that do-not-resuscitate orders should not be applied (weaker evidence) [36], that do-not-resuscitate orders are a lot of paper work or are not applicable to the situation of the dying patient (medium evidence) [28], were also considered as barriers.

*Establish and document clear, realistic, and appropriate goals of care in consultation with the patient and family (QI 21)*

We found stronger evidence that physicians' personal beliefs and values can hinder the process of establishing and documenting clear, realistic, and appropriate goals of care with the patient and family: surgeons are trained to believe that the goal of treatment is survival. Physicians tend not to accept that a patient is dying and believe that their life should be saved [21,28,31,35]. We found also stronger evidence for the barrier that surgeons in particular want to continue life-sustaining treatment and that end-of-life discussions take place later in the surgical ICU than in the medical ICU [19,20]. Stronger evidence was also found that physicians' conflicting opinions of prognosis and their focus on narrow physiological objectives, without recognition that the condition of the patient has become terminal, are barriers for timely end-of-life discussions [15-17].

Physicians are sure of making the right decisions themselves without including patients in care decisions and without consensus development (medium evidence) [21,37], and believe that families don't understand end-of-life practices, so that discussions about goals of care are not necessary (medium evidence) [37,45]. Time spent with the family is considered as wasted when the family insists on futile treatment (medium evidence) [22]. Evidence was also found for the barrier that physicians do not use appropriate communication strategies in discussions with patient or family but either argue or avoid discussions (medium evidence) [30], or inform the patient or family only about the nature and context of the end-of-life decision and do not ask them about their wishes and preferences [29,45].

Further, physicians do not recognize patients' goals of care, which are more quality-of-life related than physicians' goals of living longer (weaker evidence) [23]. The feeling of loss of

control of referred patients and the physicians' perception that doing nothing equals giving up on a patient are reasons not to refer patients to hospices (weaker evidence) [44].

*Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient's condition changes (QI 22)*

Physicians find it easier to carry on with treatment than to discuss alternative goals of care (medium evidence) [21], and surgeons consider informed consent as a contract for potentially burdensome postoperative therapy after a difficult operation (e.g. organ transplant, neurosurgery) (weaker evidence) [24].

*Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected (QI 23)*

Stronger evidence was found for the barrier that physicians are more concerned that by abandoning life-sustaining treatment they might miss something which is treatable than that they might harm patients by prolonging life-sustaining treatment and the dying process or by treating them against their preferences [17,19]. Stronger evidence was also found for the barrier that only if physicians themselves believe that life support should be withdrawn will they consider end-of-life discussions and shared decision making with the patient or family [18,29].

Medium-strength evidence was found that physicians prefer their own ideas of what is in the best interest of the patient, focusing on clinical and technical parameters to decide on withholding or withdrawing therapy, and do not respect the patient's or family's wishes to stop therapy, not even when there is a living will [27,33,34,40]. Further, medium-strength evidence was found for the barrier that, even when the team confirms that treatment is futile and inappropriate, physicians follow the family's wishes when the family wants to continue futile treatment out of concerns about legal action [16,26,36,39,42]. Medium-strength evidence was also found for the barrier that uncertainty of prognosis and potential for reversibility of illness are used as justification for continuation of treatment against the patient's or their legal proxy's wishes for palliation [25,37]. We also found medium-strength evidence for the barriers that the main factor that influences the physician to forgo therapy is unresponsiveness to treatment already offered and not the patient's or family's requests [37,40,41]. Barriers to respecting advance directives and medical enduring power of attorney expressing the patient's wish to forgo treatment are that physicians have doubts about the validity of advance directives (medium evidence) [25,27], distrust concerning the timeliness of an advance directive, feelings of betrayal when confronted with an advance directive (low evidence) [24,25] and a perception that the medical enduring power of attorney and advance directives provide an indication or guideline rather than a decision that has to be respected (low evidence) [25].

### ***Barriers with regard to physician practice***

Barriers were identified for seven of the 23 quality indicators. Lack of confidence to take responsibility in communication and patient- and family-centred decision-making was a barrier identified for quality indicators 10, 21 and 23.

*Meet as interdisciplinary team to discuss the patient's condition, clarify goals of treatment, and identify the patient's and family's needs and preferences (QI 1)*

Unavailability of attending physician due to rotation system was found as a barrier with medium evidence [22].

*Address conflicts among the clinical team before meeting with the patient and/or family (QI 2)*

Hierarchy in the team is a barrier to solving problems before talking to the patient (medium evidence) [22], and individual physicians' lack a holistic view (medium evidence) [26].

*Clarify the patient's and family's understanding of the patient's condition and goals of care at the beginning and end of each meeting (QI 7)*

Physicians do not routinely check that family members understand the information they are given and fail to discuss the family's role in decision making (medium evidence) [29].

*Prepare the patient and family for the dying process (QI 10)*

Lack of confidence to take responsibility, the physician does not refer the patient to a hospice because the family does not accept that the patient is dying (low evidence) [44].

*Establish and document clear, realistic, and appropriate goals of care in consultation with the patient and family (QI 21)*

We found medium-strength evidence for lack of confidence to take responsibility as a barrier; physicians do not take responsibility for decision making with the dying patient, but continue life-sustaining treatments until the patient dies [15]. For ICU surgeons postponing decision making until all treatment options are exhausted, until the very last moment, we found medium evidence [28]. Medium evidence was also found for other barriers related to lack of confidence to take responsibility; physicians consider a family's request for futile treatment as a mandate and not as part of normal communication about the decision-making process [17,31], and they externalize control for decision making to patients, family and consulting specialists who they believe expect aggressive treatment [17].

*Forgo life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected (QI 23)*

Medium-strength evidence was found for the barrier that lack of time and information is the reason to continue therapy, as is money already invested in the patient and the availability of resources (medium evidence) [17].

Weaker evidence was found for lack of confidence to take responsibility; the rate of withholding or withdrawing therapy was reduced at the family's request [35]; physicians are less inclined to withdraw treatment when the family insists that everything should be done than when they ask for limited therapy [48]. A family's high expectations and consequent requests to the surgeon contribute to the continuation of therapy considered futile by at least two other consultants (weaker evidence) [49].

## Discussion and conclusions

The Robert Wood Johnson Foundation's Critical Care End-of-Life Peer Workgroup has identified seven specific domains of ICU palliative care quality including adequate communication within the team and with patients and families and patient and family-centred decision making. However, no systematic description and analysis of barriers to adequate communication and decision-making has been made before. To our knowledge, this is the first time that self-reported barriers to providing quality end-of-life care in these two domains have been identified for the main professional actor in the ICU, the ICU physician.

In 36 empirical studies we identified 90 different physician-related barriers to adequate communication and patient and family-centred decision making towards the end of life in intensive care, related to ICU physicians' knowledge and skills, attitudes and practices. With respect to physicians' knowledge and skills, stronger evidence was found for physicians' lack of communication training and skills in general, including communication with colleagues, and in particular regarding the communication of the futility of further treatment to the patient and their family. Among barriers with stronger evidence relating to the attitudes of physicians, we found the lack of consensus among the treating team in end-of-life decision making, when surgeons and physicians focus only on the small percentage of patients who will survive and do not want to share responsibility with other members of the clinical team, to be a barrier to interdisciplinary team discussions; disagreement between team members and conflicting opinions about prognosis and treatment and about the futility of treatment are all barriers to the addressing of conflict among the team. The narrow interpretation by physicians of when a patient is actually dying, preventing the provision of palliative care until the last moment, is a barrier to preparing the patient and family for the dying process. The personal beliefs and values of physicians hinder the process of establishing and documenting clear, realistic and appropriate goals of care with the patient and family; surgeons and physicians are trained to believe the goal of treatment is to save the patient's life and therefore resist acknowledging that the patient is dying. Regarding the decision to forgo life-sustaining therapy, we found that physicians were more worried that they might miss something treatable than that they might harm patients with the prolongation of treatment and the dying process, even where this was against the patient's preferences. They tend to favour their own views of what is in the best interest of the patient, focusing on clinical and technical parameters, rather than respecting the patient's and family's wishes to forego treatment. Related to physicians' practice, we found they often report themselves as lacking the confidence to take responsibility for the dying patient and postpone decision making about withholding or withdrawing of treatment until all treatment options are exhausted, continuing treatment until the patient dies.

The results of our review indicate that the lack of communication skills among physicians, the weakness of their skills in prognostic estimation and their lack of knowledge about the relevant legal frameworks are all barriers to the provision of good end-of-life care to patients in the ICU. The barriers we found with regard to attitude demonstrate that physicians often see it as their job to save lives and not to let people die in the best possible way. When they have to make decisions on the withholding or withdrawing of life-sustaining treatment, physicians prefer their own ideas and focus on narrow physiological, technical and clinical parameters rather than asking patients and their families about their preferences. This suggests the lack of a holistic view of the patient's situation and prevents an understanding of what the patient sees as in his or her own best interests. Because physicians are inclined to continue providing life-sustaining treatment, they ignore the harm this may inflict upon the

patient, ignore the patient's and family's wishes to stop treatment and ignore the fact that the patient is actually dying. This means that timely end-of-life discussions are no longer possible and that the patient's wishes and preferences for the last phase of life have not been respected and their suffering continues. Palliative care, if it is provided at all, is suspended until the very last moment.

Concerning team meetings and conflicts, when different team members have different opinions about life-sustaining treatment continuation, the opinion of the consultant that treatment should be continued takes precedence, even when other team members consider such treatment to be futile. This authoritarian attitude is a barrier that prevents the provision of good end-of-life care to patients in the ICU. When the family wants to continue futile treatment, physicians have concerns about fulfilling their legal obligations and follow these wishes. However, when the patient and family want to stop therapy, physicians often continue it although the law in many countries recognizes the right of the patient to refuse treatment. Enforcement of these laws seems to be deficient, and should be strengthened. Physician-related barriers to practice reveal that physicians lack confidence in their own judgment that treatment is futile and postpone decision making about withdrawal of life-sustaining treatment until all treatment options are exhausted and consider the family's request to continue futile life-sustaining therapy as mandatory, and that they do not consider communication and decision making in the last phase of the patient's life as a normal process, whereby the wishes of the family are discussed earlier and therefore during the last moments consensus can be achieved about the futility of the life-sustaining treatment.

We compared our findings with the findings of studies on barriers to communication in end-of-life care or advance care planning perceived by general practitioners, to find out if those reported by ICU physicians are specific to practice in ICUs. Some barriers were in line with the findings of a systematic review by Slort and colleagues on barriers for general practitioners, like GPs' (General Physician) lack of availability and knowledge about palliative care, unpredictability of the clinical course, not talking honestly about end-of-life care issues and practice barriers e.g. difficulty in dealing with patients in denial and not taking the initiative to contact patients spontaneously [51]. In a systematic review by De Vlemminck and colleagues on GP-barriers to engaging in advance care planning, doubt regarding the content and practical availability of living wills was identified as a barrier to initiating advance care planning [52]. However, the background of GPs and ICU physicians is quite different. The GPs are better trained in communication with the patient and in taking a holistic approach and might have a longstanding relationship with the patient and family. ICU physicians will not have that longstanding relationship but are confronted much more than GPs with patients in the last phase of life, often in a critical condition in which communication is already difficult. The findings of these two reviews and our review emphasize all the more the need to address the ICU physician-related barriers to communication with patients towards the end of life.

Our review has some limitations. The study has been done over the last ten years, excluding studies before 2003. During the last years however, much attention in the public and professional domains has been given to end-of-life care, especially in the ICU, and we expect that the most important barriers are included in the studies published during this period. The study was limited to English or Dutch language studies so there may be studies from other countries that are not included. Moreover, by limiting this review to barriers related to and reported by physicians, we excluded barriers perceived by nurses, patients, family members

and other care providers, as well as structural or institutional factors, so an overall perspective of barriers in the two quality domains could not be achieved here.

Our results suggest that ICU physicians need to be trained in a holistic approach and in communication competencies. Under- and postgraduate medical education already sees training in communication skills as essential, as well as training in the legal framework and ethical principles of health care, defining the role and competencies of the physician who cares for patients towards the end of life, but such training is often not yet fully implemented. Palliative care guidelines and support teams in ICUs could help the ICU team to trigger a learning process in caring for patients towards the end of life without the intention of handing over such care completely to the palliative care team. Such a palliative support team could also help the ICU team, meeting as an interdisciplinary team, addressing conflicts and different opinions.

Further research is needed to investigate interventions and to develop guidelines and protocols helpful to overcome ICU physician-related barriers regarding adequate communication and patient-centred decision making towards the end of life. Also research is needed into barriers related to and reported by patients, family members and other care providers, as well as into structural or institutional barriers.

## **Conclusions**

We identified 90 different barriers, reported by ICU-physicians themselves, that stand in their way to provide quality end-of-life care with respect to communication and decision making. These barriers are related to their knowledge, attitudes and practice. It is necessary to address these different barriers to improve the quality of end-of-life care for patients and their families in the ICU. In addition to the perspectives of the physicians, it is important to examine the barriers related and reported by patient and relatives, and other health care providers in the ICU.

## **Key messages**

- Ninety different physician-related barriers for quality communication and patient- and family-centred decision making in end-of-life care in ICU were identified, related to physicians' knowledge, attitudes and practice.
- Regarding knowledge, strong evidence was found for physicians' lack of training in communication skills with patients, families and colleagues, including communication of the futility of further treatment, as a barrier.
- Regarding attitudes, strong evidence was found for multiple barriers: Physicians' focus on the small percentage of patients who will survive and not on the larger number who will not and therefore have to undergo intensive care treatment before they die; Physicians' personal beliefs and values, and their focus on clinical and technical parameters only; Physicians' training to save the patient's life only, and narrow interpretation of when a patient is actually dying.
- Regarding practice, strong evidence was found for physicians' lack of confidence to take responsibility for the dying patient.
- These barriers need to be addressed to improve the quality of end-of-life care for patients and their families. Next to the physicians' perspectives, it is important to examine the

barriers related and reported by patient and relatives, and other health care providers in the ICU.

## Abbreviations

GP, General physician; ICU, Intensive care unit; QI, Quality indicator

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

MV and DH acquired and analysed the data. All authors contributed to the conception of the study, the interpretation of the data, drafting the manuscript and revising it critically for important intellectual content, and read and approved the final manuscript.

## Acknowledgements

We acknowledge Mrs. Jane Ruthven for English language editing.

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

## References

1. Teno JM, Gozalo PL, Bynum JP, Leland NE, Miller SC, Morden NE, Scupp T, Goodman DC, Mor V: **Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009.** *JAMA* 2013, **309**(5):470–477.
2. The SUPPORT Principal Investigators: **A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT).** *JAMA* 1995, **274**(20):1591–1598.
3. Piers RD, Azoulay E, Ricou B, Dekeyser Ganz F, Decruyenaere J, Max A, Michalsen A, Maia PA, Owczuk R, Rubulotta F, Depuydt P, Meert A, Reyners A, Aquilina A, Bekaert M, Van Den Noortgate N, Schrauwen W, Benoit D, for the APPROPRICUS Study Group of the Ethics Section of the ESICM: **Perceptions of appropriateness of care among European and Israeli intensive care unit nurses and physicians.** *JAMA* 2011, **306**(24):2694–2703.
4. Nelson JE, Cox CE, Hope AA, Carson SS: **Chronic critical illness.** *Am J Respir Crit Care Med* 2010, **182**(4):446–454.
5. Cox CE, Martinu T, Sathy SJ, Clay AS, Chia J, Gray AL, Olsen MK, Govert JA, Carson SS, Tulskey JA: **Expectations and outcomes of prolonged mechanical ventilation.** *Crit Care Med* 2009, **37**(11):2888–2894. quiz 2904.



6. Nelson JE, Puntillo KA, Pronovost PJ, Walker AS, McAdam JL, Ilaoa D, Penrod J: **In their own words: patients and families define high-quality palliative care in the intensive care unit.** *Crit Care Med* 2010, **38**(3):808–818.
7. **WHO Definition of Palliative Care.** <http://www.who.int/cancer/palliative/definition/en/>
8. Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, Spuhler V, Todres ID, Levy M, Barr J, Hirsch G, Armstrong D, American College of Critical Care Medicine Task Force 2004-2005, Society of Critical Care Medicine: **Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005.** *Crit Care Med* 2007, **35**(2):605–622.
9. **Defining Standards for ICU Palliative Care: A Brief Review from The IPAL-ICU Project.** <http://ipal.ccapc.org/downloads/ipal-icu-defining-standards-for-icu-palliative-care.pdf>
10. Nelson JE: **Identifying and overcoming the barriers to high-quality palliative care in the intensive care unit.** *Crit Care Med* 2006, **34**(11 Suppl):S324–S331.
11. Clarke EB, Curtis JR, Luce JM, Levy M, Danis M, Nelson J, Solomon MZ, Members RWJFCCE-O-LPW: **Quality indicators for end-of-life care in the intensive care unit.** *Crit Care Med* 2003, **31**(9):2255–2262.
12. Cabana MD, Rand CS, Powe NR, Wu AW, Wilson MH, Abboud PA, Rubin HR: **Why don't physicians follow clinical practice guidelines? A framework for improvement.** *JAMA* 1999, **282**(15):1458–1465.
13. **10 questions to help you make sense of qualitative research.** [http://media.wix.com/ugd/dded87\\_951541699e9edc71ce66c9bac4734c69.pdf](http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf)
14. **Critical appraisal of a survey.** <http://www.cebma.org/wp-content/uploads/Critical-Appraisal-Questions-for-a-Survey.pdf>
15. Pattison N, Carr SM, Turnock C, Dolan S: **‘Viewing in slow motion’: patients’, families’, nurses’ and doctors’ perspectives on end-of-life care in critical care.** *J Clin Nurs* 2013, **22**(9–10):1442–1454.
16. Gutierrez KM: **Advance directives in an intensive care unit: experiences and recommendations of critical care nurses and physicians.** *Crit Care Nurs Q* 2012, **35**(4):396–409.
17. Barnato AE, Tate JA, Rodriguez KL, Zickmund SL, Arnold RM: **Norms of decision making in the ICU: a case study of two academic medical centers at the extremes of end-of-life treatment intensity.** *Intensive Care Med* 2012, **38**(11):1886–1896.
18. Schenker Y, Tiver GA, Hong SY, White DB: **Association between physicians’ beliefs and the option of comfort care for critically ill patients.** *Intensive Care Med* 2012, **38**(10):1607–1615.

19. Jox RJ, Schaidler A, Marckmann G, Borasio GD: **Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians.** *J Med Ethics* 2012, **38**(9):540–545.
20. Baggs JG, Schmitt MH, Prendergast TJ, Norton SA, Sellers CR, Quinn JR, Press N: **Who is attending? End-of-life decision making in the intensive care unit.** *J Palliat Med* 2012, **15**(1):56–62.
21. Coombs MA, Addington-Hall J, Long-Suthehall T: **Challenges in transition from intervention to end of life care in intensive care: a qualitative study.** *Int J Nurs Stud* 2012, **49**(5):519–527.
22. Ahern SP, Doyle TK, Marquis F, Lesk C, Skrobik Y: **Critically ill patients and end-of-life decision-making: the senior medical resident experience.** *Adv Health Sci Educ Theory Pract* 2012, **17**(1):121–136.
23. Gehlbach TG, Shinkunas LA, Forman-Hoffman VL, Thomas KW, Schmidt GA, Kaldjian LC: **Code status orders and goals of care in the medical ICU.** *Chest* 2011, **139**(4):802–809.
24. Schwarze ML, Bradley CT, Brasel KJ: **Surgical “buy-in”: the contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy.** *Crit Care Med* 2010, **38**(3):843–848.
25. Corke C, Milnes S, Orford N, Henry MJ, Foss C, Porter D: **The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors.** *Crit Care Resusc* 2009, **11**(2):122–128.
26. Sibbald R, Downar J, Hawryluck L: **Perceptions of “futile care” among caregivers in intensive care units.** *CMAJ* 2007, **177**(10):1201–1208.
27. Beck S, van de Loo A, Reiter-Theil S: **A “little bit illegal”? Withholding and withdrawing of mechanical ventilation in the eyes of German intensive care physicians.** *Med Health Care Philos* 2008, **11**(1):7–16.
28. Baggs JG, Norton SA, Schmitt MH, Dombeck MT, Sellers CR, Quinn JR: **Intensive care unit cultures and end-of-life decision making.** *J Crit Care* 2007, **22**(2):159–168.
29. White DB, Braddock CH, Bereckneyei S, Curtis JR: **Toward shared decision making at the end of life in intensive care units: opportunities for improvement.** *Arch Intern Med* 2007, **167**(5):461–467.
30. Hsieh HF, Shannon SE, Curtis JR: **Contradictions and communication strategies during end-of-life decision making in the intensive care unit.** *J Crit Care* 2006, **21**(4):294–304.
31. Palda VA, Bowman KW, McLean RF, Chapman MG: **“Futile” care: do we provide it? Why? A semistructured, Canada-wide survey of intensive care unit doctors and nurses.** *J Crit Care* 2005, **20**(3):207–213.

32. West HF, Engelberg RA, Wenrich MD, Curtis JR: **Expressions of nonabandonment during the intensive care unit family conference.** *J Palliat Med* 2005, **8(4):797–807.**
33. Bülow HH, Sprung CL, Baras M, Carmel S, Svantesson M, Benbenishty J, Maia PA, Beishuizen A, Cohen S, Nalos D: **Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt study.** *Intensive Care Med* 2012, **38(7):1126–1133.**
34. Schimmer C, Gorski A, Özkur M, Sommer SP, Hamouda K, Hain J, Aleksic I, Leyh R: **Policies of withholding and withdrawal of life-sustaining treatment in critically ill patients on cardiac intensive care units in Germany: a national survey.** *Interact Cardiovasc Thorac Surg* 2012, **14(3):294–299.**
35. Kübler A, Adamik B, Lipinska-Gediga M, Kedziora J, Strozecki L: **End-of-life attitudes of intensive care physicians in Poland: results of a national survey.** *Intensive Care Med* 2011, **37(8):1290–1296.**
36. Weng L, Joynt GM, Lee A, Du B, Leung P, Peng J, Gomersall CD, Hu X, Yap HY, Group CCCE: **Attitudes towards ethical problems in critical care medicine: the Chinese perspective.** *Intensive Care Med* 2011, **37(4):655–664.**
37. Kranidiotis G, Gerovasili V, Tasoulis A, Tripodaki E, Vasileiadis I, Magira E, Markaki V, Routsis C, Prekates A, Kyprianou T, Clouva-Molyvdas PM, Georgiadis G, Floros I, Karabinis A, Nanas S: **End-of-life decisions in Greek intensive care units: a multicenter cohort study.** *Crit Care* 2010, **14(6):R228.**
38. Schaden E, Herczeg P, Hacker S, Schopper A, Krenn CG: **The role of advance directives in end-of-life decisions in Austria: survey of intensive care physicians.** *BMC Med Ethics* 2010, **11:19.**
39. Westphal DM, McKee SA: **End-of-life decision making in the intensive care unit: physician and nurse perspectives.** *Am J Med Qual* 2009, **24(3):222–228.**
40. Sprung CL, Woodcock T, Sjøkvist P, Ricou B, Bulow HH, Lippert A, Maia P, Cohen S, Baras M, Hovilehto S, Ledoux D, Phelan D, Wennberg E, Schobersberger W: **Reasons, considerations, difficulties and documentation of end-of-life decisions in European intensive care units: the ETHICUS Study.** *Intensive Care Med* 2008, **34(2):271–277.**
41. Collins N, Phelan D, Marsh B, Sprung CL: **End-of-life care in the intensive care unit: the Irish Ethicus data.** *Crit Care Resusc* 2006, **8(4):315–320.**
42. Nelson JE, Angus DC, Weissfeld LA, Puntillo KA, Danis M, Deal D, Levy MM, Cook DJ, Project CCPWotPEiE-o-LC: **End-of-life care for the critically ill: a national intensive care unit survey.** *Crit Care Med* 2006, **34(10):2547–2553.**
43. White DB, Curtis JR, Lo B, Luce JM: **Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers.** *Crit Care Med* 2006, **34(8):2053–2059.**

44. Moss AH, Demanelis AR, Murray J, Jack J: **Barriers to quality end-of-life care in West Virginia ICU units: physicians' and nurses' perspectives.** *W V Med J* 2005, **101**(5):200–204.
45. Cohen S, Sprung C, Sjokvist P, Lippert A, Ricou B, Baras M, Hovilehto S, Maia P, Phelan D, Reinhart K, Werdan K, Bulow HH, Woodcock TT: **Communication of end-of-life decisions in European intensive care units.** *Intensive Care Med* 2005, **31**(9):1215–1221.
46. Elo G, Diószeghy C, Dobos M, Andorka M: **Ethical considerations behind the limitation of cardiopulmonary resuscitation in Hungary—the role of education and training.** *Resuscitation* 2005, **64**(1):71–77.
47. Sinuff T, Cook DJ, Rocker GM, Griffith LE, Walter SD, Fisher MM, Dodek PM, Sjokvist P, McDonald E, Marshall JC, Kraus PA, Levy MM, Lazar NM, Guyatt GH: **DNR directives are established early in mechanically ventilated intensive care unit patients.** *Can J Anaesth* 2004, **51**(10):1034–1041.
48. Yap HY, Joynt GM, Gomersall CD: **Ethical attitudes of intensive care physicians in Hong Kong: questionnaire survey.** *Hong Kong Med J* 2004, **10**(4):244–250.
49. Hariharan S, Moseley HS, Kumar AY, Walrond ER, Jonnalagadda R: **Futility-of-care decisions in the treatment of moribund intensive care patients in a developing country.** *Can J Anaesth* 2003, **50**(8):847–852.
50. Garland A, Connors AF: **Physicians' influence over decisions to forego life support.** *J Palliat Med* 2007, **10**(6):1298–1305.
51. Slort W, Schweitzer BP, Blankenstein AH, Abarshi EA, Riphagen II, Echteld MA, Aaronson NK, van der Horst H, Deliens L: **Perceived barriers and facilitators for general practitioner-patient communication in palliative care: a systematic review.** *Palliat Med* 2011, **25**(6):613–629.
52. De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, Deliens L: **Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review.** *Scand J Prim Health Care* 2013, **31**(4):215–226.

## **Additional files provided with this submission:**

**Additional file 1.** Pubmed search strategy for Medline\*: Physician-related barriers to communication and patient and family-centred decision making towards the end of life in intensive care: a systematic review (14k)

<http://ccforum.com/content/supplementary/s13054-014-0604-z-s1.docx>