



Causes and consequences of disproportionate care in intensive care medicine

Erwin J.O. Kompanje^a, Ruth D. Piers^b, and Dominique D. Benoit^c

Purpose of review

Increased use of advanced life-sustaining measures in patients with poor long-term expectations secondary to more chronic organ dysfunctions, comorbidities and/or a poor quality of life has become a worrying trend over the last decade. This can lead to futile, disproportionate or inappropriate care in the ICU. This review summarizes the causes and consequences of disproportionate care in the ICU.

Recent findings

Disproportionate care seems to be common in European and North American ICUs. The initiation and prolongation of disproportionate care can be related to hospital facilities, healthcare providers, the patient and his/her representatives and society. This can have serious consequences for patients, their relatives, physicians, nurses and society.

Summary

Disproportionate care is common in western ICUs. It can lead to violation of basic bioethical principles, suffering of patients and relatives and compassion fatigue and moral distress in healthcare providers. Avoiding inappropriate use of ICU resources and disproportionate care in the ICU should have high priority for ICU managers but also for every healthcare provider taking care of patients at the bedside.

Keywords

avoidance behaviour, compassion fatigue, disproportionate care, futility, inappropriate care

INTRODUCTION

In intensive care medicine, patients are treated who are suffering from acute and life-threatening conditions resulting from acute dysfunction or failure of one or more vital organs. However, increased use of advanced life-sustaining measures in patients with poor long-term expectations secondary to more chronic organ dysfunctions, comorbidities and/or a poor quality of life has become a worrying trend over the last decade [1–5]. This can lead to futile, disproportionate or inappropriate care in the ICU. Seventy-three percent of European ICU physicians and 87% of Canadian ICU physicians declare that they frequently admit patients with unrealistic perspectives [6,7]. In another study, 27% of a total of 1651 interviewed ICU physicians and nurses declared that they had to treat at least one patient who received disproportionate care on the day of the study [8]. Furthermore, 60% indicated that similar situations were rather common in their units.

In addition, nowadays, spontaneous death has become rare in the ICU because of the use of technical life-sustaining measures, and most patients (in some European countries over 85%) die only when

the ICU physician, in consultation with all parties concerned, takes the decision to withdraw life-sustaining measures [9–13]. Different legal, ethical and cultural frameworks that prevail in different countries, together with more in-depth individual psychological factors in physicians and nurses [14], often lead to postpone end of life decision-making [15,16]. This can result in unnecessary suffering by patients and relatives [17,18], staff–family and staff–staff conflicts [19], compassion fatigue, avoidance behaviour and burnout among physicians and nurses [20–22,23^{***},24^{***},25,26^{***}] or high staff turnover [8]. In view of the high cost of ICU medicine,

^aErasmus MC University Medical Center Rotterdam, Department of Intensive Care Medicine, Rotterdam, The Netherlands, ^bDepartment of Geriatrics, Ghent University Hospital and ^cDepartment of Intensive Care, Medical Unit Ghent University Hospital, Ghent, Belgium

Correspondence to Erwin J.O. Kompanje, PhD, Erasmus MC University Medical Center Rotterdam, Department of Intensive Care Medicine, P.O. Box 2040, 3000 CA Rotterdam, The Netherlands. Tel: +31 6 53837655; fax: +31 10 7036978; e-mail: erwinkompanje@me.com

Curr Opin Crit Care 2013, 19:630–635

DOI:10.1097/MCC.000000000000026

KEY POINTS

- Disproportionate care in the ICU can have serious consequences for patients, their relatives, physicians, nurses and society.
- Disproportionate care in the ICU can lead to violation of basic bioethical principles, to prolonged suffering of patients and relatives and to moral distress, compassion fatigue and avoidance behaviour of healthcare providers.
- Avoiding inappropriate use of ICU resources and disproportionate care in the ICU should have high priority not only for ICU managers but also for every healthcare provider taking care of patients at the bedside.

this also entails significant financial implications for society [27,28].

DISPROPORTIONATE CARE IN THE ICU

We define inappropriate care in the ICU as ‘not proper, untimely’ use of all medical possibilities. Disproportionate care in the ICU not only as ‘excessive, too much or more than enough’, but also as ‘not enough’ and medical futility, all fall under our definition of inappropriate care in the ICU.

CAUSES OF DISPROPORTIONATE CARE IN THE ICU

The initiation or prolongation of disproportionate care in the ICU can be related to the following:

- (1) hospital facilities;
- (2) physicians and nurses;
- (3) the patient and his/her representatives;
- (4) society.

Related to hospital facilities

Sometimes, admission of patients in the ICU can be judged as inappropriate. Admission of patients who only require monitoring of vital signs can be judged as ‘too much’ in the sense of overuse or out of balance. These patients do not require ICU but need some more care and monitoring than provided in the regular ward. In some studies, this category of patients account for more than 20% [29]. Oxygen saturation and ECG monitoring can easily be facilitated on regular hospital wards or medium care units. Admitting such patients to high-level ICUs can be judged as inappropriate, mostly in relation to costs. Hospital executives are facing increasing pressure to reduce operating costs. This can be reached

by reducing ‘waste’ in clinical care. Waste can be considered as any activity or resource in an organization that does not add value to an external customer [30]. One component of ‘waste’ is the inappropriate use of ICU beds and resources. The patient’s and his/her relative’s time and efforts are wasted, caregiver’s time is wasted because he/she must provide care that could have been avoided or administered to another patient, and the hospital experiences waste as it incurs the added expense of this unnecessary care.

In a recent study, Almoosa *et al.* [31] identified that a significant proportion of ICU days may be unnecessary, and therefore contribute to ‘waste’. This was mainly due to delays in end-of-life decision-making and in discharge to the wards. It is mainly the responsibility of hospital executives to reduce costs and use of resources if this is not proportionate, although each individual healthcare provider may contribute to these efforts.

Related to physicians and nurses

It is sometimes difficult for the ICU physicians to resist the impulse for trying to rescue even the mortally ill or to decline ICU admission of patients with poor expectations against the will of referring physicians or relatives. The disproportionate deployment of highly skilled ICU physicians and ICU nurses and the use of sophisticated technology are usually explained on grounds that prognosis is uncertain. Important to note is that prognostic uncertainty is more often used by physicians to continue disproportioned care than other healthcare providers [6] who perceive physicians’ uncertainty as an alibi to postpone important decisions and honest, but also difficult, communication with the relatives. However, these admissions often result only in a brief reprieve or in prolonging life that is already compromised with regard to its quality. Furthermore, inexperienced junior doctors will in doubt admit patients with grim prognosis. In one study, this accounts for 10% of all patients admitted to an ICU [29]. The use of ICU resources and care in the ICU can in these cases be judged as disproportionate.

Physician–nurse interactions and conflicts

Conflicts in the ICU are common [19] and are mostly associated with the decision-making process and with withholding and withdrawing life-sustaining ICU measures. Delivery of futile care and communication of unrealistic prospects to patients and their families have been shown to be the principal causes of moral distress in ICU nurses [8,32,33]. One study shows that conflicts between staff and

patients' relatives and conflicts between staff members were identified in 48% on both sides. However, conflicts between nurses were rarely reported [34]. Effective nurse–physician collaboration is associated with significantly better clinical outcomes and lower disproportionate care in the ICU [35].

Limited autonomy and problematic interdisciplinary collaboration may inhibit nurses' ability to apply personal and professional moral reasoning, which can lead to compassion fatigue and moral distress [26¹¹]. In the case of disproportionate care in the ICU, nurses may perceive that the ability to exercise autonomy and moral values is limited. To care for patients who, in the perception of nurses, have no prospect of survival, can be extremely morally distressing, and can lead to compassion fatigue and burnout. It is noted that nurses think that information given by them eases relatives' worries, but they feel that in order to avoid conflicts with physicians they should restrain themselves from providing it [25,36,37]. On the contrary, critical care nurses have a significant responsibility in the care of patients and families of patients having withdrawn life support [38–42].

Related to patients and relatives

Sometimes, the relatives of patients who are too sick to benefit from admission to an ICU are willing to let the patient undergo invasive life-sustaining measures causing additional suffering for the patient. They can even be resistant to assent to withdrawal of these measures [23¹¹]. Rationing and triage are crucial, but uncommon in American ICUs. It is unusual to refuse admission, even in end-stage illness [43]. Legal, economic, ethical and religious factors may add to the complexity of the situation. Sometimes, relatives refuse to come to terms with the grim patient's condition, demanding disproportionate aggressive care, impeding proper management of the case [44]. Families of patients who die after withdrawal of life-sustaining ICU measures are in unique circumstances; there is usually short time to prepare for the death of the loved one, giving rise to resistance. To avoid conflicts or legal consequences, physicians and nurses are willing to prolong intensive care against their will, resulting in waste of time, efforts and resources and unnecessary suffering of the patient.

Much has to do with honest, transparent and compassionate communication prior to the decision to forego further life-sustaining measures [45,46]. Conflicts between physicians and nurses and relatives of the patient often are based on cultural and religious traditions [47]. They can

negatively affect the quality of decision-making and patient care, as well as the satisfaction of all the parties involved [34].

Related to society

Death as well as birth is a social necessity. Death is also inevitable. It is partly to blame the medical profession that the general public think this is not only the case [48] but also society itself is to blame. Birth is seen as a happy, death as a sad event. This is why religions think in terms of rebirth after death. In a time of human enhancement and technology-based interventions in the human body, society gladly believes in the illusion that medicine can do anything. Some patients are overoptimistic and concentrate on life at all costs rather than facing death [49]. Similarly, doctors are overoptimistic in their prognostication [50] and neglect to start advance care planning conversations in order not to be faced with their own emotions and discomfort to talk about death [51]. Intensive care medicine is good in keeping patients alive who would quite certainly have died in the natural course of events. Almost half of all patients who are treated in intensive care have end-stage disease and multiple morbidities [52,53]. Society expects that even individuals with multiple morbidities at the end of their physical life would be treated in our ICUs. One in five North Americans die using ICU services, many of them aged over the age of 65 [54]. This has its price. Terminal ICU hospitalizations are more expensive than non-ICU terminal hospitalizations. These admissions can be seen as a disproportionate use of ICU resources.

We must consider a cultural shift if we want to improve care near the end of life and safe costs of dying in the ICU. This requires rationing and more effective advance care planning that seems to be difficult in a high technological environment.

CONSEQUENCES OF THE PROLONGATION OF INAPPROPRIATE CARE IN THE ICU

Initiation and prolongation of disproportionate care in the ICU can lead to the following:

- (1) violation of basal ethical values;
- (2) patients' and relatives' suffering;
- (3) moral distress, avoidance behaviour; and
- (4) compassion fatigue in physicians and nurses.

Ethics violation

Initiation and prolongation of disproportionate use of ICU sources can lead to harm, injury and

injustice, and thus to violation of ethical principles. Harm includes causing physical harm, pain and disability, mental harm and setbacks in interests. Most patients in ICU are nonautonomous, and most physicians treat them as nonautonomous, not seeking for patient's consent and values before admission [14]. The ethical principle of nonmaleficence requires intentionally refraining from actions that cause harm. However, when inappropriate care in the ICU leads to harm, this is seldom intentionally or consciously caused. Physicians and nurses ought not to inflict harm, they should prevent harm, remove harm and promote the good. But, in patient care, they seldom have the perception that they cause harm, even when others judge the use of ICU resources as inappropriate. Some state that their intention is to help patients, but obligations not to harm others are clearly distinct from obligations to help others. Generally, obligations of nonmaleficence are more stringent than obligations of beneficence.

Disproportionate care in the ICU can give rise to injustice, referring to fair, equitable and appropriate distribution of scarce resources in society. Problems of distributive justice arise under conditions of scarcity and competition, as a consequence of prolongation of disproportionate use of scarce and costly ICU resources.

Patients' and relatives' suffering

Disproportionate care can lead to suffering of patients and their relatives. Many terminally ill patients do not wish to postpone their death [55,56] and wish to remain in control in order to complete things [57]. ICU admission means loss of that control and ignoring people's need to say goodbye to their loved ones. Furthermore, relatives of ICU patients are at high risk for anxiety and depressive conditions, including acute stress disorder, post-traumatic stress disorder and complicated grief [58,59]. Risk factors for these conditions are, among others, female sex, having younger relatives and a lower educational level. On the contrary, early palliative care has been associated with improved patient and family's well being [17] and even with improved survival in a non-ICU setting [60].

Moral distress and avoidance behaviour in critical care nurses and physicians

Moral distress arises when individuals perceive constraints that prevent action in accordance with moral choice [25,61,62^{***}]. Most moral distress in ICU nurses and physicians is related to situations

during end of life of patients [22,24^{***}]. Coping mechanisms to mitigate the effects of moral distress are necessary to enhance job satisfaction and retention and to avoid compassion fatigue and burnout to occur. Nurses experience conflict regarding these decisions, yet are expected to implement actions they perceive as morally wrong [23^{***},33,63,64]. Some studies show that moral distress escalates with time [25]. As such, moral distress may cause feelings of frustration and depression and may ultimately lead to burnout or job leave.

Providing care perceived as disproportionate does not only have impact on nurses' well being, but may also lower the quality of patients' care. It may lead them to avoid patients or use distancing (including depersonalization) as a negative coping strategy [23^{***},32,65^{***},66,67]. It is also noted that nurses think that information given by them eases relatives' worries, but they feel that in order to avoid conflicts with physicians they should restrain themselves from providing it [25,36,37]. Additionally, critical care nurses have a significant responsibility in the care of patients and families of patients having withdrawn life support [38–42].

ICU nurses describe negative consequences of moral distress for themselves, patients and families [24^{***}]. Avoidance behaviour is the absence of verbal, physical or social contact with patients. Many gradations exist [66]. Avoidance behaviour is however often very subtle in daily practice; for instance not entering the room of a patient with a grim prognosis because of 'so-called' other priorities, or entering the room, but, without discussing the patient's fears and wishes or even entering the room in order to discuss therapeutic measures that are unlikely to change the patient's course. These are all strategies in order not to be confronted with our powerlessness and own fears as healthcare providers [66]. Nurses' avoidance behaviour has frequently been reported and is associated with repeated exposure to morally distressing situations [23^{***},35]. As such, it is essential that moral distress in relation with disproportionate use of ICU resources be acknowledged and examined.

Compassion fatigue

Compassion fatigue is a state of emotional, physical, social and spiritual exhaustion from witnessing the suffering of others leaving the individual fatigued, overwhelmed, helpless and hopeless about one's situation of life, causing a pervasive decline in the person's desire, ability and energy to feel and care for others [67]. Compassion fatigue in professionals is referred to as the 'cost of caring', and is mostly studied in acute responders such as fire fighters,

social workers and emergency care nurses [67–69]. Compassion fatigue is also by some authors named ‘secondary traumatic stress disorder’ identifying the negative consequences as avoidance, anger, concentrating and sleeping difficulties and hypervigilance [69]. Compassion fatigue occurs when one cannot rescue or save an individual from harm, which results in distress [69,70]. Empathy and exposure to the event are the two concepts in compassion fatigue ICU physicians and ICU nurses are likely at risk for developing compassion fatigue. However, only one study is available studying compassion fatigue in critical care nurses, reporting a low occurrence [69]. In relation to inappropriate care in the ICU, compassion fatigue is two-fold of importance: caring for severely ill patients and feeling helpless in providing appropriate care can lead to compassion fatigue in individuals and teams, and caring for these patients holds the risk that physicians and nurses suffering from compassion fatigue can decide to withhold and withdraw life-sustaining measures on invalid grounds, leading to a self-fulfilling prophecy of poor prognosis and high mortality. Furthermore, compassion fatigue leads to higher turnover and decreased productivity, and can result in higher death rates and reduced patients’ safety. As moral distress can lead to compassion fatigue and moral distress is very often related to situations during end of life of patients [22,24[■]], prolongation of disproportionate use of ICU resources forms a real risk.

CONCLUSION

Disproportionate care seems to be common in European and North American ICUs. This can have serious consequences for patients, their relatives, physicians, nurses and society. It can lead to violation of basic bioethical principles, to prolonged suffering of patients and relatives and to moral distress, compassion fatigue and avoidance behaviour of healthcare providers. Avoiding inappropriate use of ICU resources and disproportionate care on the ICU should have high priority not only for ICU managers but also for every healthcare provider taking care of patients at the bedside.

Acknowledgements

None.

Conflicts of interest

D.D.B. received a senior clinical investigators grant from the Flemish Research Foundation, Belgium.
E.J.O.K. and R.D.P. declared no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

1. Angus DC, Barnato AE, Linde-Zwirble WT, *et al.*, Robert Wood Johnson Foundation ICU End-of-Life peer group. Use of intensive care at the end of life in the United States: an epidemiologic study. *Crit Care Med* 2004; 32:638–643.
 2. Wunsch H, Linde-Zwirble WT, Harrison DA, *et al.* Use of intensive care services during terminal hospitalizations in England and the United States. *Am J Respir Crit Care Med* 2009; 180:875–880.
 3. Ho TH, Barbera L, Saskin R, *et al.* Trends in aggressiveness of end of life cancer care in the universal healthcare system of Ontario, Canada. *J Clin Oncol* 2011; 29:1587–1591.
 4. Piers R, Benoit D, Schrauwen W, Van den Noorgate N. Do-not-resuscitate decisions in a large tertiary hospital: differences between wards and results of a hospital-wide intervention. *Acta Clinica Belgica* 2011; 66:116–122.
 5. Vincent JL. Forgoing life support in western European intensive care units: the results of an ethical questionnaire. *Crit Care Med* 1999; 27:1626–1633.
 6. 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; 20:207–213.
 7. Giannini A, Consonni D. Physicians’ perceptions and attitudes regarding inappropriate admissions and resource allocation in the intensive care setting. *Br J Anaesth* 2006; 96:57–62.
 8. Piers R, Azoulay E, Ricou B, *et al.*, APPROPRIUS study group of the ESICM. Perception of appropriateness of care among European and Israeli intensive care unit nurses and doctors. *JAMA* 2011; 306:2694–2703.
 9. Prendergast TJ, Luce JM. Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997; 155:15–20.
 10. Sprung CL, Cohen SL, Sjøkvist P, *et al.*, Ethicus Study Group. End-of-life practices in European intensive care units: the ETHICUS Study. *JAMA* 2003; 290:790–797.
 11. Bekaert M, Timsit J, Vansteelandt S, *et al.* Attributable mortality of ventilator associated pneumonia: a reappraisal using longitudinal causal analysis. *Am J Respir Crit Care Med* 2011; 185:1133–1139.
 12. Sprung CL, Woodcock T, Sjøkvist P, *et al.* Reasons, considerations, difficulties and documentation of end-of-life decisions in European intensive care units: the ETHICUS study. *Intensive Care Med* 2008; 34:271–277.
 13. Curtis JR, Vincent JL. Ethics and end of life care for adults in the intensive care unit. *Lancet* 2010; 376:1347–1353.
 14. Kets de Vries M. Sex, money, happiness and death. The quest for authenticity. The denial of death. UK: INSEAD Business Press; 2009; chapter 22. pp. 168–175.
 15. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members’ experiences of ‘wait and see’ as communication strategy in end-of-life decisions. *Intensive Care Med* 2011; 37:1143–1150.
 16. Jensen HI, Ammentorp J, Erlandsen M, Ording H. Withholding or withdrawing therapy in intensive care units: an analysis of collaboration among healthcare professionals. *Intensive Care Med* 2011; 37:1696–1705.
 17. Wright AA, Zhang B, Ray A, *et al.* Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008; 300:1665–1673.
 18. Kross EK, Engelberg RA, Gries CJ, *et al.* ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. *Chest* 2011; 139:795–801.
 19. Azoulay E, Timsit JF, Sprung C, *et al.* For the Conflicus study investigators Prevalence and determinants of intensive care unit conflicts. *Am J Respir Crit Care Med* 2009; 180:853–860.
 20. Embriaco N, Azoulay E, Barrau K, *et al.* High level of burnout in intensivists: prevalence and associated factors. *Am J Respir Crit Care Med* 2007; 175:686–692.
 21. Poncet MC, Toullic P, Papazian L, *et al.* Burnout syndrome in critical nursing staff. *Am J Respir Crit Care Med* 2007; 175:698–704.
 22. McClendon H, Buckner EB. Distressing situations in the intensive care unit: a descriptive study of nurses’ responses. *Dimensions Crit Care Nurs* 2007; 26:199–206.
 23. De Villers MJ, DeVon HA. Moral distress and avoidance behaviour in nurses ■ working in critical care and noncritical care units. *Nursing Ethics* 2012; 19:1–15.
- Description of the moral distress scale and impact of event scale.
24. Wiegand DL, Funk M. Consequences of clinical situations that cause critical ■ care nurses to experience moral distress. *Nursing Ethics* 2012; 19:479–487.
- Experiences and consequences of moral distress in end-of-life care in critical care nurses.
25. Moblely MJ, Rady MY, Verheijde JL, *et al.* The relationship between moral distress and perception of futile care in the critical care unit. *Intensive Care Nurs* 2007; 23:256–263.

26. Papathanassoglou DE, Karanikola MNK, Kalafati M, *et al.* Professional autonomy, collaboration with physicians and moral distress among European intensive care nurses. *Am J Crit Care* 2012; 21:e41–e52.
- The importance of autonomy, accountability and collaboration in critical care nursing.
27. Pronovost P, Angus DC. Economics of end-of-life care in the intensive care unit. *Crit Care Med* 2001; 29:N46–N51.
28. Zhang B, Wright AA, Haiden A, *et al.* Health care cost in the last week of life: associations with end of life conversations. *Arch Intern Med* 2009; 169:480–488.
29. El-Nabulsi BA, Holy M, Al-Suleihat A, Smadi S. Appropriateness of admissions to intensive care unit. *JRMS* 2005; 12:6–9.
30. Resar RK, Griffin FA, Kabcenell A, Bones C. Hospital inpatient waste identification tool. IHI innovation series white paper. Cambridge, Massachusetts: Institute for Healthcare Improvement; 2011.
31. Almoosa KF, Luther K, Patel B. Identifying 'waste' in the ICU. *Crit Care Med* 2011; 39:30.
32. Hamric AB, Blackhall LJ. Nurse–physician perspectives on the care of dying patients in intensive care units: collaboration, moral distress and ethical climate. *Crit Care Med* 2007; 35:422–429.
33. Corley MC, Minick P, Elswick RK, Jacobs M. Nurse moral distress and ethical work environment. *Nurs Ethics* 2005; 12:381–390.
34. Breen CM, Abernethy AP, Abbott KH, Tulsy JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *J Gen Intern Med* 2001; 16:283–289.
35. Pelieu I, Djadi-Prat J, Consoli SM, *et al.* Impact of organizational culture on preventability assessment of selected adverse events in the ICU: evaluation of morbidity and mortality outcomes. *Intensive Care Med* 2013; 39:1214–1220.
36. Asch DA, Shea JA, Jedrzejewski MK, Bosk CL. The limits of suffering: critical care nurses' views of hospital care at the end of life. *Soc Sci Med* 1997; 45:1661–1668.
37. Zaforteza C, Gastaldo D, De Pedro JE, *et al.* The process of giving information to families of critically ill patients: a field of tension. *Int J Nurs Studies* 2005; 42:135–145.
38. Kirchoff KT, Conradt KL, Anumandla PR. ICU nurses preparations of families for death of patients following withdrawal of ventilator support. *Appl Nurs Res* 2003; 16:85–92.
39. Fridh I, Forsberg A, Bergbom I. Doing one's utmost: nurses' descriptions of caring for dying patients in an intensive care environment. *Intensive Crit Care Nurs* 2009; 25:233–241.
40. McMillen RE. End of life decisions: nurses perceptions, feelings and experiences. *Intensive Crit Care Nurs* 2008; 24:251–259.
41. Ranse K, Yates P, Coyer F. End-of-life care in the intensive care setting: a descriptive exploratory qualitative study of nurses' beliefs and practices. *Austr Crit Care* 2012; 25:4–12.
42. Coombs MA, Addington-Hall J, Long-Sutehall T. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. *Int J Nurs Studies* 2012; 49:519–527.
43. Ward NS, Teno JM, Curtis JR, *et al.* Perceptions of cost constraints, resource limitations, and rationing in United States intensive care units: results of a national survey. *Crit Care Med* 2008; 36:471–476.
44. Molloy DW, Clarnette RM, Braun EA, *et al.* Decision making in the incompetent elderly: 'the daughter from California syndrome'. *J Am Ger Soc* 1991; 39:396–399.
45. Curtis JR, Ciechanowski PS, Downey L, *et al.* Development and evaluation of an interprofessional communication intervention to improve family outcomes in the ICU. *Contemp Clin Trials* 2012; 33:1245–1254.
46. Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *Gen Hosp Psych* 2010; 32:433–442.
47. Høye S, Severinsson E. Professional and cultural conflicts for intensive care nurses. *J Adv Nurs* 2010; 66:858–867.
48. Leach E. Society's expectations of health. *J Med Ethics* 1975; 1:85–89.
49. Knauft E, Nielsen EL, Engelberg RA, *et al.* Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest* 2005; 127:2188–2196.
50. Glare P, Virik K, Jones M, *et al.* Systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003; 327:195–198.
51. Eliasson AH, Parker JM, Shorr AF, *et al.* Impediments to writing do-not-resuscitate orders. *Arch Intern Med* 1999; 159:2213–2218.
52. Ho KM, Dobb GJ, Knuiman M, *et al.* The effect of socioeconomic status on outcomes for seriously ill patients: a linked data cohort study. *MJA* 2008; 189:26–30.
53. Esper AM, Martin GS. The impact of comorbid conditions on critical illness. *Crit Care Med* 2011; 39:2728–2735.
54. Angus DC, Barnato AE, Linde-Zwirble WT, *et al.* Use of intensive care at the end of life in the United States: an epidemiologic study. *Crit Care Med* 2004; 32:638–643.
55. Singer PA, Martin DK, Kelner M. Quality end-of-life care – patients' perspectives. *JAMA* 1999; 281:163–168.
56. Steinhauser AE, Christakis NA, Clipp EC, *et al.* Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284:2476–2482.
57. Heyland DK, Dodek P, Rocker G, *et al.* What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006; 174:627–633.
58. Wright AA, Zhang B, Ray A, *et al.* Association between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008; 300:1665–1673.
59. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. *Crit Care Med* 2012; 40:618–624.
60. Temel JS, Greer JA, Muzikansky A, *et al.* Early palliative care for patients with metastatic non-small-cell lung cancer. *N Eng J Med* 2010; 363:733–742.
61. Rushton CH. Defining and addressing moral distress. *AACN Adv Crit Care* 2006; 17:161–168.
62. St Ledger U, Begley A, Reid J, *et al.* Moral distress in end-of-life care in the intensive care unit. *J Adv Nurs* 2012; 69:1869–1880.
- Moral distress in relatives of ICU patients, ICU nurses and intensivists.
63. Cavaliere TA, Daly B, Dowling D, Montgomery K. Moral distress in neonatal intensive care unit RNs. *Adv Neonatal Care* 2010; 10:145–156.
64. Corley MC. Nurse moral distress: a proposed theory and research agenda. *Nurs Ethics* 2002; 9:636–650.
65. Fernandez-Parsons R, Rodriguez L, Goyal D. Moral distress in emergency nurses. *J Emerg Nurs* 2013. [Epub ahead of print]
- Moral distress in 51 emergency nurses.
66. Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA* 2001; 286:3007–3014.
67. Figley CR, editor. *Compassion fatigue*. New York, London: Routledge; 1995.
68. Yoder EA. Compassion fatigue in nurses. *Appl Nurs Res* 2010; 23:191–197.
69. Maiden J, Georges JM, Connelly CD. Moral distress, compassion fatigue, and perceptions about medication errors in certified critical care nurses. *Dimens Crit Care Nurs* 2011; 30:339–345.
70. Beck CT. Secondary traumatic stress in nurses: a systematic review. *Arch Psych Nurs* 2011; 25:1–10.