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## End-of-life care: An update

BY GRAEME ROCKER MHS<sub>C</sub>, DM, FRCP

The last several years have seen welcome improvements in our understanding of end-of-life care in the ICU. Current public and scholarly interest in death and dying is reflected by a substantial increase in related publications and by improved opportunities for professional development at medical conferences with sessions dedicated to this topic. Two recently published books will serve as valuable resources for any ICU practitioner whose day-to-day activities include preparing patients and families for impending death when other goals of medical care cannot be achieved. Randy Curtis and Gordon Rubenfield's *Managing death in the intensive care unit: The transition from cure to comfort* and John Heffner and Ira Byock's *Palliative and End-of-Life Pearls* are full of practical advice on the approach to both usual and unusual and/or contentious circumstances that all physicians face from time to time.<sup>1,2</sup> In this issue of *Critical Care Rounds*, the following specific aspects of our improved understanding of end-of-life care in the ICU will be reviewed:

- Working towards achieving a “good death”
- Quality end-of-life care
- Planning ahead
- Families witnessing cardio-pulmonary resuscitation
- End-of-life skills for physicians: Insights from interviewing patients
- National and international initiatives

### Working towards achieving a ‘good death’

Several themes have permeated writings about end-of-life care in the ICU in the last few years. We recognize the increasing frequency with which treatment (but not care) is withheld or withdrawn prior to death.<sup>3</sup> Position papers have been written by various professional associations, including the Canadian Critical Care Society (CCCS),<sup>4</sup> addressing ethical and medico-legal aspects of end-of-life care in the ICU. Others have addressed the need to incorporate the principles of palliative care into the ICU.<sup>5,6</sup> Children die in ICUs less often than adults, but the burden of decision-making and the burden of grief upon families is huge.<sup>7</sup>

Nonetheless, insight has been gained into models and/or concepts of end-of-life decision-making<sup>8</sup> (Figure 1). By talking more about it, there should be less fear of confronting the reality of death or the need to provide a ‘good death’ when technological support cannot succeed.<sup>9</sup> In a recent *British Medical Journal* editorial, Richard Smith tabulated the elements that should constitute a good death (Table 1).<sup>10</sup> These elements apply to the ICU, as well as to situations elsewhere in the hospital. Members of the CCCS should ask themselves whether there are barriers to providing these elements in their own ICUs and seek ways to overcome them.



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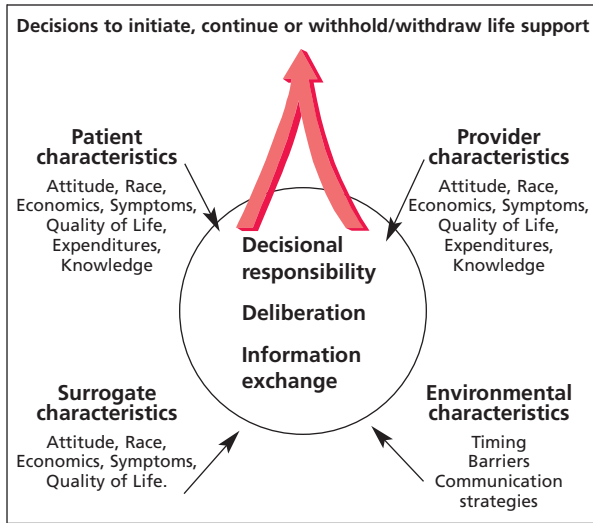
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**Figure 1: Conceptual framework for decision making in the ICU**



Meanwhile, several research groups have addressed cultural issues<sup>11</sup> and some of the biases that influence whether and how life support is withdrawn.<sup>12-14</sup> Death in the ICU can be viewed as a process rather than an event, a process during which the ICU team, the patient, and the family/substitute decision-maker reach consensus after a period of “negotiation” and mutual acceptance of the changing goals of care. During this process of negotiation, life support technologies are often utilized to provide the best death possible for the patient, while at the same time providing the best possible experience of this death from aesthetic, ethical, and social perspectives for the family and healthcare team.<sup>15</sup> Using qualitative approaches, research programs have sought to describe the experiences of participants in these end-of-life discussions. These programs have taught us a great deal about “why” and “how” we choose to use, or not use, various interventions in the ICU.<sup>15</sup> Cook and colleagues have done us a great service by not only advancing our understanding of the meaning and purpose of provision or withdrawal of life support technology, but also by highlighting the challenges we have to face when considering the utility and validity of decision-aids such as advance directives in such complex environments as the ICU.<sup>15</sup>

### Quality end-of-life care

Increasing interest in the provision of quality end-of-life care has provided the stimulus to many individual CCCS members, their institutions, and the wider research community to measure not just outcomes, but the perceptions of these outcomes from the perspectives of the next of kin. Until recently, studies on family satisfaction with care in the ICU have been few in number and limited in

**Table 1: Principles of a good death<sup>10</sup>**

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives, which ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

scope. Satisfaction with care provided to the critically ill patient is an important construct that cannot be measured by traditional family needs assessments. For example, a recent survey of 76 families of critically ill patients suggested that up to one-half of the families experienced inadequate communication with healthcare providers.<sup>16</sup> This claim was based on assessments of the families’ comprehension of what the physician communicated in family meetings. While 54% of the families interviewed had poor comprehension of what was said, half did not ask for more information. Whether lack of comprehension about what physicians say significantly affects satisfaction with care remains to be determined.

In an effort to address these issues, a research program, lead by Daren Heyland at Queens University, has determined the factors that families of surviving and nonsurviving patients rate as important to their perception of good quality care. A validated questionnaire (in 6 Canadian tertiary care ICUs) was provided to family members who made at least one visit to an ICU patient who had been mechanically ventilated for > 48 hours. The questionnaires were received by 1123 family members; 789 were returned (70.3% response rate). The results confirmed that respondents were least satisfied with communication with physicians (only 37% of respondents rated frequency of physician communication as excellent). They were most satisfied with communication with nurses (59% of respondents scored frequency of nursing communication as excellent).<sup>17</sup> This kind of result should be a stimulus for all

physicians to review their practices and make improvements where needed.

Another aspect of this research program probed the preferred model of decision-making for family members. The majority of respondents preferred sharing decisional responsibility with physicians and were satisfied overall with their role in the decision-making experience. Very few wanted to take sole responsibility for decision-making. Variables that contributed the most to satisfaction with decision-making included:

- feeling completely satisfied with the level or amount of healthcare the patient received
- completeness of information
- feeling support through the decision-making experience.<sup>18</sup>

Accordingly, physicians should take care that their verbal and non-verbal communications do not place undue burdens of decisional responsibility on family members. For example, some physicians routinely lay out the treatment options (including withdrawal of life support) and then ask the family (or the patient), “What do you want us to do?” This approach increases the decisional burden experienced by those who desire a shared or more passive role. Families participating in decision-making in the ICU setting already face considerable psychological burdens, both before<sup>19</sup> and after death.<sup>20</sup> These burdens may influence the consensus building process and may contribute to conflict. Healthcare teams in the ICU seeking to increase their understanding of these issues should familiarize themselves with processes that can help improve communication and avoid and/or resolve conflict.<sup>21</sup>

### Planning ahead

Quill has recently described how to initiate end-of-life discussions with seriously ill patients.<sup>22</sup> He reminds us that, “When physicians provide their patients with the honesty, expertise, compassion, and commitment they would want for themselves and their families, they provide the highest quality medical care possible.” He goes on to conclude, “There is little or nothing to lose in initiating palliative care discussions earlier and more systematically in a patient’s final trajectory, and so much is lost when these discussions are avoided.”<sup>22</sup>

To achieve such goals, physicians need to plan adequately in advance to make decisions with patients rationally, when the situation is stable and not in a crisis. A large body of literature exists about advance care planning for situations that might precipitate an ICU admission. For example, a recent overview by Martin and colleagues reviews the goals of care and the types of available advance directives and assesses their utility/validity.<sup>23</sup>

Unfortunately, efforts in advance care planning often fall short. Indeed, a recent publication from a Canadian-led international study underscored the failure of physicians to adequately address – in advance – the wishes and preferences of patients admitted to an ICU.<sup>24</sup> Explicit directives were recorded most frequently for patients who were seriously ill, elderly, and with primary medical (rather than surgical) diagnoses. However, fully 90% of approximately 3000 patients admitted to 15 ICUs in 4 countries did not have explicit resuscitation directives.<sup>24</sup> Previous work by Canadian investigators documented that only 6% of patients at high risk of death in the ICU had life-support preferences addressed within 24 hours of admission, while 43% had initial life-support discussions after, rather than before, cardiac arrest and resuscitation.<sup>25</sup> For ICU patients for whom directives are not established, CPR would be appropriate if this is what they would want. However, half the patients in a large international study with explicit directives chose not to be resuscitated.<sup>24</sup> In short, if these issues are not discussed with patients, their values and preferences are not understood.

It appears that most patients wish to have the opportunity to discuss end-of-life care. A recent study documented that although nearly all patients in a cardiopulmonary rehabilitation program wanted a patient-physician discussion about life support, these discussions had actually taken place for only 15% of patients.<sup>26</sup> Of concern, only 14% of patients thought that their physicians understood their wishes in regard to end-of-life care. Patients’ self-reported levels of comfort with discussions about advance directives and intubation are illuminating and appear in Table 2.

There are many barriers to effective advance care planning; however, none are insurmountable. Issues or concerns in regard to hope, trust, realistic prognoses, familiarity with wishes among families/surrogates, insufficient time for discussions can all be addressed if the will is

**Table 2: Patients and their perceptions of end-of-life discussions<sup>26</sup>**

<b>Patients would find discussions about:</b>		
	<b>Advance directives</b>	<b>Intubation and mechanical ventilation</b>
Acceptable	99.1%	99%
Informative	26.7%	26.7%
Informative and reassuring	50.5%	53.5%
Anxiety provoking but worthwhile	21.9%	19.1%
Too anxiety-provoking to pursue	0.9%	0.9%

there. Advance care plans or directives of any kind need to be subject to ongoing review, including an understanding of the rigidity or flexibility of such directives in specific circumstances.

### Families witnessing CPR

Many of us have shared anecdotal accounts about our experiences of families staying at the bedside during cardiopulmonary resuscitation (CPR). Though some adult intensivists may be resistant, our pediatric colleagues have been far more willing to accept this concept. Ellen Tsai addressed this recently in a *New England Journal of Medicine* Sounding Board article<sup>27</sup> where we are reminded that far more families wish to be present at CPR than have the opportunity to do so. We need to come to terms with our own biases and discomforts and probe the justification for excluding families from situations, however stressful, when it appears likely that a benefit will ensue.<sup>28</sup> As Tsai points out, “it isn’t that long ago that fathers were less than welcome in the delivery room.”<sup>27</sup>

### End-of-life skills for physicians: Insights from interviewing patients

Much progress has been made recently by the conduct of qualitative studies of patients’ perspectives of end-of-life care away from the ICU.<sup>29</sup> For example, patients with chronic obstructive pulmonary disease (COPD) have indicated the skills they think physicians need in order to provide high quality end-of-life care.<sup>30</sup> The most important domains were the ability to provide emotional support, to communicate, to be accessible, and to provide continuity of care. In addition, it was felt that it was important for physicians to provide patient information in 5 content areas:

- diagnosis and disease process
- treatment
- prognosis
- what dying might be like
- advance care planning.<sup>30</sup>

In contrast, in a UK study, 30% of patients with COPD felt diagnostic information was either lacking or was provided insensitively and 78% felt that they did not have enough information about their own prognosis and issues related to future management.<sup>31</sup> Of particular concern, 26% did not know that their disease was fatal.<sup>31</sup> These are the kinds of studies that should lead to a better understanding of the obligation of physicians to ensure that patients – whose deaths are not unexpected – have opportunities to

discuss their preferences for intervention or otherwise, and to do so in a timely fashion in advance of a crisis. Unplanned crises may precipitate unwanted or unwarranted admission to an ICU.

### National and international initiatives

We can be rightly proud of the contribution that Canadian intensivists have made to the literature on end-of-life care, and several members of the CCCS are involved in events or initiatives that continue to shape and influence the approach to death in the ICU. For example, The Robert Wood Johnson Foundation (<http://www.rwjf.org>) Critical Care Peer Working Group (for excellence in end-of-life care) has taken an interdisciplinary approach to developing standards for excellence that will remain influential in North American and Canadian circles for many years to come. The Anderson Foundation (<http://www.mdanderson.org>), is committed to improving the skills of physicians in end-of-life care using web-based educational modules and practical workshops. Various high impact journals (eg, *JAMA* 2000;284(19), *The Journal of Palliative Care* 2000;(16), and *Critical Care Medicine* 2001;29(12)) have recently published thematic end-of-life editions. Task forces of professional organizations (eg, The Society of Critical Care Medicine and The American Thoracic Society) continue to work on end-of-life issues. Meanwhile an NHRDP-funded multi-centre study is underway in Canada to determine what quality end-of-life care looks like from the perspective of the seriously ill hospitalized patient. These are all welcome additions to the changing landscape of end-of-life care.

### Conclusion

In 1985, a UK theologian addressed the realities of dying in the ICU as follows, “The success of intensive care is not, therefore, to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death.”<sup>32</sup> Perhaps this is a modern-day version of Seneca’s “The wise man should live as long as he ought, not as long as he can.” Our challenge for the first part of the new millennium is to recognize when our patients are dying and to work with patients and families to make the transition from cure to comfort care as seamless as possible.

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## Abstracts of Interest

### Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and healthcare workers.

CURTIS JR, WENRICH MD, CARLINE JD, SHANNON SE, AMBROZY DM, RAMSEY PG.

**BACKGROUND:** A framework for understanding and evaluating physicians' skills at providing end of life care from the perspectives of patients, families, and health care workers will promote better quality of care at the end of life.

**OBJECTIVE:** To develop a comprehensive understanding of the factors contributing to the quality of physicians' care for dying patients.

**DESIGN:** Qualitative study using focus groups and content analysis based on grounded theory.

**SETTING:** Seattle, Washington.

**PARTICIPANTS:** Eleven focus groups of patients with chronic obstructive pulmonary disease, AIDS, or cancer (79 patients); 3 groups of family members who had a loved one die of chronic disease (20 family members); 4 groups of nurses and social workers from hospice or acute care settings (27 health care workers); and 2 groups of physicians with expertise in end-of-life care (11 physicians).

**RESULTS:** We identified 12 domains of physicians' skills at providing end-of-life care: accessibility and continuity; team coordination and communication; communication with patients; patient education; inclusion and recognition of the family; competence; pain and symptom management; emotional support, personalization; attention to patient values; respect and humility; and support of patient decision making. Within these domains, we identified 55 specific components of physicians' skills. Domains identified most frequently by patients and families were emotional support and communication with patients. Patients with the 3 disease groups, families, and healthcare workers identified all 12 domains. Investigators used transcript analyses to construct a conceptual model of physicians' skills at providing end-of-life care that grouped domains into 5 categories.

**CONCLUSIONS:** The 12 domains encompass the major aspects of physicians' skills at providing high-quality end-of-life care from the perspectives of patients, their families, and health care workers, and provide a new framework for understanding, evaluating, and teaching these skills. Our findings should focus physicians, physician-educators, and researchers on communication, emotional support, and accessibility to improve the quality of end-of-life care.

*J Gen Intern Med* 2001;16(1):41-9.

### **Cardiopulmonary resuscitation directives on admission to intensive-care unit: an international observational study.**

COOK DJ, GUYATT G, ROCKER G, SJOKVIST P, WEAVER B, DODEK P, ET AL.

**BACKGROUND:** Resuscitation directives should be a sign of patient's preference. Our objective was to ascertain prevalence, predictors, and procurement pattern of cardiopulmonary resuscitation directives within 24 h of admission to the intensive-care unit (ICU).

**METHODS:** We enrolled 2916 patients aged 18 years and older from 15 ICUs in four countries, and recorded whether, when, and by whom their cardiopulmonary resuscitation directives were established. By polychotomous logistic regression we identified factors associated with a resuscitate or do-not-resuscitate directive.

**FINDINGS:** Of 2916 patients, 318 (11%; 95% CI 9.8-12.1) had an explicit resuscitation directive. In 159 (50%; 44.4-55.6) patients, the directive was do-not-resuscitate. Directives were established by residents for 145 (46%; 40.0-51.3) patients. Age strongly predicted do-not-resuscitate directives: for 50-64, 65-74, and 75 years and older, odds ratios were 3.4 (95% CI 1.6-7.3), 4.4 (2.2-9.2), and 8.8 (4.4-17.8), respectively. APACHE II scores greater than 20 predicted resuscitate and do-not-resuscitate directives in a similar way. An explicit directive was likely for patients admitted at night (odds ratio 1.4 [1.0-1.9] and 1.6 [1.2-2.3] for resuscitate and do-not-resuscitate, respectively) and during weekends (1.9 [1.3-2.7] and 2.2 [1.5-3.2], respectively). Inability to make a decision raised the likelihood of a do-not-resuscitate (3.7 [2.6-5.4]) than a resuscitate (1.7 [1.2-2.3]) directive ( $p=0.0005$ ). Within Canada and the USA, cities differed strikingly, as did centres within cities.

**INTERPRETATION:** Cardiopulmonary resuscitation directives established within 24 h of admission to ICU are uncommon. As well as clinical factors, timing and location of admission might determine rate and nature of resuscitation directives.

*Lancet* 2001;358(9297):1941-1945.

### **Life support in the intensive care unit: a qualitative investigation of technological purposes.**

CANADIAN CRITICAL CARE TRIALS GROUP. COOK DJ, GIACOMINI M, JOHNSON N, WILLMS D.

**BACKGROUND:** The ability of many intensive care unit (ICU) technologies to prolong life has led to an outcomes-oriented approach to technology assessment, focusing on morbidity and mortality as clinically important end points. With advanced life support, however, the therapeutic goals sometimes shift from extending life to allowing life to end. The objective of this study was to understand the purposes for which advanced life support is withheld, provided, continued or withdrawn in the ICU.

**METHODS:** In a 15-bed ICU in a university-affiliated hospital, the authors observed 25 rounds and 11 family meetings in which withdrawal or withholding of advanced life support was addressed. Semi-structured interviews were conducted with 7 intensivists, 5 consultants, 9 ICU nurses, the ICU nutritionist, the hospital ethicist and 3 pastoral services representatives, to discuss patients about whom life-support decisions were made and to discuss life-support practices in general. Interview transcripts and field notes were analysed inductively to identify and corroborate emerging themes; data were coded following modified grounded theory techniques. Triangulation methods included corroboration among multiple sources of data, multidisciplinary team consensus, sharing of results with participants and theory triangulation.

**RESULTS:** Although life-support technologies are traditionally deployed to treat morbidity and delay mortality in ICU patients, they are also used to orchestrate dying. Advanced life support can be withheld or withdrawn to help determine prognosis. The tempo of withdrawal influences the method and timing of death. Decisions to withhold, provide, continue or withdraw life support are socially negotiated to synchronize understanding and expectations among family members and clinicians. In discussions, one discrete life support technology is sometimes used as an archetype for the more general concept of technology. At other times, life-support technologies are discussed collectively to clarify the pursuit of appropriate goals of care.

**CONCLUSIONS:** The orchestration of death involves process-oriented as well as outcome-oriented uses of technology. These uses should be considered in the assessment of life-support technologies and directives for their appropriate use in the ICU.

*CMAJ* 1999;161(9):1109-13.

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