

# **Life support in the intensive care unit: a qualitative investigation of technological purposes (Deborah J. Cook, MD\*, Mita Giacomini, PhD, Nancy Johnson, MA, Dennis Willms, PhD and For the Canadian Critical Care Trials Group)**

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Abstract*

## **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of this study was to understand the purposes for which advanced life support is withheld, provided, continued or withdrawn in the ICU.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support can be withheld or withdrawn to help determine prognosis.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.

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Critical care medicine provides 2 major services for seriously ill patients: intense and sometimes invasive diagnosis and monitoring, to allow early recognition and treatment of biomedical problems, and advanced life support, to improve the short, and possibly long-term survival of patients with exigent, life-threatening illness.<sup>1</sup> Critical care medicine uses state-of-the-art technology to pursue its mission.

The dramatic 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.<sup>2</sup> In the case of advanced life support, however, the therapeutic goals sometimes shift from extending life to allowing life to end. Recent Canadian health research has shifted from matters of life-support administration to issues in life-support discontinuation.<sup>3-7</sup> Concurrent with this trend are qualitative investigations into end-of-life decision-making<sup>8-10</sup> and understanding the ICU as a social world,<sup>11,12</sup> as well as calls to assess the ethical and social influences of biomedical technologies.<sup>13,14</sup> However, biomedical, evaluative, ethical and social science studies of life-support technology remain poorly integrated.

These combined disciplinary perspectives can be used to examine the diverse purposes of life-support technologies as they are used in practice. "Real" technological purposes can then be addressed more explicitly in assessment exercises.<sup>15,16</sup> The objective of our study was to explore the purposes for which advanced life support is used in the care of critically ill, dying patients who are unable to make their own decisions.

## **Methods**

The descriptive aim of the research, and the social nature of the subject matter, called for a qualitative, naturalistic approach to inquiry.<sup>17</sup> The study was conducted over 14 months in the 15-bed closed ICU of St. Joseph's Hospital, Hamilton, Ont. In 1-week blocks 52 full-time nurses, 25 part-time nurses and 7 intensivists attend the ICU; every 2 months, 4 junior residents rotate through the ICU. We observed 25 ICU rounds and 11 family meetings during which withdrawal or withholding of advanced life support was discussed. Eleven cases of life-support decision-making were observed. Extensive field notes were recorded. Semi-structured interviews were also conducted with the 7 intensivists, 5 consultants, 9 nurses, the ICU nutritionist, the hospital ethicist and 3 pastoral services representatives. Interviewees were purposely selected on the basis of their involvement with patients from whom life support technology was withheld or withdrawn during the study period. We were unable to communicate with ICU patients about whom life support decisions were made because of their cognitive status or level of sedation. Interviews addressed patients about whom advanced life support was discussed, as well as life-support practices and issues in general. Interviews were audiotaped and transcribed verbatim.

Transcripts of the interviews and field notes were managed using qualitative research software. Qualitative analysis focused on interpreting the meaning of participants' discussions and actions regarding end-of-life decision-making. Transcripts and field notes were analysed inductively to identify and corroborate emerging themes. Data were coded following modified grounded theory techniques;<sup>18-20</sup> the coding scheme was revised and refined over the course of the study. We audiotaped investigator meetings, and these transcripts became part of the database. Several triangulation methods<sup>21</sup> were used to validate key findings: corroboration among multiple sources of data, multidisciplinary team consensus (the research team included 1 intensivist, 2 medical anthropologists and 1 policy analyst) and sharing of results with participants for veracity of interpretations. Theory triangulation (relating the findings to those of published studies on similar problems, concepts and

settings) was used to contextualize the findings and guide later stages of the analysis. The human subjects protocol for this project was approved by the St. Joseph's Hospital and McMaster University Research Ethics Boards. Participation was voluntary, and informed consent was obtained from participants. Confidentiality and data security measures were also reviewed with participants in the consent process.

## **Results**

Life support is characterized by the use of a panoply of technologies and myriad decisions that unfold over the course of an ICU stay. For patients who eventually die, the administration and withdrawal of life support is particularly complex. Decisions to withdraw life support barely resemble the popular imagery of "pulling the plug." Withdrawal is not a decisive event but, rather, an unfolding process. The metaphor of the "orchestration" of death describes the process of determining which life-support technologies come into play, to what ends, when, by whom and for whom. Life-support technologies are instrumental beyond reducing morbidity or preventing mortality. In the context of end-of-life decision-making, clinicians use technology to orchestrate the "best" death possible for critically ill patients under difficult circumstances. This goal is concerned less with health outcomes in the traditional sense than it is with the aesthetic, ethical and social experiences of those involved in the patient's care (e.g., significant others, family members and clinicians). In this context, technologies might be considered as analogous to orchestral instruments for expressing values and visions, as well as clinical instruments for producing health.

### ***Technological silence for prognostication***

Patients receiving advanced life support often have unclear diagnoses and prognoses, particularly early in the course of their illness. Life support is continued while prognostic uncertainty is addressed. Clinicians often speak of waiting for patients to "declare themselves," that is, for clearer prognostic signs to manifest.

The physician may spend a lot of time talking to families, trying to get them to understand that this patient is not going to make it. Sometimes, the family never does give in, but then the patient declares himself and just starts to deteriorate anyway, and the physician tells the family, "there is nothing else we can do." [interview with ICU nurse]

Life-support technology can also be withdrawn for prognostic purposes or stopped on a trial basis. The ensuing technological silence creates an opportunity for patients to declare themselves. Dialysis may be discontinued to determine whether renal failure will reverse. Mechanical ventilation may be stopped to assess whether spontaneous breathing can be sustained.

[The patient] was extubated on Friday and did okay over the evening, but by early

Saturday he had tuckered out and required reintubation, and then Monday he was extubated again. This time he lasted only two hours. Again, it didn't appear that he was ready for extubation. His parameters, weaning-wise, never really looked that good, but it was sort of ... "Well, let's just see how he does." [interview with ICU resident]

### **The tempo of life support and dying**

The withholding or withdrawal of life support can be orchestrated to occur quickly or slowly, changing the tempo of dying.

What appears to be happening really varies among staff persons as to how people are extubated. Some people are very aggressive and just take the tube out and see how they do. If they're going to make it, they'll make it. Other people are more conservative in a sense, using a stepwise approach and slowly bringing down the pressure and stuff like that. There were three different ways this person could be extubated, so it varies. [interview with ICU resident]

The pace at which life-support technologies are withdrawn, and the sequential order of withdrawal, may be influenced by many concerns. These include the potential suffering experienced by the patient, vicarious suffering experienced by others and the speed of the consequent death.

Some people walk in and yank the endotracheal tube and others will say "let's stop the drugs, let's stop the oxygen." I have trouble yanking out the endotracheal tube probably because I think that it increases the chances that the patient is going to die actively trying to breathe against an obstructed airway. I don't think that's a nice way to die. I find it a little tougher to do that than to say, "I think if we turn off the drug he's not going to last very long." For me, personally, it's a lot easier to turn off the drug. I guess it relates to how I see the patient's comfort. [interview with intensivist]

Practice variations with respect to terminal weaning or ventilator withdrawal have long been recognized but only recently publicized.<sup>22</sup> The observation that life support is withdrawn sequentially, rather than all at once, is supported by findings from a retrospective multicentre US study.<sup>23</sup> Other research suggests that physicians preferentially withdraw forms of life support that are scarce, expensive, invasive, artificial or emotionally taxing.<sup>24</sup>

Life-support technologies in the ICU may be applied continuously (e.g., mechanical ventilation for respiratory failure) or intermittently (e.g., hemodialysis for renal failure). Interventions may also be sequenced, such as the alternation of defibrillation with pharmacology in cardiac resuscitation protocols. The rhythmic nature of these acts is often overlooked as a feature of life-support decision-making. Orchestration

decisions concern how long, how often and whether to use a particular technology.

### **Harmonizing expectations and decisions**

Hours or days may pass from the time a patient's condition irretrievably worsens and the time life support ends. Life support creates an interlude during which people strive to harmonize their understandings, expectations and plans for the patient. Family members and clinicians work, and wait, for the synchronous acceptance of futility and imminent death. The family may need time to overcome denial that the patient is dying, disbelief that treatment options have run out or disagreements among themselves that death is inescapable. People need time to say goodbye.

Mr. A's son explained that some of [the family's] concern about time frames was due to the fact that Mr. A's remaining sister would not be able to arrive until Saturday morning (this discussion took place on Thursday afternoon). Dr. B conveyed that he personally had "no trouble continuing to support Mr. A until Saturday, if it is very important that Mr. A's sister see her brother."

As with many clinicians, family members may have preferences and feelings about how life support is withdrawn. This period may also be used for negotiation between the patient's wishes (usually hypothesized, rarely known) and the family members' and clinicians' personal views about specific technologies, their uses and likely effects.

Mrs. C and Dr. D arrived at a decision to begin the withdrawal process by decreasing the amount of oxygen Mr. C was receiving from 45% to 35%. Mr. C died about 18 hours later - "peacefully, in his sleep." Dr. D concluded, saying that "nothing had been really withdrawn." When questioned if the oxygen being reduced was not something being withdrawn, Dr. D replied that Mrs. C was comfortable with it being turned down because it seemed to be "more natural."

### **Conducting the orchestra versus the instruments**

At key points in life-support decision-making, family members and caregivers relate to life-support technologies collectively as "technology" itself, rather than as discrete technological tools with specific therapeutic uses. Technology thus comes to represent a global approach to achieving the goals of care. Typically, this happens early in the ICU stay, when there is a desire to "do everything" and the objective is saving life.

I would say in general the majority of times the family will say "do everything." There are some families that will say "Oh, no, do nothing, let's stop now," but the majority want to push on initially, and it's only usually after fairly extensive discussions that that viewpoint will shift at all, and sometimes it never does. [interview with consultant]

The orchestration of life support often concerns the number of technologies in play at once, and whether to add new instruments to the mix. Life-support technologies initiated early on under a more optimistic prognosis or aggressive management plan may be continued, but additional interventions or life-support measures may be withheld. At issue is the intensity of care overall, rather than the merits and demerits of specific interventions.

Dr. B stressed that it was his opinion, however, that they should not "begin new things or add things." If Mr. A were to get worse between now and Saturday, he would not do anything new to support him. To do so would be "unkind."

A collective view of technology similarly appears toward the end of the ICU stay, as an imperative to "stop doing everything." In this context, the use of technology seems aesthetically or morally offensive, as dehumanizing or degrading to the body. The inherent goal of technology has shifted from life-saving to death-prolonging or pain-inducing. In discussions, erstwhile useful instruments transform dismissively into "a

whole bunch of machines" and a source of discord.

She says that above all, she wants him to be comfortable. "No more artificial machines."

When life support is withdrawn, they usually ask the family to leave the room while the machines and equipment are removed. Once everything is gone, and it is just the patient in the bed, the family comes back until death occurs.

In some discussions about the withdrawal of life support, a discrete technology (e.g., dialysis or mechanical ventilation) can act as an archetype or synecdoche for the more general concept of life-support technology and life-support goals. By working through a decision about whether to use dialysis, for example, clinicians and family members can begin to address decisions regarding other life-support technologies more generally.

In the ICU, the decision to stop dialysis is generally tantamount to death. And usually what will happen is that we'll stop dialysis and the family will say, "Well, continue everything else," and then a couple of days later they'll have thought about it a bit more if the patient hasn't already died, and say, "Well, maybe we should start withdrawing other things as well." It's just sort of the first step on the path that eventually leads to withdrawal of active care. [interview with consultant]

## **Interpretation**

When life-support technology is used to orchestrate a death in the ICU, it can perform functions not well appreciated by conventional frameworks for technology evaluation. End-of-life decision-making concerns not only whether to use life-support technology, but also how - the timing, intensity and number of technologies. These decisions are socially negotiated and nuanced for each patient. Goals of technology use in this context include explicit social, aesthetic and ethical objectives as well as clinically instrumental objectives.

We have identified some of these technological functions. Although life support is commonly understood to be therapeutic, it may also be withdrawn on a trial basis to gain diagnostic and prognostic information. Life support may be provided continuously or intermittently. When it is withdrawn, it can be done abruptly or slowly, in numerous discretionary sequences, and to a number of clinical, social and psychological effects on patients, family members and clinicians. Periods of seemingly futile life support may create an interlude in which family members can come to terms with and negotiate the dying process. Some life-support decisions are about specific instruments, while others are about instrumentation, or the image of technology, in general.

These findings suggest several implications for practice and policy. Models of the physician-patient relationship are often portrayed as models of decision-making. This



conflation seems particularly problematic in the ICU, where patient-clinician relationships may be new or undeveloped, where emotional tensions are unparalleled, and where unanticipated situations may eclipse advance health care planning. Therefore, models of patient-physician decision-making<sup>25</sup> require adaptation to be relevant to decisions concerning advanced life support in the ICU. A given technological act (e.g., withdrawal of mechanical ventilation) may have multiple clinical and social meanings. Decisions may concern technology in general rather than specific technologies. Many discussions about styles of withdrawing mechanical ventilation leave key technologic options implicit. Individual technologies may be tacitly understood to achieve overall goals. Our findings also raise questions about the ability of increasingly popular decision aids such as advance directives to portray the complex purposes, effects and meaning of life-support technologies as they are actually used and experienced by patients, their family members and clinicians.

A key issue is implied but not directly addressed in this report. Patient autonomy notwithstanding, the orchestration metaphor generated by our analysis alludes to "composers" and "conductors" who coordinate how technologies play out in the ICU. The influences of social dynamics, culture and consensus building on perceptions of the form and function of ICU technology are beyond the scope of this report,<sup>26</sup> but they represent fruitful areas for investigation. Future frameworks of life-support withholding, administration, continuation and withdrawal should accommodate the multiple functions of technology, including its social and personal impact on dying and grieving.

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## Footnotes

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