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Can rationing possibly be rational?

Annie Farlow was just short of three months old when she died in an Ontario hospital of what her parents believe might have been a treatable respiratory condition.

Born with the chromosome disorder Trisomy 13, Annie had little chance of surviving to her teens, but her parents, Barbara and Tim Farlow, had taken comfort in the hospital's assurance that their daughter's genetic disorder, also known as Patau syndrome, wouldn't preclude her from receiving the same level of care as any other child suffering from a medical condition.

But months after Annie's death, the Farlows discovered that physicians at the hospital had not initiated emergency resuscitation measures in their daughter's case with the same alacrity as they would in others. They also found out that a physician had placed a "do not resuscitate" order on Annie's chart before obtaining their consent, and subsequently their daughter had been administered an undisclosed quantity of narcotics that, in the Farlows' opinion, could have caused her "unexplained, rapid" decline.

The circumstances surrounding Annie's death have left the Farlows asking age-old questions that plague Canadian patient advocates, health care professionals, ethicists and policy makers in the face of growing health care resource scarcity: When is it appropriate to limit or withdraw potentially beneficial treatment? Who should make those decisions? How should decisions be made?

"I never took the position that my daughter had a right to any and all treatments, but the unilateral decisions we believe the doctors made should have been made transparently. We have a right to know and appeal the limits of the system, and be provided with whatever care is possible within its confines," Barbara Farlow says. "Not only do I believe my daughter was denied a chance to prolong her life, the secrecy in which decisions seem to have been made also meant she was denied timely palliative care, and she suffered greatly at the end."

Farlow has since joined other Canadians in calling for an "open, honest and public" conversation about health care rationing in hope of addressing hidden bias in current decision-making processes and developing ethical solutions for future resource shortages. "We recognize resources are finite, so the question becomes not if, but how we ration. Openly, transparently, democratically and with careful consideration for the rights of the vulnerable? Or quietly, without debate and behind closed doors?"

Health expenditures consume more than 50% of revenues in six of Canada's 10 provinces, not including federal transfers, and are on pace to consume some 75% of revenues in five provinces by the year 2019, according to the Fraser Institute (www.fraserinstitute.org/research-news/research/display.aspx?id=10758).

Canada's aging population and the ongoing development of expensive therapies for life-threatening illnesses are further escalating pressures on the health care system, particularly intensive care units. Surveys estimate that Ontario, among other provinces, will need 80%–93% more intensive beds over the next 20 years, while about 87% of

intensive care physicians indicated they had provided “futile” care at least once in the previous year (www.cmaj.ca/cgi/doi/10.1503/cmaj.070144).

“We have to start making some difficult rationalizations about who we’re going to treat,” argued a cardiac surgeon at a January town hall meeting on health care transformation hosted by the Canadian Medical Association (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3797). “We don’t say at 85 you’ve lived well and there are some criteria by which I’m going to do a double valve replacement on you, but we should judge whether or not the potential years of life saved can be justified by that treatment.”

Many patients may not need hospitalization near end-of-life, when the majority of health care costs accrue, and would be better served by such strictures, added panelist Dr. John Ross, provincial advisor on emergency care for the Nova Scotia government. “I know a number of quite demented people right now who are getting various types of tests done, dialysis and various types of interventions. When you look at where this effort is going, what the end point is, is that really a valuable way to spend that diagnostic testing and dying person’s time?”

There are those who believe that Canada has already entered into a “scarcity model” of health care resource allocation, says Krista Flint, a disability rights activist from Calgary, Alberta. “It’s evidenced in things like the exclusion criteria built into new provincial pandemic planning protocols. In the case of a flu pandemic, for example, having a developmental disability now excludes you from access to a ventilator.”

Such protocols set a precedent for withholding and withdrawing beneficial treatment from vulnerable groups, she argues.

In a similar vein, the government of Ontario is in the midst of developing new critical care triage guidelines to clarify which patients should receive the province’s limited intensive care resources

(www.health.gov.on.ca/english/providers/program/critical_care/cct_access.html).

Under Canadian law, doctors do not have to provide treatment that they deem “futile,” says Dr. Laura Hawryluck, the physician lead on the strategy, assistant professor of medicine, and critical care physician at the University Health Network in Toronto, Ontario. However, without clear consensus about what constitutes futility, clinicians have no clear standard for weighing medical versus nonmedical criteria in their decision making, she adds.

Studies have found that bed availability, patient age and physician attitudes, as well as pressure from superiors and family members, or the threat of legal action, all come into play in decisions to admit patients to intensive care (*Crit Care* 2006;10:242).

Moreover, nonmedical reasons behind triage decisions are rarely discussed openly, while institutional discussions on what constitutes appropriate use of scarce resources and how to incorporate cultural and religious beliefs into the decision-making process remain vague.

Hawryluck has proposed a working definition of futility as being “the use of considerable resources without a reasonable hope that the patient would recover to a state of relative independence or be interactive with their environment.”

But without consensus on what constitutes “considerable resources ... reasonable hope ... relative independence ... (or) interactivity” with one’s environment, such a definition can easily become a proverbial slippery slope to denying treatment to the

elderly, the disabled or people with chronic diseases who might otherwise live longer and have a quality of life that they find acceptable, Farlow says.

“These are really existential questions about judging quality of life,” says Rhonda Wiebe, cochair of the Council of Canadians with Disabilities end-of-life ethics committee. “I worry we’ll get to a place where we’re the sum of our illnesses. I know that if there’s one respirator and two people, one who will need it for 12 hours and the other who will need it for the rest of their life, there’s a split second allocation decision that’s going to be made, and likely in the favour of the healthier person.”

Many physicians already have difficulty balancing responsibilities to their patients with the “intense pressure” they’re under to conserve resources, says Dr. Ellen Tsai, a pediatric interventionist at Kingston General Hospital in Ontario. “We don’t like to admit that we’re placing value on people’s lives and I think many physicians would prefer not to have that decision on their shoulders at all. At the same time, as the people who are best able to determine the medical benefit of a treatment, I think it would be wrong of us to entirely abdicate that responsibility.”

Some 80% of resource allocation decisions are currently made by physicians at the bedside, effectively putting physicians in the role of “double agents,” says Margaret Sommerville, founding director of the McGill University Centre for Medicine, Ethics and Law, in Montreal, Québec. “There’s a clear ethical rule that a doctor has a primary obligation of personal care for each patient, meaning a doctor cannot put the interests of a group, society or another patient in front of the best interests of the patient he or she is treating.”

Patients, families or surrogate decision-makers who disagree with a physician are “left with no other alternative than to go to court to get an injunction to prevent discontinuing treatment,” while few cases make it to trial because most patients die before their case can be heard, says Mark Handelman, a Toronto-based lawyer who specializes in disputes over end-of-life treatment. There are also considerable legal ambiguities surrounding end-of-life decision-making authority (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3910).

A solution to many of the thorny issues surrounding such decisions might be to remove physicians from the rationing process entirely, Sommerville says. “At an institutional level, hospitals and health authorities have an obligation to take into account other people’s requirements, rights and needs, and can put efficiency ahead of any one patient in ways a doctor cannot.”

Potential criteria proposed for future rationing schemes at institutional, regional or provincial levels include limitations on treatments by age, life expectancy or a patient’s personal responsibility in an illness, but “none of them are foolproof,” says Tsai. “A lot of talk about health care rationing fails to focus on actual algorithms for implementation on the ground. We have difficulty saying you’re a 73-year-old former smoker who now has end stage heart disease and your score is 52 and this is where you fit on the scale of resources we’ll provide.”

Public agreement on what services are fair game for exclusion is also unlikely to reach far, judging from past attempts to transparently rationalize care in the United States, England, New Zealand and the Netherlands (www.cmaj.ca/cgi/content/full/164/11/1583). The state of Oregon’s experience suggests

that the more transparent a decision to ration care, the more difficult it is to implement because public opposition invariably emerges.

“No one wants to be seen as the person that started the conversation on who we exclude from universal health care,” Farlow says. “But we’re already excluding people like my daughter in other subtle ways, so the time to talk is now.” — Lauren Vogel, *CMAJ*

Editor’s note: Seventeenth of a series on end-of-life care

Part I: Preparing for the inevitable (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3704)

Part II: Advance directives: Obstacles in preparing for the worst

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3743)

Part III: End-of-life planning framework calls for fewer checklists, more conversation (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3746)

Part IV: Tools help patients tackle tough choices for end-of-life care

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3750)

Part V: National home care standards urged

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3731)

Part VI: Access to palliative care varies widely across Canada

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3763)

Part VII: Framework urges physicians to proceed with caution on palliative sedation (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3766)

Part VIII: Pocket-sized help for people with dementia

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3705)

Part IX: Grief therapy for those left behind (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3793)

Part X: Providing hospice in the womb (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3776)

Part XI: Providing palliative care to the homeless

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3756)

Part XII: England examines funding options for end-of-life care

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3849)

Part XIII: Paramedic program reducing emergency room congestion

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3897)

Part XIV: Legal ambiguities surround authority to make end-of-life decisions

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3910)

Part XV: “Seniors emergency departments” yield health improvements, advocates say (www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3868)

Part XVI: Seniors overmedicalized, experts say

(www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3886)

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