



## Why I am not a futilitarian

When doctors say no: the battleground of medical futility

Susan B. Rubin

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Only a few years ago, patients and their families were battling in courts with physicians and hospitals for the right to have unwanted life support withdrawn. While patients argued that no medical intervention could be administered (or continued) without consent, physicians were reluctant to withdraw life-prolonging treatment on the grounds that this would run counter to their commitment to the preservation of life. The struggle extended beyond courtroom walls as society at large attempted to define the authority given to physicians and patients to make treatment decisions. In cases whose plaintiffs became household names — Karen Quinlan, Nancy Cruzan and Canada's own Nancy B. — the right to refuse medical interventions, whether by the patient or a surrogate, was unequivocally established.

The issue has now been turned on its head, and the thoroughly brilliant analysis found in Susan B. Rubin's *When Doctors Say No* couldn't be more timely. In Canada today, physicians sometimes refuse to provide or threaten to withdraw life-sustaining treatment *against* the wishes of patients and their families. One such case has recently attracted national media attention. Andrew Sawatsky, a 79-year-old man with Parkinson's disease, was admitted to a long-term care facility after suffering a series of strokes. Because he was no longer able to speak for himself, his wife of 43 years urged physicians to "use all ... means to keep him alive if his medical condition deteriorates."<sup>1</sup> Physicians and the hospital unleashed a two-punch response. Helene Sawatsky was, as the *Globe and Mail* reported, deemed "not competent to act for him since she disagrees with the medical ex-

perts," and the Public Trustee assumed legal supervision of the case. A do-not-resuscitate (DNR) order was unilaterally written on the patient's chart on the grounds that cardiopulmonary resuscitation (CPR) would be medically futile.<sup>1</sup> The case has yet to be decided by the courts.

As the Sawatsky case illustrates, futilitarianism — the belief that physicians may unilaterally refuse to provide treatment they believe to be useless — has gained considerable support among Canadian physicians. Bioethicists George Webster and Pat Murphy recently observed: "On any number of occasions ... clinicians have said to us that they no longer have to have the permission of patients to write a DNR order, if they think [CPR] would be 'futile.'"<sup>3</sup> Rubin correctly ascribes a complex etiology to this state of affairs: the shifting boundaries of the physician-patient relationship, reaction against the growing emphasis on patient autonomy and ever-increasing pressures on physicians to restrict resource utilization. These factors have given rise to two articulations of medical futility: "strong" and "weak." Both understandings of futility, Rubin rightly observes, are morally flawed.

The "strong" version of futility, first described in 1990<sup>4</sup> and mirrored in the CMA's joint statement on resuscitative interventions,<sup>5</sup> makes a distinction between quantitative and qualitative futility. A treatment is qualitatively futile if it "merely preserves permanent unconsciousness or ... fails to end total dependence on intensive medical care."<sup>4</sup> Rubin points out, as have others,<sup>6</sup> that judgements about qualitative futility are

not about probabilities but about values. Allowing the values of physicians to trump those of patients gives undue emphasis to the evaluations of physicians. "Nothing in the therapeutic relationship between physicians and patients supports the deliberate imposition of physicians' own idiosyncratic value judgments (or their professional values) on patients in this fashion" (p. 85). Indeed, it is the patients who are in a "privileged epistemic position and hence their wishes should be given primary consideration" (p. 88).

A "weak" version of futility has garnered considerably more support in the bioethics literature. Roughly corresponding to "quantitative futility," it allows physicians to unilaterally override a patient's wishes when there is good evidence that an intervention cannot produce the intended effect.<sup>7</sup> This position claims validity on the basis that such unilateral decisions are based on facts rather than values. Rubin uses a social constructivist critique to challenge the fact-value distinction. Social



constructivism sees scientific knowledge as unavoidably value laden. "[S]cience is understood to be, most fundamentally, a social practice, with its own specific rules and orientations to problems, its own biases about the kinds of knowledge worth pursuing, and its own particular relation to the world around it" (p. 97). Empirical study unavoidably involves value-laden choices as to the importance of possible questions to be studied, what constitutes a clinically relevant outcome and acceptable probabilities of error. The notion that facts are "value free" is a fiction, and, since we have rejected unilateral physician decision-making based on values, neither can the "weak" version of futility be sustained.

*When Doctors Say No* is the most thorough philosophical rebuttal I have found of medical futility as the basis for unilat-



eral decision-making by physicians. Rubin acknowledges that such decision-making may be legitimate, but only in cases in which broad social discourse — not mere intraprofessional discourse — has given physicians the right to engage in it. Our society has not yet had the needed debate as to whether, for example, people in a persistent vegetative state ought to receive life-sustaining treatment. Even given such a consensus, exemptions for those with strongly held religious beliefs would likely be invoked.<sup>8</sup>

Canadian physicians must retreat from appeals to futility and engage in open dialogue with patients in which the values of both parties are open to scrutiny. When physicians believe that a particular choice is favoured (or disfavoured, for that matter), they should use moral suasion — but not coercion — to attempt to convince the patient of their view. In the most difficult cases, physicians should use other available resources, including bioethicists and hospital ethics committees, to facil-

itate compromise. Rubin's superb book reminds us that only in this way can trust, the cornerstone of the physician-patient relationship, be preserved.

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## The peculiar genius of John Nash

### A beautiful mind

Sylvia Nasar

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John Forbes Nash, Jr., the subject of Sylvia Nasar's *A Beautiful Mind*, underwent at the age of 31 a "strange and horrible metamorphosis" from a quirky but indisputable genius in pure mathematics to a certified paranoid schizophrenic confined to a psychiatric hospital. When asked by a fellow mathematician how someone devoted to reason and logical proof could believe that aliens were sending him messages through the *New York Times*, he replied: "Because the ideas I had about supernatural beings came to me the same way that my mathematical ideas did. So I took them seriously."

Nasar, an economics correspondent for the *Times*, was drawn to Nash because his revolutionary work in game theory (a rebuttal to zero-sum theory known as the Nash equilibrium) now forms the mathematical basis for theo-

ries of rational behaviour in economics, political science, sociology and evolutionary biology. Her biography also reflects a fascination with the defining qualities of genius. There were many exceptional minds among the graduate students at the Institute for Advanced Studies at Princeton when Nash arrived in 1949. A much-loved pastime in the common room was a version of kriegspiel that involved a game of chess played with 3 boards. Two players, sitting back to back, moved their pieces on their own boards but could not see their opponent's moves. A third chessboard, visible only to the umpire, recorded the moves of both players. Nash was outclassed at the game by colleagues who were not destined to distinguish themselves either by madness or a Nobel Prize. Nor did they match him in eccentricity or aloofness. Nasar's por-

trayal of Nash presents social ineptitude as a cardinal sign of the creative genius. Nash was often alone and had few close friends. He never attended class and read amazingly little. Rather than digesting the work of his predecessors in the field, he interrogated colleagues about what the "really important problems" were and then proceeded, virtually in isolation, first to construct established proofs de novo and then to make radical theoretical leaps. He was frequently observed walking about the campus, whistling Bach and quite evidently *thinking*. One faculty member came upon him stretched out on a table in the professors' lounge, staring at the ceiling, deep in thought. His statements were often so unexpected, so provoking and so self-aggrandizing that Nash's sudden slide into full-blown mental illness in the spring of 1959 was not immediately recognized for what it was.

The next 30 years of Nash's life were to a large extent governed by the medical profession's evolving understanding of schizophrenia. Psychotherapy (which laid the blame for Nash's illness largely at the feet of Alicia, his courageous wife) gave way to insulin shock therapy, electroshock treatments and antipsychotic drugs. Nasar provides a close and often moving account of the remarkable devotion of his wife and the agonizing decisions that had to be made about the management of his illness. She also conveys the kindness of his colleagues, who provided a safe, unofficial haven for "the Phantom" in the halls of Princeton. These colleagues were astonished when, in the late 1980s, Nash's mind surfaced from its delusional sea and delighted when, in 1995, he was awarded the Nobel Prize in economics for the work he had done in game theory during his early years at Princeton. How to account for this spontaneous remission — Nash refused to take antipsychotic drugs after 1970 — is a matter of conjecture, and the price that Nash has paid for both his illness and his recovery is a distressing calculation. What does seem clear is that between genius and madness there is more than a zero-sum game.

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