Seeking Medicine’s Moral Centre

Ethics, Bioethics, and Assisted Dying

By

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For Dr. Margaret Cottle: Colleague, friend, and physician.

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Chapter 4: The Challenge of Terri Schiavo: Lessons for Bioethics - Time to Redefine the Ethical Principles of Care for Restricted People, *Journal of Medical Ethics 2005*

Chapter 5: Confusing the Issue: The Carter Case, *Toronto Star 2011, Nov. 16*

Chapter 6: 'End Of Life' Often Means 'Ending Life', *Toronto Star, Dec. 15. 2012*

Chapter 7: Living Versus Dying with Dignity, *Huffington Post, Nov. 30, 2015*

Chapter 8: Old Age Alone Shouldn't Be Considered a Justification for Physician-Assisted Death, *Globe & Mail April 9, 2018*

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Chapter 10: A Sceptics Report: Canada's Five Years' Experience with MAiD (medical termination), *HEC Forum 2022, 12 Feb, 2022*

Chapter 11 The Canadian Question: What's So Great About Intelligence? *Cambridge Quarterly of Healthcare Ethics* 1996: 5 2): 307-310.

Chapter 12: Disabled are not Dogs, *Vancouver Sun 7 Feb. 2001, A15*

Chapter 13: Disability or End of Life? Competing Narratives in Bioethics. (with Joe Kaufert) *Theoretical Medicine 24**:** 459–469. 2003*

Chapter 14: The Ideology of Normalcy: The Ethics of Difference, *Journal of Disability Policy Studies* 2005; *16 (2): 123-129.*

Chapter 15: Were Polio to Return, Today, *Canadian Medical Association Journal, April 22, 2008 178 (9) 1244*

Chapter 16: Disabling Disability Amid Competing Ideologies, *Journal of Medical Ethics 2018; 44: 575–579.*

Chapter 17: Does the "Sanctity of Human Life" Doctrine Sanctify Humanness, or Life?, *Cambridge Quarterly of Healthcare Ethics 1999, 8, 557–560*

Chapter 18: Absent Virtues: The Poacher Becomes Gamekeeper, *Journal of Medical Ethics 2003; 29:337–342*

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Preface

Philosophers, at least most Western philosophers, are rarely pragmatic. They work on the high plane of ideals and principles with little attention to their practical application. Their method is one that asserts premises, or axioms, and then presents their defense and explication. The questions they ask are lofty rather than mundane: What is Justice? What are We? What is the nature of a good life? For moral philosophers, "applied work is relatively straightforward and not particularly intellectually challenging" (Blumenthal-Barby, Aas, et al. 2021). Others simply transpose their principles into a practical response to the realities of daily life and its myriad dilemmas. That's the theory, the "epistemological status of bioethics" (Reichlin 1994). But even there the arguments remain grounded in a theoretic whose application permits no practical testing. There is no certain path from "What are we?" to the question: "What the hell should I do?"

In medicine, philosophers may write about the bedside, and the possibilities of care, but they do not serve at the beside where the complexities of care reside. Another way of working is from the ground up, from the case or event to the ideas they suggest. Theists will point to Biblical parables, brief stories that imply but do not proclaim a specific moral good. A few philosophers, Plato was the most famous, similarly used the simple example to make profound points. In *Phaedrus*, for example, a story about medicine is used to emphasize the difference between simple book learning and experiential knowledge (Edman 1956, 314-315). Plato's stories, set as dialogues, mark the particular in route toward global ideals.

Montaigne was another, a skeptical moralist who dismissed the pronouncements of philosophers as passing social fads (Bakewell 2011). "What am I to make of a virtue that I saw in credit yesterday, that will be discredited tomorrow, and that becomes a crime on the other side of the river?" (Schneewind 1998, 45). The test for Montaigne was whether he could incorporate the broad dictates of this or that moral perspective into his life in a way consistent with his own ideas of good or bad, right and wrong. And so he gave us an idea in his stories of a life lived, of what is right and what is to be refused, but did so without a template for how we might live our own.

Until recently, medicine's ethical framework was built, Montaigne-like, from the bottom up, from the duties of the practitioner to the patient and thus to society at large. As citizens, practitioners followed a Hippocratic tradition based on a Greek sense of person and community. They "could not conceive of themselves as living apart from, or in opposition, to this community, with all its customs and forms of social life" (Singer 1983, p. 8). In this vein, the Hippocratic Oath presented a set of practical injunctions that, first and foremost, enjoined practitioners to the care of the person irrespective of all other considerations: "Into whatever homes I go, I will go for the benefit of the sick, avoiding any voluntary acts of impropriety or corruption … whether they are freemen or slaves" (North 2012).

Montaigne would have liked that and its sense of equality and justice as virtues in practice. In *Epidemics,* Hippocrates enjoins physicians to "Practice two things in your dealings with disease: either help or [at least] do not harm the patient." Today we call that *nonmalfesiance,* a moral dictate emphasized by the injunction to "abstain from whatever is deleterious and mischievous" (Hajar 2017). Implicit in the Hippocratic ethic was life as a protected, moral good. And so it followed that there were injunctions against "deadly medicine," to hasten the end of life as well as "a pessary to produce abortion." The Oath ends with the promise that those who serve faithfully will receive the appreciation and respect of the community at large. Medicine thus was declared a communal good in which the care of each was acknowledged by the public to be for the benefit of all. Some, today, rephrase that more generally: "Medicine must always be treated as a public good, never as a commodity" (Sullivan, 2000, 675).

The Hippocratic operating system thus was grounded, implicitly, in a morality that emphasized beneficence (do good), nonmalfesiance (do no harm), justice (treat all persons irrespective of gender or status), and respect for the patient's privacy ("Whatever I see or hear in the lives of the patient …I will keep secret, as considering all things to be private"). That was necessary to assure the relationship between patient and practitioner was one of focused care and concern. All this was invoked in service of life as a principle value, something to be fostered and protected through the practitioner's duty to care for the patient and in that way serve the community-at-large. The intrinsic moral worth of each person was grounded in their relations to and within the greater society whose robust health was the resulting good.

In the 1970s, a group of moral philosophers declared that changes in bioethical sciences, medicine, and medical technologies required a new moral centre. The result, first codified in Beauchamp's and Childress's *Principles of Bioethics,* seemed at first similar to the Hippocratic ethic albeit argued on the plane of moral philosophy rather than practical injunctions. Its principles again were beneficence (do good), nonmalfesiance (first, do no harm), justice (treat people equally) and to these were added autonomy as a value focused upon the primacy of the person in care. This was a new ethic divorced from the perspective of the physician or the caring relationship in service of the greater community.

Bioethicists have sought to apply their vision of practice in a way that has been anything but Hippocratic. Notably absent was life as an independent moral good. Beneficence became bounded in practice by notions of resource scarcity limiting the parameters of available patient care. The practitioner's primary obligation was no longer first and foremost to the patient but instead to the state, employer, or whomever controlled health resources. Nonmalfesiance was adjusted to permit abortion and assisted dying. Most radically, it took medicine from the domain of a physician's practice to that of the autonomous individual-as-patient within a commercialized culture devaluing the practitioner as little more than a technician. All this happened without any critique.

One reason offered for a review of medicine's moral structure in society was that the science of medicine had, since the 1950s, evolved remarkably. Those graduating from medical school as late as the 1970s did so with little understanding of the genetics, genomics, and proteomics that have transformed contemporary medical science. And, too, vast areas of surgery have changed with cardiac stints, orthopedic joint repair and laparoscopic techniques. Indeed, it is hard to think of an area of clinical practice that has not been radically changed in recent decades by advancing knowledge and evolving technologies.

Whether these required a rethinking of the moral operating system of medicine and the ethics of its application is in retrospect unclear, however (Koch 2011). And while evolving medical science and its technologies are subject to rigorous critique and testing, the moral philosophers' bioethics has suffered no similar review. How would a Montaigne review the result of 40 or so years of moral philosophers' application of bioethics? How would its resulting moral operating system fit, in practice, with Montaigne's conception of right and wrong? The articles in this volume seek, Montaigne like, to present concrete reflections of this transition from a Hippocratic to a bioethical medicine.

Written over three decades, these reports were published as magazine investigations, newspaper opinions, and critical essays. All were prefaced by years of work in gerontology and with the chronically ill. My interdisciplinary degrees in medicine, ethics, and the geography of diseases, endemic and pandemic, eased the transition from writing first for popular and then increasingly for professional publications. Across these working years I also served as a consultant in chronic care and ethics at hospices, hospitals, in clinic and for Justice Canada in the famous cases of *Regina v Carter* concerning medical termination.

While academics may find the inclusion of popular writings strange in a book like this, they serve as critical, evidentiary touchstones in an attempt to understand the shifting culture of care, its anthropology. "The media have in some ways not only been hanging around bioethics, but arguably played the key role of midwife in helping to bring bioethics into existence" (Caplan 1993, S14). They evidence the social context in which bioethics and its policies contributed to the popular embrace of a change from medicine's traditional, vocational ethic in which the physician was a trusted carer to a bureaucratic and commercial ethic acknowledging the physician's technical expertise but dismissing the practitioner's role as a principal, knowledgeable partner in an ethics of care.

I began as a reporter asking a reporter's questions. Why did Jean Brush murder her husband? Did Cecil Brush, a patient with moderately advanced dementia, really, "ask for it"? Would that have made it acceptable? More important, perhaps, why was this something people applauded as a good rather lamented as something sad if perhaps understandable? Individual cases present clear examples and invite, for the reporter, more complex readings of specific events.

The arc of these writings move from the concretely reportorial toward the ethical and philosophic: How do we understand the necessities of care in a society that while promising autonomy does so within an "ethics of the lifeboat" where the sacrifice of some is assumed to be necessary for the survival of others (Lasagna 1992)? Who is valuable, or more valuable, and who is not? What happens when the Hippocratic vocation becomes just a profession or, worse, simply another job no more morally fraught than that of a salesperson at the local mall? In your reading, remember Montaigne: Ask if this or that act or policy seems right to you as if you were the person being written about rather than the person reading of others. Ask if the narrative of today fits a personal sense of right and wrong. Most importantly, perhaps, ask what we should promote as a society, together.

Some of the academic articles began as well-paid, popular pieces whose fees supported more formal writings. The popular anchors and focuses each of the sections of this book. In each there is an arc from the singular case to the context of an event and from there to the ethical and, if I may, philosophic. The first section's focus is, as the Dutch call it, "medical termination:" Euthanasia, physician assisted dying (PAD), and Medical Assistance in Dying (MAiD) are all names for it. In both Europe and North America, but especially in Canada, it was the most contentious issue with which questions of right and wrong, of ethical or inappropriate behaviour in medicine were confronted. Debates over its introduction opened the question of what precisely is meant by patient autonomy and whether there is a "right to die" without a balancing, more traditionally Hippocratic "right to live, with dignity." The second section considers issues of difference, "disabilities," which grew in part out of questions of medical termination and the worthiness we assign to those with cognitive, physical, or sensory limits. The third section focuses on bioethics as a moral operating platform.

These are followed by a discussion chapter that presents an anthropology of medical ethics and its changes as the traditional, vocational ethic was replaced by a commercially and politically grounded bioethics of care. It does this through a review of the accumulated evidence of the individual pieces that, together serve here as ethnographies. The result attempts to answer a series of questions. In this new ethic of medicine who do we care for? What are a physician's ethical duties and what are society's duties in the face of sometimes conflicting moral operating systems? Are we equal as persons or measured on a descending scale of cognitive, physical, or sensory abilities? Is life itself a contingent good or one that is absolute irrespective of limits? In the evolving science of the day do we embrace a genetic cleansing to insure healthier, future generations, or perhaps, like the transhumanists, simply await a computer übermind that will magically solve the thorny questions of ethical practice today.

Several of the more academic pieces have been well cited by others. Their reading here is enriched, however, in the context of the accumulated articles. Together they create a historical narrative of the effect of a medicine transformed by a moral perspective whose practical, bureaucratic, and commercial ethic makes of each of us isolates, autonomous beings whose choices, while promoted as sacrosanct, are bounded by economic limits and the social imaginings of community and society. What was lost when the concrete injunctions of the Hippocratic ethos were exchanged for a thinly principled bioethics? How do we understand this transition of one moral operating system to another? In rereading the works of three decades I kept asking, myself, "What would Montaigne make of that, or Plato?" And perhaps, in your read, you might ask that, too.

Introduction

In February 1994, Jean Brush was anointed a public heroine by local media after stabbing her husband of 57 years' multiple times with a kitchen knife in their home near Toronto, Canada. She then inflicted several non-fatal wounds to her arms after writing a tearful suicide note saying his death, and now her own, were acts of love. And, really, he wanted it. She survived. Cecil did not. Two days before his murder Sue Rodriguez, a person with ALS (amyotrophic lateral sclerosis) died in British Columbia at the hands of or with the assistance of—the precise details were never made clear—a physician reportedly brought from Washington State expressly for her then illegal medical termination. Rodriguez had unsuccessfully sought an exception to legal prohibitions against medically assisted suicide, as it was then called, asking famously, "If I cannot give consent to my own death, whose body is this? Who owns my life?" (Fenton 2013). Answering that, given recent experiences in Canada with Medical Aid in Dying (MAiD), is one of the goals of this volume.

The first story in this collection, *The Myth of Loving Murder*, began what became a broader investigation into an emerging narrative in which Cecil Brush's murder was transformed from a lamentable if perhaps understandable event into a commendable act of love. It signalled a growing, popular approval of the early termination of those ill but not dying and in treatable pain as a clinical, ethical, and social good.

At that time, various media presented Cecil Brush's death as a love story while regularly reporting on the deaths attributed to Dr. Jack Kevorkian and his "suicide machine." None of those who traveled hundreds or thousands of miles for his service were at the end stage of an incurable, painfully untreatable illness. Had they been they would not have been able to travel. In the reportage of those deaths there was rarely if ever consideration of the manner in which less drastic treatments might have served to improve rather than terminate the lives of the deceased. So in 1998 I undertook an assignment for what became *On the subject of Jack Kevorkian*, a forensic review of the first 88 deaths publicly reported deaths.

What was becoming clear was that challenging traditional prohibitions against the induced deaths of the chronically fragile was becoming a simplistic popular narrative. It was propelled, in part, by the example of the Dutch euthanasia movement that began in the 1980s with first decriminalization and later the legalization of physician-assisted death. And so, after a period of teaching and research in Holland, I published a study of that country's euthanasia laws. First commissioned by a Canadian magazine, it was then considered but eventually rejected by a CBC Radio public affairs program that did not like its conclusions. Notre Dame University's Dave Thomas invited me to publish *Living versus Dying with Dignity* in the *Cambridge Quarterly of Healthcare Ethics* he edited.

What drove those with chronic conditions to seek an early death rather than the supportive care that was or should have been available? Is there an equal right to compassionate life for those with chronic limits? What did this new emphasis mean for those with cognitive, physical, or sensory differences who did *not* want to die but instead sought, often unsuccessfully, the support—professional and public—required to live rather than die with dignity? In the evolving story lines, academic and public, there seemed to be a growing sense that early termination of those with treatable chronic conditions was an efficient as well as a moral good.

In the mid-1990s I was engaged at the Hospital for Sick Children in Toronto, Canada to study, and if possible resolve, the then very thorny public debate over graft organ transplantation eligibility. In both Canada and the U.S. persons with Down syndrome were being denied service in favour of other, more or less normal individuals. The result was a book (*The Limits of Principle*) and more popularly, *What's so great about intelligence*? Both considered in different ways the assumption that one can easily triage life-saving resources on the basis of genetic, cognitive, or sensory differences. If Sue Rodriguez could claim autonomy as a rationale for medical termination, why couldn't those with Down Syndrome claim autonomy as a justification for their transplant eligibility? Two issues—medical termination and disability (*The disabled are not dogs*) —soon fused in my attempts to understand then evolving medical and social ethics (*Disability or End of Life).*

Ethnography, Anthropology

In retrospect, these articles can be understood as ethnographies, descriptive building blocks for an anthropology of contemporary medical ethics: clinical, legal, and social. The idea is not new. In 2006 Sargent and Smith-Morris promoted an anthropological review of autonomy as a serviceable ideal in the evolving bioethics of the day. More recently, in 2018 medical anthropologist Carolyn Smith-Morris reviewed a series of ethnographies focused on the "human and structural possibilities of care" in different societies. Then, in 2020, O. Carter Snead proposed an anthropological analysis to "uncover, illuminate, and critique the concept of human identity and flourishing that underwrites current [American] law and policy (Snead 2020, 4). Anthropologies and ethnographies rely on available data preserved at the level of organizational reports and public records for specific populations, for example veterans (Solomeo, Ono, Stewart et al. 2016).

While news is commonly thought of as "history in a hurry," or "the first draft of history" (Schafer 2010) journalists *are* ethnographers. They serve their communities as observers, "they write it down … inscribing social discourse through the close description of events, turning each from a passing, forgettable event into an account whose relevance is lasting" (Geertz 1973, 19). But too often the single event is forgotten until set in a narrative collection where a larger pattern, a greater whole can be seen. These commentaries, reports, and studies describe and critique, case by case, the evolving, new ethics and its application. In doing so they return to immediate consideration names now half-remembered that once briefly filled popular media and academic debates: Janet Adkins, Cecil and Jean Brush, Roger Foley, Jesse

Gelsinger, Hassan Rasouli, Jack Kevorkian, Terry Schiavo, Terry Urquart, Ryan Wilkieson, and so on. Together these individual pieces create an ethnographic platform whose "aim is to draw large conclusions from small, densely textured facts" (Geertz 1973, 28).

"Moral reasoning is principally a matter of getting the correct description of a situation, determining which moral law pertains to it, and figuring out what action that moral law requires for the given situation" (Johnson 1993, 7). "Figuring out" what the moral law really is, and what it requires, at least in theory, is one thing. Seeing its effects is another. "Philosophical positions exist in the realm of reasons, and those reasons have no essential reference to time and place" (Brender and Krashnoff 2004, 1). But we live and die *in* place and *at* a time. Together these articles bring to the present the evolving consequences of an ethic grounded in the tradition of high moral reasoning rather than one built, bottom up, from the crucible of experience. Reviewed critically, the arc of these narratives interrogate the limits of the philosopher's application of thin, moral principles in the ordering of complexly thick realities.

Setting the philosopher's argument in the context of its application over (and in) time results in an archeology of knowledge of a kind championed by Michel Foucault, an uncovering of relevant antecedents. As Foucault put it, the problem "is no longer one of lasting foundations, but one of transformations that serve as new foundations, the rebuilding of foundations. What one is seeing, then, is the emergence of a whole field of questions, some of which are already familiar …" (Foucault 1972, 12). Here, that archeology permits an anthropology grounded in ethnographic analysis, of a medical ethics set upon a thinly principled, moral operating system.

Foundations

Across these histories one sees the transformation from a traditional, Hippocratic platform of physician advocacy and treatment to something contractual, distanced, and contingent upon potentially available if typically scarce resources. The older ethic was bottom-up, focused upon the practitioner's obligations to and relations with a patient. The new ethic was top-down, a set of principles proclaimed by moral philosophers most of whom lacked any clinical experience. In the way of philosophers, the rationale for and indeed the necessity for this transition was simply declared axiomatically.

The foundational text of the new ethic, Childress and Beauchamp's 1979 *The Principles of Bioethics,* began with the pronouncement that "Developments in the biological and health sciences rendered the tradition, vocational ethic inadequate." More damning was the assertion as fact but without substantiation that the older, Hippocratic ethic often neglected "problems of truthfulness, privacy, justice, communal responsibility, and the like". Childress and Beauchamp then promised a "philosophical reflection on morality and ethics" in medicine that would provide a more robust ethical platform better able to order medical practice in society today.

The result was a set of principles while similar to those implicit in the Hippocratic Oath focused instead upon individual autonomy as a, and indeed *the* primary moral good. The ideal was grounded in Emmanuel Kant's idea of "self-rule that is free from both controlling interferences by others and from limitations, such as inadequate understanding, that prevent meaningful choice" (Childress and Beauchamp 2001, 58). But is the layperson's understanding of the complex choices for care adequate in the evolving technologies of medical practice. How is 'self-rule' balanced against the reality of medicine as a relational, cooperative practice? What does it mean when we live in families and communities that can restrain or support us, setting the parameters of available service? Where is 'self-rule" in a society that insists clinical choices are necessarily limited by financial circumstance, personal and social? Here was Clifford Geertz's *Culture, Thick and Thin,* the makings of an anthropology that considers complexly textured events set against a thinly principled set of cultural definitions and their resulting imperatives.

Ideology

With the murder of Cecil Brush and the applause it engendered the focus for me became understanding bioethics-in-action through the reportage of events that might reveal the effect of its applied ideology. In a point-counterpoint in *The Journal of Disability Policy Studies*, Princeton University's philosopher Peter Singer took strong exception to my description of bioethics as an *Ideology of Normalcy*. I didn't understand, he wrote, that "bioethics is a branch of applied ethics, which in turn is a branch of philosophy, and the hallmark of Western philosophy since Socrates has been its willingness to question everything . . ." (Singer 2005, 131-2). That bioethics is grounded in the traditions of western philosophy does not mean it is anything *but* an ideology, however, "that part of culture which is actively concerned with the establishment and defense of patterns of belief and value" (Geertz 1973, 231).

Bioethics' *raison detré is* the construction of a pattern of belief with attendant values grounded in a Kantian perspective. "Kant invented the conception of morality as autonomy" (Schneewind 1998). To him we owe bioethics' insistence on morality as self-governance in a social space where individuals might choose their own treatments irrespective of the views of authorities, clinicians, or other officials.

Calling it ideological simply permitted its assumptions to be taken not as given but instead open to questioning and critique. There is nothing radical in this. After all, all social and scientific disciplines are *all* grounded in ideologies that set their parameters and perspective. Harvard's Richard Lewontin (1996) described biology as an ideology—a set of accepted definitions and values—ordering the subjects chosen for study and the methods of their investigation. In the same vein, Joseph Schumpeter described the ideologies underlying economic theory as, "mere clotheslines on which to hang propositions of economic logic" (Moura 2018, 127).

That was the key. If I wanted to understand the particular, I had to understand the reported events across bioethics' philosophical clothesline, both the individuals (think Sue Rodriguez) symbolizing the theory and the reasoning behind their decisions. For moral philosophers and medical ethicists, ethical dilemmas are a matter of simply "weighing considered judgments about particular cases against general principles, applying technical concepts from metaphysics and epistemology, and engaging in debates in moral theory and philosophy of science" (Blumenthal-Barby, Aas, et al. 2021). It is never that easy at the bedside, however. Embracing the individual as a discrete isolate independent of all clinical, familial, and social contexts separated "decision making moments from the series of being, [the] long layers and intertwined histories that produce them" (Mol 2002, 168). That became the focus of the work I needed to do.

Physicians, central actors in the traditional Hippocratic ethic, were demoted by advocates of the new as little more than technicians. The result was a kind of professional character assassination dismissing the Hippocratic, vocational ethic as a "foundational authority" irrelevant in the new moral operating system of bioethical medical practice (Veatch 2012, 4). But physicians, and most patients, saw the role of practitioners in a caring relationship as something more than a set of simple transactions. Here was the *Hippocratic Thorn in Bioethics side*. Dilemmas of care are *always* interpersonal engagements involving family, patients, and practitioners. Options for care are always influenced less by paternalistic edict than the limits of the medical systems proscribing care protocols made available by insurers or, in Canada, provincial health ministries. In the end it is still the physician or nurse whose responsibility to care is legally and practically primary. The new ethic ignored this to create an impossible "ideal of solidarity, beneficence, and community; that endorses self-centred, even possessive individualism . . . that wrongly devalues forms of valued dependence that are ubiquitous in human life" (O'Neil 1994, 182).

Popular to Academic

In the mid 1990s, Notre Dame's bioethicist Dave Thomasma invited me to speak at a bioethics meeting on whether persons with Down syndrome should be denied graft organ transplantation (*What's so great about intelligence?*). Were persons of differences less qualified on ethical or pragmatic grounds to receive scarce, life-preserving medical care? Pragmatic medical ethicists like Hastings Center cofounder Daniel Callahan (1987, 1990) embraced what Paul Farmer described as a "socialization of scarcity," and a resulting willingness to give lesser care to some irrespective of patient wishes *or* practitioner recommendations (Rosenbaum 2022, 1471). In this new ethic those with differences negative to the norm—those with Down Syndrome, for example, or minimally conscious persons following a brain injury (Fins 2015) — were perceived as lesser and thus more or less expendable.

From this new perspective the physician's principal obligation was not first to the patient but instead to "fostering the common and collective health of society" defined by many, like Daniel Callahan (1987) and Louis Lasagna (1991), by economic limits requiring a prioritization of the needy. Despite the insistence on autonomy as a principle value, in this ethic the needs or wishes of a person in care would be a secondary concern (Rothman 1992). The Hippocratic tradition's primary moral focus, the person in a relationship of advocacy and care, faded in the face of this more utilitarian, economically focused agenda (Menzel 1993, 33). So, too, did the bioethicists' promise of autonomous decision making when those wishes conflicted with the economic and structural limits imposed by health care bureaucracies.

In the 1950s societies mobilized to save the lives of a class of young adults who survived poliomyelitis with withered limbs and long-term respiratory deficits. *Were Polio to Return Today* would we similarly cheer those saved to long-term, severe restrictions like the famous "iron lung"? Or would we ask if perhaps those that might be saved would better end their lives (or have them ended) than live with presumably disabling limits? To understand how what once had been universally condemned was being normalized I joined the American Society of Bioethics and the Humanities (ASBH) in 2004. That year the focal debate was *The Challenge of Terry Schiavo*, a Florida woman long in a coma or a state of at best very minimal conscience. Was she still a person equally deserving ongoing care or was her continuance simply sentimental?

In part, the underlying issues were philosophical: Is humanness something unique, something to be protected no matter the abilities of the person (*The Disabled Are Not Dogs*)? When was a condition so severe that death would be preferable to continued if restricted life? In a different key, did society provide sufficient resources that the choice of a life with dignity despite restrictions would be at least equal to a choice to terminate a life earlier than it might naturally occur? For me, the questions were to be asked from the bottom up, from the lives of those affected. My continuing work as a consultant in gerontology and chronic care engaged these issues as the requests of this or that person within a context of family dynamics and cultural histories. As a consulting ethicist I wondered at the means by which the new ideology seemed to have been publicly accepted with little debate or any critique *from* experience.

I wanted to find a Foucault-like anthropology and realized, one day, I had the makings of it. The ideology that is bioethics offered the context, the thinly principled clothesline on which practical injunctions were hung. The assignments I received, and the cases in which I was engaged, provided the thick experiential basis with which these changes could be reviewed. The resulting narratives these articles describe presents a portrait of the complex ideologies and resulting conflicts that, today, infect the realities of medical practice. The resulting discussion reveals, as anthropologies are supposed to do, the groundwork for an understanding of the culture change that has occurred. That is attempted in the final, discussion section. It is incomplete and tentative but points the way toward an anthropology that best describes how a moral operating system stable for millennia was summarily rejected in favour of another.

Section One:

Medical Termination

Euthanasia, physician assisted death, Medical Assistance in Dying (MAiD), etc.

Chapter 1

The Myth of Loving Murder: The Constructed Tale of Jean and Cecil Brush

In its final public form, there is much that is satisfying, even edifying about the story of the August 1994, death of Cecil Brush at his home in Stoney Creek, Ontario. That he was stabbed to death with a household knife by his wife—after she had failed in an earlier attempt to poison him—in no way detracts from the insistence by all who recorded this tale that it was in essence a story of love.

Reporters began writing the love story of Cecil and Jean Brush soon after their fifty-six- year old daughter, Joan Myers, returned from work to find her parents lying in a broad pool of co-mingled blood on the floor of their Stoney Creek home. He was dead, stabbed by his wife, who was herself bleeding from five non-fatal and self-inflicted wounds. A murder-suicide note, later published by the *Toronto Star*, was near at hand.

Slightly less than eight months after fatally stabbing her husband, frail, ethereal, eighty-one-year-old Jean Brush was given a suspended sentence and 18 month's probation after pleading guilty to the charge of manslaughter. She was hailed by some as a hero, a prophet of things to come. "History may very well look down on this case and say Jean Brush showed great courage in doing what she did," her lawyer, Frank Genesee, told the press.

If Cecil Brush had not been eighty-one years of age, mostly blind and partially deaf, it would have been harder to transform a tale of violent and premeditated murder into a narrative of selfless heroism. Had he been only blind and deaf and not also in the early stages of Alzheimer's disease it is likely his less than frail, still hearty 81-year-old widow would now be doing time in one or another state facility reserved for the incarceration of violent offenders.

But these were the facts: Cecil Brush was old, blind, and mostly deaf. He was affected by colitis, a messy and inconvenient disorder of the bowel, and in thrall to Alzheimer's disease. With these facts firmly before the public eye, the insistence of Jean Brush that she killed her husband after 57 years of marriage because she still loved him, cherishing the life she had lived with him if not the life that he had left, was simply irresistible.

[Her Lawyer] Frank Genesee called the story of Cecil and Jean Brush, murdered and murderer, a "modern day Romeo and Juliet story," whose moral is the need for a law in Canada authorizing assisted suicide. That was also the subtext of the comfortable myth embraced by reporters and editors who participated in its telling. The moral of Cecil Brush's death by his wife, at least in the hands of journalists covering this story, was: don't live too long. Don't be diagnosed with Alzheimer's disease. And if you do live overlong and have a dementing illness, your life is thoroughly expendable.

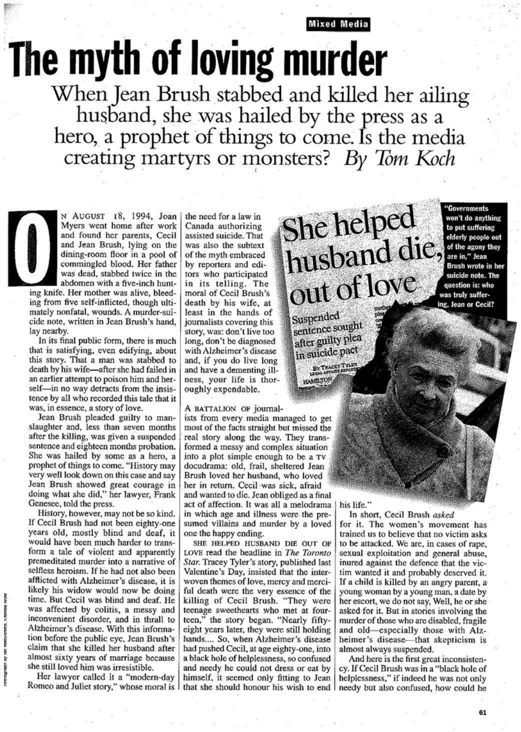
* * *

The story constructed by a battalion of journalists from every media made violent death at the hands of a heroic loved one into a happy ending. It transformed a messy and complex situation into a plot simple enough to be a TV docudrama: Old, frail, sheltered Jean loved her husband, who loved her in return. Cecil was sick, afraid, and wanted to die. Jean obliged as a final act of affection. It was all a drama in which age—or at least the illnesses of age—were the presumed villain and murder by a loved one the happy ending. Case closed.

"She Helped Husband Die out of Love" read the headline in the *Toronto Star*. Tracy Tyler's story, published on Valentine's Day, February 14, 1995, insisted from the start on the interwoven themes of love, mercy and merciful death as the very essence of the murder of Cecil Brush.

"They were teenage sweethearts who met at 14," the story began. "Nearly 58 years later, they were still holding hands," it continues. "So when Alzheimer's disease had pushed Cecil, at age 81, into a black hole of helplessness, so confused and needy he could not dress or eat by himself, it seemed only fitting to Jean that she should honor his wish to end his life."

In short, Cecil Brush asked for it. The women's movement has trained us to never believe the victim asked to be attacked. We are, in cases of rape, sexual exploitation, and general abuse inured against the defense that the victim wanted it, and probably deserved it. If a child is killed by an angry parent, a young woman by a young man, a date by her escort, we do not say, "well, she or (he) asked for it." But in stories involving the murder of those who are disabled, fragile and old—especially those with Alzheimer's Disease—that skepticism is suspended.



Mixed Media

The myth of loving murder

When Jean Brush stabbed and killed her ailing husband, she was hailed by the press as a hero, a prophet of things to come. Is the media creating martyrs or monsters? *By Tom Koch*

On August 18, 1994, Joan Myers went home after work and found her parents, Cecil and Jean Brush, lying on the dining-room floor in a pool of commingled blood. Her father was dead, stabbed twice in the abdomen with a five-inch hunting knife. Her mother was alive, bleeding from five self-inflicted, though ultimately nonfatal, wounds. A murder-suicide note, written in Jean Brush's hand, lay nearby.

In its final public form, there is much that is satisfying, even edifying, about this story. That a man was stabbed to death by his wife—after she had failed in an earlier attempt to poison him and herself—in no way detracts from the insistence by all who recorded this tale that it was, in essence, a story of love.

Jean Brush pleaded guilty to manslaughter and, less than seven months after the killing, was given a suspended sentence and eighteen months probation. She was hailed by some as a hero, a prophet of things to come. "History may very well look down on this case and say Jean Brush showed great courage in doing what she did," her lawyer, Frank Genesee, told the press.

History, however, may not be so kind. If Cecil Brush had not been eighty-one years old, mostly blind and deaf, it would have been much harder to transform a tale of violent and apparently premeditated murder into a narrative of selfless heroism. If he had not also been afflicted with Alzheimer's disease, it is likely his widow would now be doing time. But Cecil was blind and deaf. He was affected by colitis, a messy and inconvenient disorder, and in thrall to Alzheimer's disease. With this information before the public eye, Jean Brush's claim that she killed her husband after almost sixty years of marriage because she still loved him was irresistible.

Her lawyer called it a "modern-day Romeo and Juliet story," whose moral is the need for a law in Canada authorizing assisted suicide. That was also the subtext of the myth embraced by reporters and editors who participated in its telling. The moral of Cecil Brush's death by his wife, at least in the hands of journalists covering this story, was: don't live too long, don't be diagnosed with Alzheimer's disease and, if you do live long and have a dementing illness, your life is thoroughly expendable.

A battalion of journalists from every media managed to get most of the facts straight but missed the real story along the way. They transformed a messy and complex situation into a plot simple enough to be a TV docudrama: old, frail, sheltered Jean Brush loved her husband, who loved her in return. Cecil was sick, afraid and wanted to die. Jean obliged as a final act of affection. It was all a melodrama in which age and illness were the presumed villains and murder by a loved one the happy ending.

She helped husband die out of love read the headline in *The Toronto Star*. Tracey Tyler's story, published last Valentine's Day, insisted that the interwoven themes of love, mercy and merciful death were the very essence of the killing of Cecil Brush. "They were teenage sweethearts who met at fourteen," the story began. "Nearly fifty-eight years later, they were still holding hands.... So, when Alzheimer's disease had pushed Cecil, at age eighty-one, into a black hole of helplessness, so confused and needy he could not dress or eat by himself, it seemed only fitting to Jean that she should honour his wish to end his life."

In short, Cecil Brush *asked* for it. The women's movement has trained us to believe that no victim asks to be attacked. We are, in cases of rape, sexual exploitation and general abuse, inured against the defence that the victim wanted it and probably deserved it. If a child is killed by an angry parent, a young woman by a young man, a date by her escort, we do not say, Well, he or she asked for it. But in stories involving the murder of those who are disabled, fragile and old—especially those with Alzheimer's disease—that skepticism is almost always suspended.

And here is the first great inconsistency. If Cecil Brush was in a "black hole of helplessness," if indeed he was not only needy but also confused, how could he

She helped husband die, out of love

Suspended sentence sought after guilty plea in suicide pact

By Tracey Tyler
Legal Affairs Reporter

Hamilton

"Governments won't do anything to put suffering elderly people out of the agony they are in," Jean Brush wrote in her suicide note. The question is: who was truly suffering, Jean or Cecil?

Photograph by Ian MacDonald, Canada Wide

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And here is the first great inconsistency. If Cecil Brush was in a "black hole of helplessness" caused by Alzheimer's Disease, if indeed he was not only needy but also confused, how could he beg to die? If he was aware enough to ask his wife to euthanatize him, then perhaps he wasn't so helpless and disoriented after all. His exact words, Jean Brush told reporters, were: "Jean, please do something, do something." For a mostly blind and pretty deaf old man, that could mean anything from an expression of discomfort to a general request for an immediate kind assistance. It seems unlikely that it meant, as reporters and the courts assumed, “Stab me until I bleed to death, and then kill yourself.” And if indeed he was in a “black hole of helplessness,” who would credit such a request, anyway?

“At one point, despairing over his condition, they [Cecil and Jean] discussed what could be done,” Genesee explained. “When Cecil Brush offered a suggestion, Jean asked him to repeat it by scribbling it on a piece of paper. ‘I want to sleep and not wake up,’ he wrote.” That’s pretty oriented and aware for a mostly blind, mostly deaf man assumed to be too confused to live. The lawyer did not explain why his client decided to get her husband’s words in writing; did not suggest they perhaps were part of a planned defense for an act of premeditation rather than one of helpless rage or selfless love. And to be fair, nobody asked him about Jean Brush’s request that her husband commit his “despair” to paper.

Frank Genesee called his client’s murder of her husband a “love-suicide pact.” But if Cecil Brush was as confused as everybody said, then he couldn’t agree to anything. Jean Brush, her legal defender, and their chroniclers wanted it both ways: Cecil Brush had to be oriented enough to make an informed choice for death, to participate in a “love-suicide pact,” and yet be so captured by the deficiencies of Alzheimer’s disease that he was made helpless and unaware by that illness.

Cecil Brush’s limitations created a situation of fragility and need. But we do not generally accept those as reasons for the murder of loved ones. It would not be surprising if his infirmities led to moments of depression or despair. With others who have cared for fragile seniors (or younger people permanently injured in an accident), I’ve heard that wish— “I want to sleep and not wake up” —expressed many times. People suffering at every age from significant impairments may say it, now and again, as they struggle to accommodate to the realities of a restricted life. When life is challenged by illness, accident, or any chronicity, people will also sometimes say, “It’s not worth it. My life is