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Karen Ann Quinlan: Dying in the Age of Eternal Life; and Death Dying and the Biological Revolution: Our Last Quest for Responsibility

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BOOK REVIEWS

KAREN ANN QUINLAN: DYING IN THE AGE OF ETERNAL LIFE by B. D. COLEN. New York: Nash Publishing. Index. 1976. Pp. 204. $7.95 cloth.

DEATH, DYING AND THE BIOLOGICAL REVOLUTION: OUR LAST QUEST FOR RESPONSIBILITY by ROBERT M. VEATCH. New Haven and London: Yale University Press. Biblio., index. 1976. Pp. ix + 323. $12.95 cloth.

Joan A. Lang and Marc M. Seltzer***

> . . . (I)n saving Karen Ann Quinlan, a group of well-meaning physicians created a modern Frankenstein's monster. For they took the near lifeless body of a young woman and, rather than leaving her to herself in order that "the slight spark of life which [they] had communicated would fade, that this thing which had received such imperfect animation would subside into dead matter," they . . . worked against all odds and the wishes of the Quinlan family for more than a year. And what they worked so hard to save was a monster . . . .[1]

From the Age of Enlightenment until recent times, the dream of achieving dominion over nature and conquering disease and other natural calamities by the application of technology has seemed to come nearer to realization with each breakthrough in science. The mechanical wonders that fill this century would have astonished our ancestors. One dream, that of conquering death itself, is wonderfully depicted in Mary Shelley's tale of *Frankenstein* in which Dr. Frankenstein is blinded by pride in the abilities of his science. Believing that he could master the processes of life and death, and falsely confident that he could control his creation, he unleashed a monster.

B. D. Colen and Robert M. Veatch express trepidation about

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1. B. D. COLEN, KAREN ANN QUINLAN: DYING IN THE AGE OF ETERNAL LIFE 71 (1976) [hereinafter cited as COLEN] (paraphrased from Mary Wollstonecraft Shelley's introduction to her novel *Frankenstein*).

the "monsters" that may be unleashed by modern medical technology. Their works are part of a growing body of literature concerned with the impact of medical technology on the condition of life in its final stages. Colen and Veatch consider the particular circumstances and implications of the Karen Ann Quinlan case. Her saga is known to most of us, for it became, for a time, a *cause celebre*. According to our bent, we were enthralled by the personal and family tragedy, intrigued by the legal issues, or perplexed by the moral and philosophical issues which her case dramatized. However, the importance of the issues raised by the *Quinlan* case transcends the story of her life and death. Both authors seek to place *In re Quinlan*[2] in a wider context and to make us aware of other troubling cases resulting from recent advances in biomedical technology.

Thus, Colen and Veatch ask us to consider a variety of vexing problems: the badly crippled accident victim in a deep coma, the terminally ill cancer patient lingering in great pain, the newborn baby with severe birth defects, and other problems exacerbated by our new-found ability to prolong life. Typical questions which they present are:

> 1) What are the legal and moral responsibilities of the attending physician treating a patient in deep and irreversible coma? Should he or she do all within his or her power to sustain heart beat and respiration for as long as possible, regardless of the patient's capacity to regain consciousness?
>
> 2) What are the legal and moral rights and privileges of the patient? May a competent patient in his or her sole discretion determine what further treatment should be discontinued when such treatment is essential to sustain life?
>
> 3) What are the legal and moral rights and responsibilities of the patient's family and society at large? May family members or court-appointed guardians determine that further treatment is to be discontinued for a hopelessly comatose patient?
>
> 4) When should a patient be deemed "dead"?

2. 137 N.J. Super. 227, 348 A.2d 801 (1975).

The last is perhaps the most surprising of the questions we are asked to consider. Not so very long ago death seemed relatively simple, in practice if not in theory. Assaulted by any of a variety of illnesses or injuries, a person's heart stopped beating, breathing ceased, and perhaps with a symbolically significant "last gasp," the body grew still and cold. The person was dead, and no great skill was required to know it.

Advances in medical technology have changed this, at least for those living in the technologically developed Western nations. Once-stilled hearts can be jolted into starting again; a machine can be supplied to do the breathing. What once seemed miraculous is now routine. The constant narrowing of the kinds of therapies considered "extraordinary" as opposed to "ordinary," and the difficulty of drawing any "bright line" between them, evidence the rapid pace at which the biomedical revolution is proceeding.

Often, the results do seem miraculous. Human beings, even with medical histories that resemble Karen's, or worse, are saved from what would have once been certain death, and returned to normal or at least acceptably limited lives. But, inevitably, there are failures. The "best" failures, many feel, are those who die. The real problems—emotionally, morally, legally, and economically—are the partial failures—or partial successes, depending on one's viewpoint. These are the cases like Karen Ann Quinlan.

Legally, Karen Quinlan still lives. Colen and Veatch ask us to consider, however, what that means in light of the ability of modern science to sustain indefinitely the traditional "vital signs." Is that human shape which Colen calls a "monster," and which even her doctors describe as a "brain-stem preparation" and "grotesque," still a "human being" named Karen? Her parents are themselves desperately confused about this, judging from a fascinating conversation related in Colen's book.[3] They speak of her in the past tense at times, even refer to her as a "vegetable," yet continue to visit her twice daily. They have fought passionately to disconnect her from the machine which breathes for her, but would not dream of disconnecting her from the tube which supplies her nourishment. They fought for the right to direct her

3. COLEN, *supra* note 1, at 29-43.

doctors to turn off her respirator, but both said they would also fight to avoid having to turn it off themselves. The issues are murky, and the principles to guide their resolution are unclear or in conflict. Distinctions which seem crucial to one person seem irrelevant to another.

The only thing beyond dispute is that the issues are complex and that we cannot reasonably expect to find simple answers. Yet neither can we afford to muddle along without answers, for technology innovates so much faster than we can muddle that the gap would only grow wider. It is to the credit of both Colen and Veatch that they urge us not to succumb to the temptation to avoid the unpleasant and the difficult. As Roderic Gorney cogently observes in his book *The Human Agenda:*

> Up to now the rate of change in our lives has been slow enough to permit the processes of evolution of values to remain automatic and therefore largely unconscious. Today the rate of change we now produce in the condition of our lives is too swift for the processes of spontaneous evolution of values to keep up. For the first time in two million years we must learn to exercise a new freedom—the option to *choose* our values *consciously.*
>
> But no one today is equipped for such responsibility. . . . Today it has become impossible for any mind to encompass the available knowledge, while ironically it is becoming indispensable for every mind to do so. The time when we could leave our survival to specialists is past. The responsibilities of citizenship . . . require us all to be competent generalists.[4]

The Veatch book admirably serves this goal by addressing in an engaging way the principal medical, legal, moral, and philosophical issues raised by the impact of the "biomedical revolution" on our lives and deaths.

While Veatch and Colen address many of the same issues, and indeed argue for many of the same conclusions, their backgrounds and their books are quite different. B. D. Colen is a journalist, and in fact, according to the dust cover of his book, is the *Washington Post* reporter who "broke the story" of the *Quinlan* case. He has specialized in medical feature writing and bioethics and was nominated for a Pulitzer Prize for reporting on the

4. R. GORNEY, THE HUMAN AGENDA 9 (1972).

Quinlan case. His book, billed as "both a case history and a thorough examination of the larger public issue it represents," employs newspaper-style interviews and vignettes taken from several cases, including *Quinlan,* to dramatize his theses. Colen suggests that "Karen Ann's physicians insisted upon making her a prisoner of medical technology,"[5] that this is an increasingly common dilemma today, requiring our immediate attention,[6] and that it is our obligation to recognize the inevitability of death and to learn to care better for the dying.

Robert M. Veatch, on the other hand, is a scholar. Holding a B.S. from Purdue, an M.S. in Pharmacology from the University of California Medical Center, a B.D. from Harvard Divinity School, and an M.A. and Ph.D. in Religion and Society from Harvard where he specialized in medical ethics, he has been for several years Director of the Research Group on Death and Dying of the Institute of Society Ethics and the Life Sciences. His ideas on the social and ethical problems of death and dying and on the rights and responsibilities of being human, therefore, have taken shape over years of research, debate, and writing. His book impressively reflects this background.

The *Quinlan* case provides the impetus and the context for Colen's exploration of the issues of life- or death-prolonging decisions; for Veatch, the case, one of many analyzed, falls into place as one which provided public exposure to issues with which he evidently has long been concerned. His concern is "our struggle for freedom and justice in a world increasingly moved by a technological priesthood who can lead us simultaneously to salvation and damnation."[7] He wants "to probe the new social and ethical problems of death and dying that have been generated by those revolutions."[8] He brings to bear a wealth of interdisciplinary learning and helps to clarify many of these complex issues that inhabit a still largely uncharted landscape.

Both Veatch and Colen provide a large number of short descriptions of cases similar to the *Quinlan* case which serve as an

5. COLEN, *supra* note 1, at 11.

6. *Id.* at 12.

7. R. VEATCH, DEATH, DYING AND THE BIOLOGICAL REVOLUTION: OUR LAST QUEST FOR RESPONSIBILITY 18 (1976) [hereinafter cited as VEATCH].

8. *Id.*

introduction to these problems. The value of these examples for the general reader lies perhaps most importantly in providing a glimpse of what is, to many, an entirely alien environment, the strange twilight world in which the badly injured or deformed keep a slender hold on life, sustained by the artifices of modern technology.

The Colen book is a popular account which may stimulate the interest of those who, through newspaper reports, are somewhat familiar with the issues and dilemmas existing at the frontiers of medical treatment. However, its lack of bibliography or cross-references to the growing literature in this field diminishes its usefulness as a starting point for further inquiry. By contrast, the Veatch book contains many references to this literature, and due to its thorough and comprehensive approach may serve as a starting point for further exploration.

Both Colen and Veatch consider the circumstances in which medical treatment may be withheld or withdrawn in the light of the legal and ethical responsibilities and rights of physicians, patients, and their families. Both authors comment critically on the limits placed upon the freedom of action (and inaction) of patients and their physicians by legal rules and by the "chilling effect" of the law's uncertainty. For Colen, these limitations are impediments to sane and human accommodations to these highly personal tragedies, and he expresses understandable, though confused, frustration with the sluggishness of legal reform and the imperfections of the law. Colen insists that the *Quinlan* case is no case at all, meaning that situations like Karen Ann Quinlan's do not belong in the courts, but should be handled extrajudicially.[9] Veatch, by contrast, proposes elaborate legislation aimed at improving the present archaic and ambiguous state of the law.

9. In *In re* President and Directors of Georgetown College, Inc., 331 F.2d 1010, 1015-18 (D.C. Cir. 1964), views similar to those of Colen were expressed by Circuit Judge (now Chief Justice) Burger. Judge J. Skelley Wright had ordered that a blood transfusion could be given to an adult woman without her consent when the transfusion was necessary to save her life. *In re* President and Directors of Georgetown College, Inc., 331 F.2d 1000 (D.C. Cir. 1964). She had objected to the transfusion on religious grounds. The court of appeals denied a petition for a rehearing *en banc* of Judge Wright's decision. Judge Burger urged that the court of appeals should have dismissed the petition on jurisdictional grounds rather than merely deny the petition. In so doing, he expressed his view that such cases are beyond the competency of courts of law.

His proposals imply that the methods of social engineering can at least ameliorate the difficulties that are the "unnatural" by-product of advances in biomedical technology.

While Colen's plea for leaving the legal system out of the efforts to resolve these difficult human situations may strike a sympathetic chord, it is naive. Legal rules will inevitably be applied to some, if not all, such situations, either directly in the courts or indirectly through their influence on the attitudes of participants. Colen himself feels that one of the hidden reasons for seeking judicial relief in the *Quinlan* case was to overcome the attending physicians' resistance to acting in the face of their apprehension of malpractice liability.[10]

Additionally, there are deep and wide differences of opinion among many persons and interest groups as to the proper role of the doctor, patient, family, and courts in these situations. The legal system is ideally situated to serve as the means of resolving these differences in a rational and fair way. In the final analysis, the legal system has an obligation to society at large to formulate reasonable and intelligible rules which protect individuals from the vagaries of arbitrary decision-making. Of course, we have not yet approached that goal. There is much room for reform.

Law reform proposals touching upon the medical and ethical dilemmas related to death and dying have mainly taken the form of legislative action, such as California's Natural Death Act. Such legislative responses have thus far seemed unsatisfactory.[11] This failure is perhaps understandable in view of the complexity of the intense moral issues which lurk in the background of the legal issues. The complexity of the moral issues is brought into particularly sharp focus by the question of whether there is a fundamental right under the Fourteenth Amendment to the United States Constitution to refuse medical treatment. The issue is both legal and moral, because the resolution on the legal question depends upon notions of a "higher law" which transcends the literal text of the Constitution. As Veatch points out, the *Quinlan* case is important for its recognition of a constitutional right to refuse

10. The New Jersey court specifically found that Dr. Morse's decision was indeed in accord with and based on his conception of medical standards and practice and not a result of concern over possible liability. *In re* Quinlan, 137 N.J. Super. 227, 259, 348 A.2d 801, 819 (1975).

treatment. The far-reaching significance of this decision is that such recognition would place fundamental limitations on the capacity of government, either legislatively or by judicial action, to impose criminal or civil liability upon doctors who comply with their patients' requests to stop further medical treatment.

The constitutional analysis in the *Quinlan* decision is based upon a series of recent decisions by the United States Supreme Court which recognize the existece of a fundamental right of privacy.[12] *Griswold v. Connecticut*[13] and the Abortion Cases, *Roe v. Wade*[14] and *Doe v. Bolton,*[15] illustrate the application of the so-called "due process—natural law" formula[16] for recognizing fundamental rights which are "implied" from explicit constitutional guarantees and which cannot be abridged by government action absent a showing of some compelling and legitimate countervailing state interest. The view that fundamental rights exist with respect to the conduct of one's own life, including the right to determine whether certain medical treatment shall be given, is based on a demarcation between public and private life embodied in the notion that "some types of choices ought to be remanded, on principle, to private decision makers unchecked by substantive governmental control."[17] The constitutional debate on these issues reflects two countervailing social values: the protection of personal autonomy and the interest of the state in protecting citizens against themselves.

Both Colen and Veatch strongly adhere to the view that society has no right to overrule the competent patient's decision to refuse medical treatment. This view of the fundamental right of a person to exercise dominion over his own body, which is recognized

11. *See* Winslade, *Thoughts on Technology and Death: An Appraisal of California's Natural Death Act*, 26 DEPAUL L. REV. 717 (1977).

12. The New Jersey Superior Court considered and rejected a claim of a right to refuse treatment based on the Free Exercise Clause of the First Amendment, 137 N.J. Super. 227, 267, 348 A.2d 801, 823 (1975), and the Eighth Amendment's proscription of cruel and unusual punishment, 137 N.J. Super. 227, 269, 348 A.2d 801, 824 (1975).

13. 381 U.S. 479 (1965).

14. 410 U.S. 113 (1973).

15. 410 U.S. 179 (1973).

16. For a discussion of the development of this formula, see Adamson v. California, 332 U.S. 46, 80 (1947) (Black, J., dissenting).

17. Tribe, *Foreward: Toward a Model of Roles in the Due Process of Life and Law*, 87 HARV. L. REV. 1 (1973).

in the Abortion Cases, is based on a view of personal liberty most eloquently expressed by John Stuart Mill in his seminal essay, *On Liberty:*

> The only purpose for which power can rightly be exercised over any member of a civilized community against his will is to prevent harm to others.[18]

The *Quinlan* decision firmly endorses this principle.

Another aspect of the *Quinlan* decision that deserves comment is the recognition of the right of third parties to assert the rights of incompetent patients like Karen Ann Quinlan. Veatch, in particular, explores the intricacies of this controversial issue.

Beyond the legal issues, we cannot hope to understand or resolve the issues involved in death and dying without at least attempting to penetrate our basic attitudes toward death. Many thinkers, past and present, have addressed this problem, for death is not, after all, anything new. Psychology and psychiatry have explored "the death instinct," one of Freud's more controversial and mysterious postulates; philosophers such as Heidegger have pondered death's meaning; religions have formulated tenets to deal with the problem of how to bear the end of life; historians and anthropologists have studied death rituals—to name only a few of the relevant disciplines. Science has not so much pondered death as attacked it, transforming it, or attempting to, from "mysteries to be contemplated and deepened . . . into problems to be solved."[19]

Perhaps because of the magnitude of this work and thought, both Veatch and Colen have granted scant space to consideration of two disciplines which have contributed most importantly to our struggle to understand the meaning of death—psychology and philosophy. It is beyond the scope of this review to try to remedy that lack, but for the interested reader two major sources can be recommended as starting places: Ernest Becker's remarkable Pulitzer Prize-winning book, *The Denial of Death,*[20] and the writings of Dr. Elizabeth Kubler-Ross, the best-known being her

18. J.S. MILL, ON LIBERTY (1859).

19. DEATH INSIDE OUT 5 (P. Steinfels & R. Veatch ed. 1975) (introduction by P. Steinfels, quoting P. Ramsey).

20. E. BECKER, THE DENIAL OF DEATH (1973).

book, *On Death and Dying*.[21]

One of Becker's central ideas seems particularly relevant in that it suggests an explanation of some of our attitudes and actions in human dramas such as Karen Quinlan's. Becker argues that the terror of death is universal and "a mainspring of human activity—activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man."[22] This is alluded to in various places by both Veatch and Colen. But Becker goes on to theorize that one of our major human reflexes in the face of this terror is the urge to heroism. Through heroic acts we can, if only temporarily, shake a fist at fate, defy and deny the overwhelming terrors of the universe, and claim victories to soften our despair at the inevitability of final defeat and decay.

Becker's theory does seem to render more intelligible some of the choices we make as a society. We will risk the lives of many trained men to rescue the couple who have foolishly stranded themselves on a mountaintop; follow intently the drama of an all-out effort to rescue a handful of trapped miners, though we have not made it a priority to remedy the working conditions which got them there; spare no effort or expense to "save" a Karen Quinlan, while somehow finding that the expense of providing adequate health care services to the ghetto and the barrio can be spared.

Despite these reservations, the books by Colen and Veatch are serious and thought-provoking. They persuasively make a case for the importance of reexamining our attitudes towards death and dying in the light of our new powers. Yet, after all is said and done, it may be that choices about the meaning and manner of one's own death, like numerous decisions made in life, will continue to be rooted more in personal character and style than in reflections upon abstract analyses or legal theory. Two writers quoted by Veatch and Colen serve as a fitting reminder of the ultimately personal meaning of death, which each of us must face alone, and reflect the diversity of individual stances possible before the prospect of death:

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21. E. KUBLER-ROSS, ON DEATH AND DYING (1969).

22. BECKER, *supra* note 20, at iv.

A dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong, as well as useless, to resist.

Stewart Alsop, *Stay of Execution*[23]

Do not go gentle into that good night . . . Rage Rage against the dying of the light.

Dylan Thomas[24]

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23. COLEN, *supra* note 1, at epigraph.
24. VEATCH, *supra* note 7, at 278.

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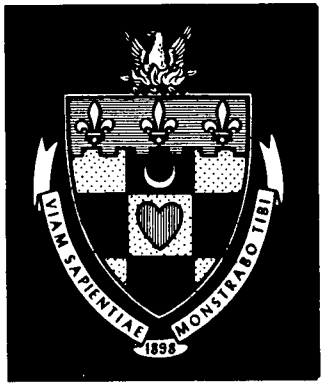

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