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[Nine Book Reviews]

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Aging, Dying, After-life: Seven Books on Death

When a society becomes affluent, having attained a life-style and comfort-level far beyond that which is required for optimal survival, its thoughts shift to things other than survival. Such thoughts focus primarily on "meaning" (the meaning of one's life, of the universe, of religion, etc.), and on "futuristics" (the future of the species and of the world, the extrapolation of present life-styles into future consequences, and the death of our bodies).

The increasing research on death and dying is an outcome of the leisure of affluence. We have more time to think; to think about our finality as corporeal beings, and to think about our post-death future. A second causative agent responsible for the death-and-dying surge is our highly-sophisticated an ti-death technology, to which I refer in the

February 1976 issue of LQ (in the review of Jerry B. Wilson's Death by Decision: The Medical, Moral, and Legal Dilemmas of Euthanasia).

And as the thought-level of a society is raised, so is its volume of publication. Its reflections are transformed onto paper for wider dissemination, and for profit. At times the only purpose seems to be the latter.

I have selected for brief review seven recent publications that deal with the phenomenon of aging and dying, from several different perspectives. Their quality, sophistication, and accuracy are scattered across a wide spectrum.

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Death Inside Out: The Hastings Center Report

Peter Steinfels and Robert M. Veatch, editors

The Thomas More Association, 180 N. Wabash Ave., Chicago 60601, 1975. $X+149\ p., \$7.95$

The Hastings Center (Institute of Society, Ethics and the Life Sciences) is an outstanding organization operated by outstanding personalities. One must truly respect the quality of their research and publications. Except this one.

In his Preface, Daniel Callahan states that "(This) collection of essays...does not...represent the work of our research group in its totality...." In fact, it is unclear whether the 12 articles reprinted under this cover were written specifically for this work or not. The reader is given the distinct impression that the authors wrote their articles for this report, whereas at least "Death: Process or Event?" and "Death as an Event" first appeared elsewhere, and no credit is given to the original source.

I do not object to the raising of funds via a collection of essays. I do object when such a collection is subtly implied to be collected for a specific book. In an article by Kass (p. 104), reference is made to two other articles by Morison and Kass, both of which appear in the book; however, the source of the two works, *Science*,

is not given (whereas the sources of other works are listed routinely throughout the book).

This is not a "Hastings Center Report." Although the book is billed as a "dialogue" and its authors as "contributors," it is in reality mainly a collection of essays written at various times and for various publications. Legally, the editors are in the clear. Ethically, they may have failed to attain the high standards which we have learned to expect from the Center.

The most difficult task to be conquered in evaluating the growing number of publications on death is to separate those authors, theses, or books that merely ride the bandwagon from those that steer it. This book, unfortunately, takes a seat in the rear.

Living and Dying at Murray Manor

Jaber E. Gubrium

St. Martin's Press, 175 Fifth Ave., N.Y. 10010, 1975, 221 p., \$8.95 (\$4.50 paper)

Murray Manor does not exist. But it represents the typical large nursing home, with 360 beds. The book "examines the social organization of care in a . . . nursing home," documenting "the way in which the 'work' of everyday life in a nursing home is accomplished." It examines the role of the staff, the social relationships of the residents, even the floor plans of the home.

There are some very personalized descriptions of the residents' actions, downs, and general attitude. References are made to "the first-floor-dominated rumor mill," the top staff's attempts to make "the Manor's public places . . . look like home," the decision-making process that leads to room assignment and occasional bedrestraint, and patient interviews.

The author compares the top staff's concern for total patient care with the floor staff's concern for physical care and routine. The complex social setting, with a need to maintain ties with the outside world as well as to establish a socially-stable "inside" world, seems to be overlooked, or

at least misunderstood, by both staffs. "... top staff is insulated from the ongoing complexities that exist within the social world of clientele."

The book presents a remarkably accurate portrait of the typical high-quality nursing home. The dynamics of staff-resident, and of resident-resident, interrelations are explored in detail, the needs of residents for some equilibrium between privacy and socialization, and the mechanical, routine, time-clock attitude of floor staff, are all depicted vividly. This is a valuable resource for one who seeks a comprehensive view of "the final years," a view that is not oriented on arm-chairacademics, but on long-term onsight inspection by the author.

It is unfortunate that we "admit" people to hospitals, but "put" people in nursing homes. Perhaps the terminology can be improved as nursing home management becomes improved. In the meantime, however, anyone who anticipates being "put" in a nursing home within the next few years should read this book; it will ease one's apprehension.

How to Face Death Without Fear

Selections from the book "Preparation for Death" by St. Alphonsus Liguori Norman J. Muckerman, C.S.S.R., editor

Liguorian Books, Liguori, Mo. 63057, 1976. 64 p., \$1.00

This pamphlet falls short of the intent of its title. It is an extraction from a 218-year-old book, and as one might expect, it has little relevance to today's death bed ecology, ICU-isolation from family, and technology-sustained metabolism.

Instead, the stress is upon fearing the devil, and on death-bed reconciliation. The pamphlet is an attempt to ease the fear of dying, yet one reads: "... in a little while no one will speak of him any more." "(his nearest relatives) will soon be consoled by the thoughts of their share of his estate." "On our death depends whether we shall be forever happy in heaven or forever lost in hell." "... that awful hour..."

One must ask if the book, with its countless and repetitive quotes from scripture, helps us to face death without fear, or threatens us with 'How to fear for your soul as you are dying.'

I suppose that a small group will benefit from the rather general, and never concrete, format of the pamphlet. And I suppose therefore that it has value. But it made me more uneasy about my own death than I was before. It did not relate to me what I feel I would need when faced with masked men and women against a sterile white background, with tubes exiting my body in all directions, swinging to the rhythm of an electron-fed breathing machine.

The Dilemmas of Euthanasia

John A. Behnke and Sissela Bok, editors

Anchor Press/Doubleday, 245 Park Ave., N.Y. 10017, 1975, viii + 187 p., \$2.95

A very valuable little book. One of a few that does not pretend to have all the answers on this complex problem.

Behnke and Bok have assembled, with a few exceptions, seven works that present a very professional and balanced view of euthanasia. Bok writes on "Euthanasia and the Care of the Dying," Eric Cassell on "Permission to Die," Robert Glaser on "A Time to Live and a Time to Die." Stanley Joel Reiser presents a well-documented, but slightly loaded, historical perspective, and David Meyers outlines the major legal aspects with clarity. Some individual works, such as Cassell's, are not balanced but instead sharply polarized in their views; however, the overall effect of this compilation is a balanced one.

The editors emphasize that the discussion on euthanasia has been "hampered by a dearth of relevant empirical information and by a lack of careful definitions." Four of the articles were originally published in *BioScience* in 1973.

The reader is made aware of many serious questions, such as:
"... is euthanasia an act of putting the patient to death, or can it also describe suicide and omission or cessation of care?" and "Is there any difference between killing a person and letting him die through omitting a remedy?"

There are several debatable statements, and as long as the reader is on his guard, not accepting everything in print, this resource can be an excellent launching-pad for serious discussion. Such statements include (1) "... those few patients who request euthanasia ought to have the right to decide whether or not they wish to take such odds and continue to suffer, or choose to die." (2) "Most terminal patients . . . do not suffer pain." (3) " . . . we should arrive at a consensus concerning some categories of justifiable suicide . . . " And a most frightening finding from a poll conducted by Diane Crane: (5) " . . . withdrawal of treatment by the physician depends less upon the consent of the patient or his agent than on the physician's assessment of the patient's prognosis and type of deficit."

One is rendered aware of the dangers of death-legislation, via reference to Hitler's regime and such groups as the "Realms Committee for Scientific Approach to Severe Illness Due to Heredity and Constitution." "The hundreds of thousands of people killed through these organizations included mentally ill, epileptics, the aged sick, and sufferers from neurological diseases such as infantile paralysis and brain tumors."

There are several appendixes, including of course "A Living Will" and "A Definition of Irreversible Coma." There is a conspicuous absence of "The Christian Affirmation of Life" published by the Catholic Hospital Association, which stresses the transitional (and not final) per-

spective on death.

The book ends with an appropriate conclusion: "There are no easy answers . . . What is called for is one's best wisdom and judgment, applied in each instance in terms of individual circumstances."

Death and Beyond

Andrew Greeley

The Thomas More Association, 180 N. Wabash Ave., Chicago 60601, 1976. 144 p., \$7.95

Father Greeley is now well known for his enjoyment in tearing apart other human beings. Perhaps we all do so at times. It is fun to see someone else do the tearing, however. Our animal instincts admire anyone who has the fortitude to bring another person down. I also indulge in such therapy on occasion. But then our "human" self surfaces, and overcomes our "animal" self, at least temporarily, and we come to realize that there must be a better tool of communication and of socialization than the tearing apart of fellow social beings. In that temporary moment of reality, we begin to realize that when we feel pleasure in the degradation of other people, or of their beliefs, we are really copping out. Instead of bringing ourselves up from a down, we try to bring others down with us.

In this book, the author again manages a few slurs, but most importantly, he describes the methods by which he compiles the data upon which he bases his writings. I am grateful for the book, for it showed me the extent to which one must lay faith in Father Greeley's analyses.

Managing a reference to "a rapidly vanishing minority of believing and practicing Catholic Christians," the book begins with a very artistic look at life and death, a very well documented and positive outlook on the Resurrection, the meaning of death, the Easter experience. In response to "Is this all there is?," he replies "How come there is even this?" "We are born with two incurable diseases: Life—always fatal—and hope—never curable."

He continues to redeem himself, in this reviewer's opinion, by statements such as "What sort of God would it be who would absorb us into Himself and snuff out our own individuality in the process?"

But after such enlightenment, Father Greeley then offers data to justify a belief in life after death. You cannot prove eternal life; you must have faith in its existence. But Greeley says: "... psychic research, parapsychology, the study of altered states of consciousness... enable us to conclude with a high degree of confidence that there is a dimension of the human composite which is able to operate, at least for brief periods of time, independently of the human body."

He asked people, at cocktail parties and the like, if they ever had "ecstatic episodes" (out-of-body experiences). The question asked of 1500 people was: "Have you ever had the feeling of being very close to a powerful spiritual force that seemed to lift you out of yourself?" And he chastises the

scientific community for rejecting

I cannot put a finger on Greeley's thesis. Is he attempting to increase the probability of life after death by showing how many believe in such? Yet he stresses that one cannot prove eternal life. Is he attempting to allay the fear of death? Yet he stresses, in his opening remarks, "We know that what is born with spring will die in the cold of the following autumn and winter . . . that which is blooming now is living off the corruption and decay of that which lived in the past."

All in all, a very confusing book.

Handbook on Euthanasia

Susan M. and Robert L. Sassone

900 N. Broadway, Santa Ana, Calif., 1975. 144 p., \$1.50

The authors are very powerfully opposed to euthanasia. One can sense the immense feelings they harbor. This small book is their attempt to share their views with us. Every facet is discussed; the standard arguments, the living will, the well-publicized criteria for personhood.

Perhaps this book is not as professional a presentation as some others on the subject, but one must read it if one hopes to attain a glimpse at all views on this matter. Especially useful is the testimony by Kubler-Ross, Sackett, and others before the U.S. Senate.

I recommend this book highly for anyone who wishes to catch the sense of one's gutsy and unpolished reaction to euthanasia.

The Release of the Destruction of Life Devoid of Value

Karl Binding and Alfred Hoche, with comments by Robert L. Sassone

(Originally published in German, 1920.) 900 N. Broadway, Santa Ana, Calif., 1975. 112 p., \$1.50

Another very powerful book by Sassone. This one reminds us of the atrocities of the Nazi regime. According to the author, "This is the book which the defendants blamed . . . for their actions in killing innocent human beings in unprecedented ways and quantities (in the Nuremberg trials)."

From the original German version, one reads such familiar statements as (1) "Everyone should have the right to terminate his own life." (2) "The elimination of pain is also healing." (3) "Granting death with dignity is not dependent on the consent of the tortured sick person. Of course, death with dignity should never be granted against his known wishes, but very often, persons who are momentarily unconscious have to be submitted to this healing intervention." (4) "(the incurable idiots) are just a caricature of true man . . . In time of higher morality-our time has lost all sense for heroism-these poor people would be delivered from themselves by legal authority." And it goes on. Hoche wrote of the "financial burden" imposed by the ill and deformed. "The question of whether we should spend all of this money on ballast type persons of no value was not important in previous years because the state had sufficient money. Now, conditions are different, and we really have to deal with this question. Our financial condition could be compared to that of a very dangerous expedition into the wilderness which can succeed only if everyone is pulling his own share. In such a case there is no room for persons capable of only giving half, quarter or one-eighth effort." It becomes clear that, in 1920, "death with dignity" was but a convenient phrase designed to ease the conscience of a society that was becoming determined to kill all who could not provide.

And such is equally clear in 1976.

One wonders to what extent are the U.S. Public Health agencies embarking on the same course that led to 1940 Germany, when they advocate the abortion of all babies found defective via amniocentesis, or when they begin to perform cost-benefit analyses on human lives. It is not impossible that the Western nations could become the Nazi terror of 1985.

The Myth of the Hyperactive Child and Other Means of Child Control

Peter Schrag and Diane Divoky

Pantheon Books, a Division of Random House, 201 E. 50th St., New York, 1975. 285 pp.

The book is intended to stimulate informed action against a new ideology of child control, i.e., the widespread use of drugs, psychological testing, "predelinquincy screening," behavior modification, data banks, etc. The authors charge the public school as a formidable power forcing inappropriate diagnosis, dangerous drugs or other atrocities perpetrated on children in the name of socialization. These programs, claim the authors, are conditioning an entire generation to rely on the institutions of the state and on technology to define and engineer its health, thereby distrusting its own instincts and seeing nonconformity as a sickness.

For those parents who lack effective means to protect their children, the authors have furnished strategies in an appendix entitled "The Elements of Self-Defense."

The book reads like a report of a child-control police state engaged in "punishment to fit the crime" activities. In its intent to document how people apply labels first and then prescribe treatment to fit the labels (not necessarily the treatment to fit the child), the book is very unfair to those who are genuinely concerned with the education, welfare, and needs of children. All

parents, teachers, schools, and professionals in the field of Learning Disabilities, even the caring ones, have become the victims of this book's critique; for the book reads like a vendetta against them. This group has become the scapegoat for the relatively few involved in the criminal-like activities documented by the authors.

By criticizing the organizational efforts of those who have put up a combined united front out of concern for children, and by making the people who are concerned with the development and well being of children appear guilty of inappropriately using labels, medication, and special programs. Schrag and Divoky are themselves guilty of implicitly indulging in their own kind of labeling. They paint a rather bleak picture of special education; but special education has not been achieved by the good will of the public. It has been created by law-a law with a two-edged sword: one which gives the means to achieve an end by force; the other which protects the individual from being abused by these means.

What the authors document is shocking and disgraceful. Indeed, it exists. What the authors have done is to take cases that exist and unfairly say, "This is the way it is with all." The information and ideas they relate are important and must be critically examined by all of us!

Too often, a book of this kind is frequently quoted but not read. Those strong in their convictions. who have made up their mind to a particular point of view, often seek to reinforce and confirm their own convictions by using sections of just such a book. Taking an extreme position, the authors have polarized positions without giving any thought to providing an opportunity for probing and assessing these critical issues. They have set the stage for opinionated critics of "learning disabilities" and "special needs," who must grind their axes, to use this book to attest to the fact that they are right and everyone else is wrong. And so once again, the needs of children are neglected.

The people, yes, the people,

Until the people are taken care of one way or another,

Until the people are solved somehow for the day and hour,

Until then one hears, "Yes, but the people. What about the people?"

> (Sandburg, 1930, THE PEOPLE, YES, REVISITED)

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Genetic Screening: Programs, Principles and Research

Barton Childs et al.

National Academy of Sciences, Washington, D.C., 1975. 388 pp. \$6,00 paper

A Committee for the Study of Inborn Errors of Metabolism (National Research Council) has reported on the history, present status, future potentials, and problems of genetic screening. Genetic Screening is a monument to effective self-criticism within the scientific community. It is at once remarkably thorough and wonderfully readable.

No major human, societal, or scientific aspect of genetic screening is overlooked. Phenylketonuria (PKU) is given most attention. But Tay-Sachs Disease, Sickle Cell trait and disease, monitoring of alpha-fetoprotein, and chromosome analysis are considered. The focus is constantly returned to the criteria by which we can judge and plan new screening programs because of experiences with those of the past.

A welcome sense of urgency (that screening be done well if done at all) animates the report. Conversely, one has no feeling that the authors are naive or overly enthusiastic. Persistent inadequacies of the American PKU screening programs are drama-

tized in one appendix, which describes the more successful British system.

Chapters are devoted severally to legal, economic and ethical aspects of screening. But concern for these dimensions is apparent throughout the book, Dr. Norman Fost's brief chapter on ethical issues offers a clear and helpful discussion of the "ideal ethical observer," and of the appropriate role of the ethicist in health care. Fost's attentive and active presence is also evident in other chapters. His special concern for the intricacies of informed consent must have influenced the drafting of passages where that issue arises. Perhaps more importantly, recurrent expressions of concern for the service aspects of screening could not have been produced single-handedly; they must reflect a welcome bias of the entire committee.

To list only the important points made in the report would occupy too much space. I should like to single out two.

It is affirmed that screening is legitimate for a) medical intervention in disease management,
 reproductive information for carriers, c) enumeration of trait frequencies in populations, and d) research on evolutionary patterns or on feasibility of proposed new screening should never be impressed on

people, or employed for political eugenic purposes.

2) Large genetics clinics operate almost exclusively under government research grants. Counseling (direct active service to persons coming to the clinic) often must be done surreptitiously rather than as an integral element of the clinic operation. This is unconscionable, and represents a serious failure of societal commitment to public health in provision of a basic (albeit rather new) form of preventive health care. So, I strongly endorse the committee's unequivocal position: "no screening program (whether for service or research) that is in any way related to health should fail to offer (facilities for genetic counseling)" (p. 261).

The final section of the report is a synopsis of all its major points, and is available as a separate pamphlet useful in its own right. Genetic Screening is an achievement of great value to anyone interested in the subject. from whatever perspective: medical practice, public health policy, legal or ethical or sociological implications of health-care systems and research. It can simultaneously serve the practicing physician who desires deeper insight into the genetic aspects of health problems.

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