LIFE SUSTAINING TECHNOLOGIES AND
THE ELDERLY

Legal Issues: Italy

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for the Office of Technology Assessment, U.S. Congress, 1986

The assistance of Osvaldo Geiser in the preparation of this report is gratefully acknowledged.
LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY

WORKING PAPERS, VOLUME 4:
USE OF LIFE-SUSTAINING TECHNOLOGIES IN OTHER COUNTRIES

July, 1987

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These are contractor documents prepared for the OTA assessment, Life-Sustaining Technologies and the Elderly. The complete set of contractor reports for this assessment consists of five volumes. OTA makes these documents available for the use of readers interested in these topics. These contractor documents have not been reviewed or approved by the Technology Assessment Board. The findings and conclusions expressed are those of the authors and do not necessarily reflect the views of OTA, the Advisory Panel, or the Technology Assessment Board.
With sadness, I note here the unexpected death of my colleague's 30-year-old friend who had been receiving dialysis treatments. Mr. Geiser's work on this OTA project brought him into contact with medical personnel who pointed out that his friend would be better off having a kidney transplant — especially since he was so young and would automatically have "priority." He intended to pass along this advice to his friend, who apparently had not been so advised yet and apparently intended to continue dialysis indefinitely. The friend's condition unexpectedly worsened. When a nurse was preparing to take blood from his arm, a nursing colleague pointed out that the patient was already dead.

His family believe that both the original handling of the kidney ailment (resulting in the need for dialysis) and their son's death resulted from medical misjudgment and mismanagement. They did not, however, permit an autopsy nor do they intend any legal action whatsoever. Case closed.
# TABLE OF CONTENTS

I. INTRODUCTION ...................................................... 1
   A. Demographic Profile: Aging of the Population ............ 1
   B. Role of the Family ........................................... 2
   C. Role of the Elderly .......................................... 2
   D. Attitudes toward Death ...................................... 3
   E. Role of the Church .......................................... 3

II. STRUCTURE OF THE HEALTH CARE SYSTEM .................... 4

III. THE RIGHT TO TREATMENT AND THE RIGHT TO REFUSE TREATMENT ... 10
   A. The Right to Treatment ..................................... 10
   B. The Right to Refuse Treatment; the Right to Die ........ 11
      1. The Current Controversy ................................. 11
      2. The Church's Position(s) ............................... 12
      3. Legal Issues: Defining the Moment of Death ......... 16
      4. Legal Issues: De Jure vs. De Facto; Physicians' Attitudes ... 18
      5. The Decisionmakers: Doctors, Families, Patients .... 20
      6. Proposed Law on Euthanasia ............................ 22

IV. LIABILITY .......................................................... 23

REFERENCES (including personal contacts with informants)

APPENDICES:
   A. National Health Service
   B. Health: Goodbye Services; Nearly Everyone of Us Will Pay
   C. Therapeutic Tenacity: the Case of Calvino
   D. The Man of Civil Rights: Fortuna is Dead
   E. Public Opinion on Euthanasia, Active and Passive
   F. Processed for Maltreatment
   G. Patient's Bill of Rights
I. INTRODUCTION

No one seems to believe that technology has much to do with the problems of the elderly in Italy: "It's not a question of technology, they need social assistance" (Crocella); "It's not technology, it's a sociological problem" (Mori); "It's not technology, it's a moral problem" (Merli).

Only indirectly is the problem viewed as "technological" or stemming from technological advances. Mori (ethicist and expert in jurisprudence) notes that before advances in technological health care made the prolonging of "vegetative" life possible, there was no need to distinguish between active and passive euthanasia. And demographers point out that the "technology" of contraception and safe abortion, together with changing economic and social values, have caused the sharp post-war decline in Italian fertility, which in turn has resulted in a serious aging of the population.

A. Demographic Profile: Aging of the Population

The population of Italy was 47.5 million in the 1951 census, rising to 56,244,000 by 1981— an annual increase of .064% in the 1951-61 decade, but only .038% in the decade 1971-1981. Post-war crude birth rates dropped from 22/1000 population to 11.3 in 1980 (well below the US rates of about 15). Crude death rates were 30 in the immediate post-war period, dropping sharply to 10 and remaining stable. Migrations abroad also declined, from over a million in the years 1951-61 to less than a quarter million in the subsequent decade.

In 1951 the population 60 and above number 5.7 million, or 12.2% of the total population, rising to nearly 10 million at present, or 17.4%. Persons over 80 more than doubled in 30 years, now numbering 1.3 million.

Life expectancy was 65.6 in 1950-53, rising to 72.8 in 1974-77 (undoubtedly even higher now in 1986), due primarily to reduced natality and declining infant mortality.

It is projected that by the year 2000 (with continued low fertility and a net migration of zero) the population will number 56.2 million among whom the elderly over 60 will constitute 22.1%; nearly one fourth of the female population will be 60 and over. (Comitato Nazionale Italiano sui Problemi della Terza Età, mimeo from the House of Deputies)

It is unnecessary to point out the specific changes in social and economic life that these changes imply, nor the added burden on the health care system and social services (Natale 1981).
Italian Regions

1 - Piemonte
2 - Valle d'Aosta
3 - Lombardia
4 - Trentino Alto Adige
5 - Veneto
6 - Friuli Venezia Giulia
7 - Liguria
8 - Emilia Romagna
9 - Toscana
10 - Umbria
11 - Marche
12 - Lazio
13 - Abruzzo
14 - Molise
15 - Campania
16 - Puglia
17 - Basilicata
18 - Calabria
19 - Sicilia
20 - Sardegna
While it is risky to generalize about an entire nation — whether the subject be national character, health statistics, or provision of public services — it is particularly important in the case of Italy to point out regional distinctions. The North — including French-minority zones in Aosta and German-speaking minorities in the South Tirol (Alto Adige) — is generally more "European" in orientation and social indicators, while the South (including Sicily, Sardegna, and Calabria, as well as Napoli — areas from which a large proportion of Italo-Americans emigrated) is more "Mediterranean" in culture, social and demographic characteristics. Rome is geographically central, but grouped for statistical purposes with the North (this despite large migrations post-war from impoverished southern areas which have strongly influenced life in the capital city). Some examples of regional differences: life expectancy at birth is 70.6/77.2 (male/female) in all-Italy (1977-79), but only 69.7/75.5 in Campania (Naples and surrounding province). Hospital beds per 1000 inhabitants are 8.2 in North-Central regions, only 6.2 in the South. Significant for the topic discussed here are proportions voting for the Christian Democratic party in the 6/83 parliamentary election: 37.3% in the South, 30.8% in North-Central. Divorces are more than double in North-Central areas (27.6 vs. 13.6 per 100,000 population) than in the South. Northern suicide rates are higher, while Southern crime rates are higher. Expenditures for social security and health are far higher in the North. (Istituto Centrale di Statistica 1985 and Istituto di Ricerche sulla Popolazione 1985)

B. Role of the Family

From films, books, friends, and sociological literature, Americans have no doubt heard often how important in daily life is the Italian family. In Italy, one quickly learns that to have one's car repaired, a sofa re-upholstered, or to find a job, family connections are essential. The Family has also been likened to a small state: since the government does not provide certain services, the family must. Sickness is a prime example of the centrality of family care, where a good deal of nursing, particularly for the terminally ill, is expected to be done by female members of the family.

C. Role of the Elderly

The trend in Italy is not unlike that in many other industrialized nations, except that it is happening later. From a role as respected, wise, and in some ways powerful, the elderly person increasingly finds him/herself in the
role of the "peso" (weight, burden), particularly when sick. Most refuse to go to the few nursing homes that exist; despite names suggesting luxury (Villa Bella, etc.), such homes are very expensive and often accused of providing atrocious care. In limited instances a state-paid nurse provides domiciliary care, but daily chores for the frail but not sick elderly are expected to be performed by the family. The role of the elderly female is the subject of social research and journalistic attention, especially as many who grew up in a world in which divorce was unthinkable and women did not have paid employment now find themselves divorced, unskilled in the marketplace, and impoverished.

D. Attitudes toward Death
Death and funerals are often noted as a particularly revealing aspect of a culture, though often misunderstood by outside observers. Elaborate floral arrangements, mournful public processions for funeral cortea (snarling traffic for many blocks around), and minutely prescribed death-related ceremonies and duties are characteristically "Mediterranean" and thus more common in Southern Italy. (Americans who have seen too many movies might jump to the conclusion that expensive elaborate highly public funerals are invariably for decedents of the Mafia.)

Mori (see list of informants) characterizes Italian attitudes toward death as more "tabu," "closed," and "secret" than those of more northern countries. Others refer to Italian funerals as "highly emotional, sentimental," or as "occasions for family reunions." Italians visiting cemeteries in northern countries, for example, say they are struck by their beauty and openness (lacking high walls, family compartments, shields of cypress trees): "I've even seen people go to cemeteries to stroll /as in Pere Lachaise, Paris/; we're far too morbid to do that" (Mori). Caskets are open before the funeral, except of course in cases of gross disfigurement; widows are expected to kiss the dead husband. Cremation, opposed by the Catholic Church, is very rare.

E. Role of the Church
Nominally more than 90% of the population is Roman Catholic. To understand Italy at all, one must appreciate its close ties with the history and current center of power of a worldwide religion, and the recency of the country's political independence from the Vatican. (The first Concordat between Italy and the Vatican was signed in 1929 by Mussolini, only revised in 1984.)
This is not the place to draw conclusions concerning the de facto power of the Catholic Church over state affairs, as it is clearly still a matter of considerable public dispute. In fact, over the strenuous objections of the Vatican, liberalized divorce and abortion laws were passed in recent years. But the relationship between the Vatican and Italian politics can be viewed by quick reference to the role of the Christian Democratic party (DC). Italy's 45th post-war government has just been formed, with a 5-party coalition. The Prime Minister is a Socialist, but the largest party is Christian Democrat, about a third of the electorate. Together with three other right-of-Communist parties (but excluding the fascists) they make up the government. The Communist Party is the second largest vote-getter (actually the largest in the European Parliament elections last year); it constitutes the opposition. Until recently the government of Rome was Communist, but has returned to DC control. The Church's role in all of this is ostensibly indirect, but generally acknowledged to be considerable. Pope John Paul II openly urges voters to vote for the DC party, and for decades it has been common practice for the full weight of the Church to have been brought to bear to assure the defeat of the Communist Party in various elections and referenda — though the influence has not always succeeded.

In medical matters, as we will see below, the Church has considerable influence: many hospitals are Church-run, staff in public hospitals are often religious personnel; coinciding with the entry of the Communist party into the government of the city of Rome, the Vatican withdrew religious personnel from public city hospitals, creating a staffing crisis; large numbers of health personnel are trained in Church institutions, after having received Church-sponsored education; medical societies are a primary channel for dissemination of Church doctrine and current papal teaching. Papal decrees, speeches, etc., whether to medical societies or to Parliamentary deputies, are not "orders" but they are suggestions taken quite seriously by practicing Catholics and their colleagues, all of whom function in an environment heavily influenced by the Church.

II. STRUCTURE OF THE HEALTH CARE SYSTEM
(See also Appendix A, National Health Service.)
Italy has a comprehensive health law which applies nationally, to which regions may add their own laws and services; for example, in the regions "rosse e ricche" (red and rich), primarily in the North, additional services are provided, such as social assistance, domiciliary care including social workers as well as nurses, etc.
Law #833 of 1978 was an effort to "rationalize" a fragmented system of separate provisions; various entities existed according to the type of employee — engineers, agriculturalists, lawyers all had separate health units. There could be an abundance of services in one quarter of a city while others were lacking. All entities were public, and it was obligatory to belong and pay in, both for health care and pensions. (Only the "liberal professions" and storekeepers were exempt.) The system cost more than it was taking in. Virtually all parties agreed to a change, including the extreme right which "didn't dare oppose" (Crocella). The Communists contributed to the formulation of the law, but by the time it was to be implemented, they were no longer part of the ruling coalition. Implementation has been slow.

All citizens, plus foreigners from countries with reciprocal agreements, are entitled to free medical care under law 833. (Its financing and operation are said to be similar to the British system.) Care includes physician visits, medicines, ambulances, hospital treatment, laboratory analyses etc. Gradually, certain categories of services have been excluded and certain fees introduced — e.g., patients pay a small sum for prescriptions; dental care is excluded, as are thermal bath cures, certain specialists, particularly expensive technologies such as CAT scans (unless prescribed by a national health service physician and performed in a public hospital or clinic). Patients may choose their own doctor, many of whom provide services in both public and private settings. Those who wish to avoid long waiting lists (e.g., 60-90 days to enter a public hospital) and the grossest inefficiency may pay for private clinics and doctors. Private hospitals and clinics are less frequent in Northern regions because public services there function more efficiently. Services are provided in hospitals, clinics, and in ambulatori (or outpatient) settings, all of the above both private and public, with religious personnel in all settings. It is common to hospitalize patients for many days for diagnostic tests, especially prior to surgery. "Parking of the elderly /in hospitals/, especially in vacation time" is common (Manni 1985).

Hospices are virtually unheard of; the Italian word "ospice" is a "home for the aged." Italians generally prefer to die at home. "Why create a new type of health facility just to provide a non-hospital setting for the dying, which is what the family is supposed to do?" (Anon.)

Families attempt to anticipate the time of death in order to remove the patient from a public hospital. If he dies in such a hospital, there are expenses in removing the body, but more importantly, the head physician legally has the

Mori points out that UK/USA-type hospices can mute the issue of euthanasia, since comfort, pain alleviation predominate over life-sustaining techniques. (1985b)
right to order an autopsy. Legally, the family has no right to refuse, but if they "weep or threaten," the result may in fact be no autopsy. Autopsies are quite contrary to Italian culture, but the law permitting them passed under pressure from medical researchers "because there's never enough material for medical research" (Merli).

The 1986 finance bill, hotly debated in Parliament at the end of 1985, contains sharp cutbacks in all sectors, but health is to be most drastically affected. Only parts of the bill were actually passed, but other proposals have gone into effect by decree, such as a rise from £1000 to £2000 for each prescription, and a rise from 15% to 25% in the proportion of the cost of medicines and lab analyses that patients will have to pay; those in the poverty class would be exempt. (See Appendix B, "Goodbye Health Services.") The proposal would also regulate the number of beds, now 6.5 per 1000 population, to be 1 per 1000 within 3 years, and bed use to be not less than 75% (referring to non-acute conditions needing low-intensity care); hospital stays should average no more than 10 days for acute conditions.

The current National Health Service functions through a network of "local sanitary units" (USL). There are now 20 in Rome, for example, with proposals to create maxi-USL's or Super-USL's. (Letters to the editor point out that such a rearrangement of boundaries may ensure a hospital in every USL, but will not bring hospitals closer to homes. The present districts are based on political considerations, bearing no relation to the distribution of services, some of which are concentrated in a few zones of the city.)

Among the numerous recent "scandals" reported in the press concerning the health care system is the unanimous decision by members of Parliament to ensure that they will not have to stand on lines and trek from physician to authorizing centers; instead, a USL just for their own (and that of the constitutional judges and President) has been created within their work office buildings. "The men of the Palace /Palazzo Chigi, where Parliament meets/ have carved out for themselves an island of happiness in the chaos of the health bureaucracy. Not exactly a USL just for them, but almost so.... A 'little law' — passed with unanimous accord of all political parties, from fascists to communists..." continues the article in Giornale (politically right-wing), noting that in such a way the elected representatives can shield themselves from full comprehension of the malfunctioning of the system for the ordinary citizen. (Giornale 1985).
The "scandalous" conditions (a term used regularly in the press in reference to health care) are graphically summed up by the plight of the USL director in Rome. The following poignant comments indicate his frustration at being charged with managing — and presumably improving — services, while being blocked in his efforts to do so by a variety of individuals, organizations, and traditional practices. Rome's situation is atypical in the sense that it is the capital and thus suffers many of that city's unique problems, but it can also be viewed as "representative" in the sense that conditions are neither so bad as in the South, nor as good as in the North.

In Lazio (the region surrounding Rome) there are more licenced clinics than elsewhere because the public hospitals barely function.

54% of the Lazio health budget went on these private services, in contrast to only 4% in Veneto (including Venice) and 12% in Lombardia (including Milan).

Health care absorbs a low percent of costs; most goes for administration. One hospital bed day costs £750,000 in licenced (private) clinics (about $400). "Private hospitals get rich on public funds."

USL number 1, in the center of Rome, where parliamentarians go, was controled by the Communists when in power; USL number 2 by the Christian Democrats. Both are considered "showcases." USL 1 has a budget of £220 billion — as a major industry — with 2 specialist hospitals, 19 policlinics (outpatient), 3 private licenced clinics, 2 private religious hospitals, plus the Vatican-run Bambino Gesu (pediatric) and Bene Fratelli (on the island in the Tevere). It serves 150,000 persons with 1.3 million services annually. It has 2300 employees, including doctors. Half the budget goes to licenced clinics. £76 billion goes to staff, and £20 billion to current expenditures. There is nothing left over to build more modern structures or machinery — and this is a "showcase" USL.

There are many reports to the police — too many people in line, mice in cellars, cockroaches in the operating room, poor security.

"The fire vigil, unions etc. take me to court twice a week."
"Everyone is denouncing everyone else — the doctors against the administrators, the nurses against the doctors, the unionists against the health directors. Now they're denouncing me, or threatening to do so, if I try to save money....Take the example of absenteeism. We uncovered a clinic where they signed out at 2 PM, then were registered only 5 minutes later at another medical center across the city. So I decided to install time clocks, but they reported me for anti-union behavior." So he decided to fight only the most important cheaters, the head physicians, who do as they please, but he was denounced to the court, and the court of last resort went against him, saying the
physicians have the right to organize their service hours according to their own needs. He then discovered that unique among 20 Rome USLs, there is the capacity to electronically control all pharmaceuticals, day by day, physician by physician. He tried to use this capacity to counteract over-prescribing; he found 12 physicians who repeatedly prescribed unnecessarily — e.g., 20 prescriptions a day for one patient for months. From then on, there have been 300,000 fewer prescriptions a year, saving £4 billion a year in one USL alone. But when he tried to save £800 million on laundry that was being contracted out, he was denounced. He has been denounced because risk indemnity for radiology is too generous, denounced by a physician for abuse of power, by unionists for damages caused to health by the hospital environment, by patients because their refunds were not provided promptly, and by companies because of lateness in revision of contracts (such as laundry service). He has been denounced by the pretura for violation of hygienic and accident security standards, and denounced for scarce use of the outpatient clinic. In fact, he says, it was he who pointed out that there were not enough physicians in the outpatient clinics and far too many pediatricians, which he has to keep on contract because of a union agreement; physicians who see no more than two patients a week are on full salary. Expenditures for bandages were reduced from £200 to £26 million after he prohibited their use as cleaning cloths (although it is suggested that the bandages might have been sold as well as having been used for polishing). But all such efforts to save are useless because expenses are based solely on historical experience, with automatic hikes in each category for inflation. Instead of putting money into new machinery to save billions, the system continues to function in the same way, benefitting only the firms which get contract work and the usual political parties. (Espresso, 1985).

At the time of writing, physicians all over Italy were engaged in a three-day strike, threatening others in the months ahead; hospitals have been reduced to emergency service, and the involvement of veterinarians threatens to halt commerce in animal-based products as well. There are a number of issues but the primary demand on the government is for a contract for physicians that is separate from that for other health workers, in order to provide doctors with "more autonomy."

To balance somewhat the plaintive lament of the USL administrator, we might add to the chorus of criticisms of the health service the points made in a recent hour-long TV program on the "politzation of the health service" (by the Radiotelevisione Italiana 2). Some central comments follow:

An elderly man was recently found dead — after 8 days — in the toilet of a USL office; the toilet obviously had not been cleaned for over a week.

In one hospital, patients must whistle for care — once for a doctor, twice for a nurse. A doctor sewing up a patient may find there is insufficient suture to complete the operation and have to "borrow" from another hospital nearby.
It is now commonplace for patients to have to be moved from one hospital to another when "abandoned" by hospital staff who all go on vacation simultaneously.

It is also commonplace to find elderly patients confined in hospital for months for no particular treatment.

Our major problem is too ambitious a plan, attempting to provide everything to everyone, resulting in the "Spaghetti Welfare State" where no one gets served adequately; it's an effort to imitate Northern countries, but without their resources. Equality for all at any cost, ends up impoverishing all. We spend so much to enable everyone to have free care for their common cold that we haven't the funds for life-saving medicine.

(The director of a private clinic contrasts the public hospital with his clinic. He served in the war resistance, was personal physician to a number of notable figures on the left, and his comments should be seen in that context.) If an elevator stops in our clinic, it's fixed in 10 minutes, or if the CAT scanner is broken, in an hour, while employees in the public hospitals leave when their hours are over, regardless of whether there's work to be done. Our personnel stay on the job. A patient can get a urinalysis done in our clinic in a day, thus costing only £700,000; in a public hospital a full workup takes 7 days and costs £2,800,000.

The difference between the public USLs and private health services is—because of the extremely poor management of the former, with layers of top administrators totally lacking in management experience; expenses in the public health sector are guesswork, year after year, with no one ever having attempted to predict them or suggest a ceiling; when they exceed expectations, as they always do, the public pays the following year in a variety of taxes.

The bottom line is the importance of distinguishing the government's role as administrator from its political role. With only 30% of the vote, the Christian Democratic party holds 55% of the top administrative posts in the health service, many of them lacking management experience. We must end the notion of "party hospitals."

The above lengthy citations are included here in order to place the problems of the elderly in the context of a health service in genuine crisis. Decisions about access to care, selections of patients to receive treatment, and customs that have developed regarding the sensitive issues of terminating interventions are all found within the above-described situation. In the mid-1960s, there were barely 500 medical students at the University of Rome at the laurea level; now there are 22,000; many charge that the quality of their education has much deteriorated; and that the flow of wealthy patients to other countries seeking more adequate services is an expected result, while others maintain that despite all its difficulties, the system still manages to produce qualified physicians and other health personnel, has equalized access to services so that the poor now have far greater access to care than before the 1975 "reform," and that better management and "reform of the reform," including its depoliticization, will right the many wrongs that now form the substance of journalistic alarm.
III. THE RIGHT TO TREATMENT AND THE RIGHT TO REFUSE TREATMENT

A. The Right to Treatment

Apart from the conditions of law 833 noted above, we include the following: every patient for whom a doctor prescribes dialysis has the right, by law, to receive such treatment, although in practice it is a matter of "first come first served." The elderly patient is unlikely to be served even if he is first to come, however. ("The elderly often have grave complications on dialysis." Anon.) In fact, a third of needy patients in the public system do not have access, although some private organizations step in and provide machines, often located at great distances from patients' homes. Some are provided for in-home use.

There is no right to transplants. Indeed, large numbers in need go abroad, and there is a negligible number performed in Italy. (The Center of Organ Transplants assists some patients in need. Private collections for special cases to go abroad are reported in the press.) There is a widespread reluctance to donate organs; the Italian Association of Organ Donors is attempting to sensitize the public to the great need. Until eight years ago, the law required family consent to remove an organ for transplant; now the law requires only that the family not object. A proposed law would require everyone to carry a donor card — either a negative indication on the card or the lack of such a card would automatically indicate permission to remove organs.

"A generally healthy 80-year-old has the right to any and all treatment that persons of younger ages have. The de facto treatment that varies by age becomes an issue only when the elderly are seriously ill." (Merli) The elderly receive antibiotics in a manner no different from younger patients; abuse of drugs is "common all over the Western world." (Anon.) With few exceptions, if you can name it, you can buy it in Italian pharmacies, without prescription; many say that doctors overprescribe because they feel that patients do not feel adequately treated unless they leave the office with at least three prescriptions.

There is no such thing as formal "do not resuscitate" orders; hospital personnel ALWAYS try to reanimate patients, regardless of age." (Merli)

When the elderly person, or the not-so-elderly person is in coma and is
a famous personality, such as the 61-year-old writer Calvino (see Appendix C), no doctor dares NOT to continue with all possible means, even after publicly announcing that the individual is brain dead. (Merli)

There are no laws governing other technologies, all of which are a question of availability on the one hand (extremely limited for sophisticated technologies, many of which lie broken and un repaired for lengthy periods even in the few facilities that ostensibly provide them) and the autonomy of the medical profession to make decisions on the other hand. Age "definitely enters into" many decisions to withhold or withdraw hydration and nutrition (Anon.); medical caregivers "instinctively" provide less care to the elderly and the dying (Merli). /See below, De Jure/De Facto, and Decisionmakers: Doctors and Nurses./

B. The Right to Refuse Treatment; The Right to Die

1. The Current Controversy: There is no Italian Right to Die Association, but there is a euphemistic organization for the "study of death" (thanatology). The euthanasia debate surfaces and subsides regularly, often provoked by an external event: the Quinlan case, a recommendation by the European Community Parliament (1976), a conference of physicians (held in Nizza, Italy, but organized by French Nobel prizewinners), the new Dutch law, and most recently by Socialist deputy Fortuna, whose death at the end of 1985 effectively closes the euthanasia debate for the time being. (See Appendix D re Fortuna.)

The official Roman Catholic views on euthanasia are found in papal addresses, duly reported in all the press (including the left wing papers), but most fully in Osservatore Romano emanating from the Vatican. The right-wing press rarely mentions the subject, except to report Catholic teaching. Medical journals contain almost no discussion. Mori (consulted extensively for this report) writes scholarly philosophical articles on the subject, but these undoubtedly have very limited readership. And a joint Protestant Catholic left-leaning biweekly, Com Nuovi Tempi, raises the issue regularly but has a readership of only 400,500.

The debate in Italy, as elsewhere, becomes extremely emotional. Definitions get lost in the shuffle. Public speakers may attempt to draw a distinction between active and passive euthanasia, but the difference is lost in sensationalist charges of "murder." The original meaning of "good death" or "sweet death" is no longer remembered in general discussion; the difference
between "kill" and "let die," between "do" and "do nothing" or "withhold" and "withdraw" treatment are smothered in emotional debate. For those who feel that continually attempting to educate the public that the word means "good death" and not killing is a hopeless task, it is considered wiser to let the word simply take on the meaning of kill and not use it at all in connection with passive measures. For example, Barni (president of the Italian Association for Legal Medicine — connected with the Rome-based Institute for Legal Medicine) (1984:165) suggests that these four issues need to be more clearly disconnected: abortion; non-intervention in the case of minors, the unconscious, or the incapable; suspension of reanimation therapy in patients clinically dead; and euthanasia as an active means to precipitate the death requested by a patient, or if unconscious, by his family or as otherwise decided. Barni adds that the refusal of cure (diagnostic tests or therapy) is not "euthanasia," but that refusal of cure and a request to suspend treatment should be granted only in exceptional cases.

2. The Church's Position(s)

Those who wish to support the right to refuse treatment, or the right of caregivers to suspend treatment, tend to cite different religious documents and sources than those of another view — the former citing Pope Pius XII in the 1950's, or the Sacred Congregation of the Faith in 1980, and the latter citing the current Pope John Paul II.

"There is no need for organizations to promote 'Good Death.' The Church has a monopoly on buona morte." (Anon. physician, a surgeon in a Vatican hospital — where the Pope went when shot — who argues that it is certainly permissible to withhold and withdraw in circumstances of imminent death.) The same source reminds us that in Medieval times, there were religious confraternities "per la buona morte" (for the good death). Merei agrees: "The Church is not opposed to suspension of treatment."

"Pain alleviation is the primary concern for the elderly dying patient."

These physicians, and others, refer to Pope Pius XII: "Any form of direct euthanasia, that is the administration of narcotics to provoke or hasten death is illicit....One of the fundamental principles of natural and Christian law is that man is not master of his body and existence, only its user....It is licit to alleviate pain on the one hand even if administration of narcotics has, on the other hand the double effect of shortening life, if there is no direct causal link between the narcotic and the
shortening of life" (Pio XII, 1957, emphasis added).

Again, citing Pius XII: "The fundamental principles of anesthesiology, as science and as art, and the ends it pursues do not raise objections. It combats forces which...produce harmful effects and impede a greater good. The doctor, who accepts its methods, does not enter into contradiction either with natural moral order or with the Christian ideal. He is trying, according to the order of the Creator (Genesis 1:28) to place pain under the power of man, and uses to this end the findings of science and technology." (Pius XII, 1957a) "If the same narcotics administered shorten the length of life, would it be necessary to renounce them? In the case posed, it concerns solely the avoidance on the part of the patient of insupportable pain, for example in the case of inoperable cancer...if the administration of narcotics provokes two distinct effects, the relief of pain and the shortening of life, it is licit; it is necessary, however, to see if there is a proportionate balance between the two, if the advantages of one compensate for the disadvantages of the other." (Ibid., the pope answering questions from the audience of anesthesiologists)

Speaking of reanimation to doctors and others, Pius XII declared explicitly that it IS licit to interrupt the process of reanimation when a state of clinical death is established. In fact, he pronounced himself "in favor of the family which, at a certain point in verification of the irreversibility of the patient's condition asks for the removal of a respirator, declaring that this can be licitly insisted upon until the doctor interrupts his efforts since there is, in this case, no direct effect on the life of the patient and is not euthanasia." (Pius XII, 1957b) (Note that the family, apparently, must persist in such requests until the doctor concurs.)

In 1980 the Sacred Congregation for the Faith issued a declaration, which analysts described as "more open" than earlier positions, calling more on personal responsibility, and noting the difference between "proportionate" and "disproportionate" measures, the latter being deemed not obligatory.

"The present text insists less than Pius XII on the idea that only God is master of life and death. Or more exactly, the Biblical idea is translated thusly: 'Every man has the duty to conduct his own life according to the design of the Creator. His life is given him as a gift which he should value, which finds its fullness only in eternal life.'...The present document, compared with earlier ones, in fact distinguishes with more
precision suicide and sacrifice in light of a great cause...the example of "Holy" Kolbe /the priest who offered himself in a concentration camp in order that Jews be spared — not yet sainted at the time of the citation/...On the other hand, noteworthy is the firmness shown in condemning suicide and euthanasia if done for existential reasons....It is not a question of a fatalistic or painful conception of death. The document does not deny the tragic aspect of the last moments of earthly existence, but recalls Christians of today to that which they've forgotten, that this is above all an encounter with Christ, entrance into a new communion with God....Suffering is not, in itself, a savior, redeemer....It should not be considered an inevitable element of the human condition....Prudence requires the attenuation of suffering. A heroic attitude is laudable....Concretely the choice is rarely between pain and non-pain. Even helped by medical means, the sick (especially the dying) person lives in a situation of depression, humiliation, slow and successive cancellation....Fighting against pain, using drugs that are progressively potent, presents the risk of shortening the elderly person's life. But Pius XII referred to the double effect principle. It is possible to tolerate such a risk if it is not wanted for itself and if the risk is run only indirectly....The classic documents distinguished between "ordinary" and "extraordinary" therapy; many moralists have renounced this criteria which is very relative. They go less far than many doctors who, in line with their profession (to protect life at any cost) risk prolonging the life of larvae....The present declaration poses a series of four solutions, concrete, for precise situations....The first is that of the use of disproportionate therapeutic measures (paragraph IV). In one environment the measures will be ordinary, in another extraordinary. It is a secondary aspect; that which counts is to know if there is proportionality between the measures used and other aspects of the situation: the quality of life which it is possible to attain, taking into account the status of the sick person and his physical and moral resources.' It is possible to legitimately judge, in certain cases, that 'the investment in instruments and in personnel is disproportionate to the predictable results, and that the measures set in motion impose on the patient discomfort or suffering out of proportion to the benefits which he could receive from them.' In a certain sense, one could talk of a conflict of duties and of duties with rights...but taking into account that in any case there is no transgression of a moral minimum absolute as in the case of direct euthanasia
or abortion...It is not a question of giving to the individual conscience the right to determine good from bad...The conscience (of doctors, of the patients, and of their relatives) works in continuity with moral obligations, but also with 'certain aspects of the case.' One sees without doubt the danger of certain possible abuses, but on the other hand a large place is given to 'personal responsibility.'" (Delhaye 1980:795-798 emph. added)

It might be noted — by this non-theologian — that the issue of personal freedom of conscience is one of major difference between Catholic and Protestant teaching, as is the fundamental basis of whether God or the person is "master" of his body and destiny.

The present pope, generally viewed as very conservative on a number of issues, has not unexpectedly taken a more restrictive stand than his predecessors on the issue of euthanasia. In October 1984, Giovanni-Paolo II reaffirmed opposition to abortion and euthanasia in a presentation to the congress of Italian Anesthesiologists' Association. "The Church, as you know, is not for the support at any cost of pain. The Church considers licit action which tends to reduce or eliminate physical pain....However, although confirming this principle which has its roots in the Bible, we exhort Christians and all believers to tolerate suffering in union with Christ....In suffering, in fact, the believer finds the strength to purify himself and to cooperate in the salvation of his brothers." (John Paul 1984)

Most recently, John-Paul addressed a congress /scientists, October 1985. It is interesting to see the different emphases given by the press: while the Italian press referred to the Pope's re-condemnation of euthanasia, the International Herald Tribune trumpeted his support for "death with dignity." The casual reader might think that this means passive euthanasia, or painkillers that both alleviate pain and may also hasten death. But a more careful reading (particularly of the entire text which we obtained in English translation from the Vatican) shows that "dignity" has many interpretations, and that such measures are NOT included in the definition of dignity as used here. John Paul again notes that suffering is part of normal human existence, and that when one is about to encounter Christ one should not be drugged to unconsciousness. "According to the Pope, to confront the problem of euthanasia, it is necessary to begin with two presuppositions: life is a value and death a natural event. From this we derive
that life cannot be interrupted, not even to alleviate the suffering of a painful death, and that death cannot be avoided since it is part of human experience. It is correct that scientists and doctors dedicate themselves to prolonging human life, and for means to better it, but not to overcome it. 'Only God' said the Pope 'is master of life.' Stern judgment also for those who help the sick to confront death in an unconscious state, because thusly they impede them from encountering Christ in full consciousness.

The best thing, according to Woytyla, is that the sick person suffer with patience and at the end die in his 'natural' time. Every attempt, every cure which tries to alleviate pain of this passage goes against the 'natural' condition of human life. One can resort to narcotics only if the patient does not have the 'moral force' to tolerate the suffering." (ADISTA 1985)

In the same address, John-Paul declares that it is permissible to use experimental technologies, even if they carry some risk, when more ordinary methods fail or are not available, and it is also possible, with the patient's consent, to terminate such extraordinary measures if results fall short of expectations. Account must be taken of the patient's wishes, those of his family, and the doctor's advice. There is no obligation to initiate such extraordinary, possibly risky, methods of care. He thus appears to be coping with the difficult definition of what means are extraordinary and which are ordinary by referring to experimental, potentially risky methods and declaring these non-obligatory and interruptable, while making no reference to the interruptability of other measures. (Osservatore Romano 1985)

3. Legal Issues: Defining the Moment of Death; Clinical Death

It is not by chance that we have placed religious considerations before legal ones in this report, for laws, court decisions, as well as common custom are heavily influenced, if not dictated, by Church teaching.

Since there is no Italian law specifically forbidding euthanasia, other than the wider law concerning homicide, one must look to the law on transplants for word on defining death. (As noted above, there are few transplants in Italy, Merli of the Institute for Legal Medicine points out that the transplant law protects physicians from prosecution, rather than regulating their behavior.) There have been efforts to codify transplant law for over 25 years (Merli), with little success. The law of 1975 Number 644 has now been in effect over a decade; in 1983 a revision was proposed, which is under discussion in the Senate. While doctors seem to
wish to keep the law — or rather the non-law — on euthanasia, vague, leaving them scope for "the exercise of common sense, not like you Americans with a lawyer at every bedside," there is considerable support for clarification of the transplant law — in order not to restrict, but to further protect, physicians. The 1975 law refers to measurements of heart, respiration and brain activity: two circumstances are distinguished (Merli): when the heart stops, it is permissible to enter the body 20 minutes later to remove surviving tissues. If, however, it is the kidneys, heart, or lungs that are to be taken for use in transplant, then a flat electroencephalogram for 24 hours is sufficient. Article 5 refers to a committee composed of one legal doctor, one anesthesiologist for reanimation, and one neurologist specialist in electroencephalographia. The committee must observe the patient for 12 hours to determine the moment of death. The proposed new law — taking into account advances in neuro science, would require one doctor to determine if brain function has irremediably stopped. The organ donor "must be surely dead, but not too much." (There is little chance of a mis-translation of this charming phrase, since the words are all quite simple. Perhaps a cultural gap exists, but my collaborator could also not fathom what "not too dead" really means — except the obvious interpretation that the heart must still be viable even if the patient is dead in a legal sense.) The proposal also refers to brain death, or flat brain waves for only 3–4 hours, even if heart and lungs are still functioning, leaving to medical science and the doctor's conscience the decision, taking into account "the particulars of the situation." (These, presumably, would include the patient's age, and possibly his potential "quality of life.") The bill seems unlikely to pass.

Meanwhile, between the 1975 law and the present proposed law, in 1977 there was a presidential decree (Number 409) which contained seven titles concerning the ascertainment of death and authorization for removal and transplant, consent, referrals to regional centers, etc. — based on the recommendations of the European Council that transplants be permitted if no contrary will has been expressed by the donor.

After days of front-page lamentations in all the major newspapers, the way was finally cleared for performing heart transplants in Italy in eight specially equipped centers. The delay stemmed from "bureaucratic bungling" (refusal by the health minister to sign the final permission), and resulted in headlines about one patient who died while waiting, and another whose
identified donor was finally buried without removing his heart. (This patient, however, became the first to receive a new heart when the bureaucracy finally moved and another suitable donor was found.) Recent headlines carried the story of the 8-year old whose family had collected $65,000 so she could go to America for a heart transplant; the money will be returned, since she received the heart of an Italian 7-year-old instead.

4. Legal Issues: De Jure vs. De Facto; Physicians' Attitudes

Italy, as elsewhere, has examples of yawning gaps between law and actual practice, or, where law is fuzzy, of wide differences in interpretation. Most of these discrepancies in Italy can be summed up in one sentence: the doctor decides.

Two strongly divergent opinions can be cited by prominent physicians, both important operatives at Gemelli Hospital — Vatican-run, considered probably the best hospital in Rome, associated with Catholic University. Our anonymous consultant says, for example: "Doctors will do everything to save a young person who's had an accident, but for a tumor in an old person, we only try to minimize the pain." "If a terminal patient is awake, we never unplug him, but water might be substituted for nutrition in the tube." "It is not only age that determines decisions, but potential quality of life." "Consult the patient? Not really. Consult his family? Why? The doctor decides." From the same hospital, professor Corrado Manni, director of the Institute of Anesthesiology and Reanimation of the Universita Cattolica del Sacro Cuore, maintains that no one ever asked him to help him to die, that euthanasia means "to give death" and is therefore always homicide, and that to suspend treatment is equivalent. He says that modern medicines are now available that will alleviate pain without hastening death, so the "double effect" argument is now moot. If the doctor does NOT insist on every possible therapy, he maintains, then patients will not trust their doctors. Therapies that may have been considered extraordinary and risky 50 years ago now have a better chance of success today and should be pursued; even if they don't succeed in curing the present patient, their experimental use will benefit future generations. He is certain that the majority of Italian physicians agree with him, and that his views are in no way based on Catholic teaching but rather on 30 years of professional experience. (Osservatore Romano 1985A) Despite their apparent difference of opinion on the initiation of extraordinary means, or their interruption, these two physicians have in common the opinion that the decision belongs to the physician, not to the patient or his family.
Merli, director of the Institute of Legal Medicine, comments on this and related issues:

It is 'instinct' for the doctor to treat an older person differently from younger ones.

There has been a gradual evolution in practice toward greater willingness on the part of hospital personnel to withhold extraordinary treatment or to unplug the plugs when the patient is irreversibly comatose.

Passive euthanasia is, de facto, widely accepted, although there are conscientious objectors there, too.

No one technically has the right to unplug, but they easily do so. Doctors do. Nurses will refuse, for fear of its being considered out of the range of their competence.

Many publications use a hard-to-translate expression: accanimento terapeutico (the "cane" referring to dog) — dogged therapy, or therapeutic doggedness, or tenacity — i.e., hanging on, bulldog style, continuing with heroic measures, regardless. The "gradual evolution" referred to above by Merli includes a growing recognition that such bulldoggedness is not necessary.

There are no laws prohibiting the gradual increase of pain-killers, but as seen above there are controversies within the Church as to when they may be licit; Merli indicates that no doctor would fear a lawsuit if he were to gradually increase the dose of morphine, for example.

On the subject of cost, we find two quite different views: Mori says that "of course costs matter; as long as the state pays, there's no limit to the life-prolonging experimentation that physicians and technicians will engage in", while Merli also says "of course costs matter" adding, however, that "it's not possible to do everything for everyone, so plugs get un-plugged to make room for the next patient."

The most striking comment of all was by Merli, who likened the Italian hospitals to a battlefield, commenting that "medicina di guerra" (wartime medicine — i.e., triage) was being practiced there, abandoning patients who are going to die anyway.

Mori the ethicist (1985) suggests that opposing views on euthanasia are further apart theoretically than in practice. That is, there is broad general agreement on the need to lessen suffering and — with some exceptions such as Manni, cited above — on the non-necessity to pursue "extraordinary", "heroic", "disproportionate" therapies.
5. The Decisionmakers: doctors, families, patients'—surrogates

According to Article 32 of the Italian constitution, no one can be forced to accept a particular health treatment unless it is in the public good, as in the case of vaccinations; the law is intended to prevent experiments on the human body. Exceptions, of course, include the court-ordered transfusion for a Jehovah's Witness minor in the event it is denied by the parents. In the case of the recent heart transplant, the 8-year old patient and her family are Jehovah's Witnesses; the parents made the physician and his team promise not to resort to blood transfusions in the course of the procedure, which happily was accomplished without the need for blood. The newspaper accounts do not further discuss whether the court might have intervened, over parental objections and over the doctors' promises to let her die rather than resort to a transfusion. Merli says "If someone wants to die, they can simply refuse treatment." Attempted suicide is not punishable. The patient merely signs a non-consent form for intervention. Consent forms are ostensibly routinely signed for all surgical interventions, but in practice are frequently omitted. A physician in Turin has recently had his license suspended — no further legal action is anticipated — because a 16-year-old abortion patient died following the use of a highly experimental technique that neither the patient nor her family knew was to be used.

A parent cannot decide to subject a minor to non-emergency or non-essential intervention, such as a nose job; the minor's will, in such a case, takes precedence ("leave my nose alone"). In the case of conflict, as regards abortion, for example, the minor may override parental refusal of treatment through recourse to the courts.

Barni (1984:165) contends that the refusal — on the part of a patient or surrogate — of care is normally to be condemned, but is not morally wrong if the patient refuses a particular therapy and if it is objectively or subjectively considered extraordinary or unusual.

While there is some mention in the press of the concept of Living Wills, usually with reference to models in other countries, these are apparently unacceptable both to the majority of the medical profession, who would find their decision-making role threatened, and by "the Jesuits" who would argue that man is not master of his body and therefore not in a position to dispose of it in such a way...giving that responsibility to God's surrogate in a white coat.
Barni (1984:170) suggests that not only can a patient refuse treatment, but that a physician who persists in medical or surgical treatment against a patient's will is engaging in unacceptable conduct according to medical ethics and may even be bordering on illicit conduct punishable by penal law (the closest anyone seems to come to suggesting that battery or privacy issues may enter in). There is, by the way, no Italian word for "privacy," although in recent years the borrowed word "privatezza" has entered the language.

Despite the unacceptability of a Living Will by the majority of the medical profession, a well-known Milan physician may be said to have declared his own such Will, orally: E. Malan, director of the Surgical Clinic of the University of Milan, a propos exceptional interventions in the case of Generalissimo Franco, said "As doctor and surgeon, I must say that such a way of proceeding is justified and right. As a man I could have my doubts about certain things. For myself, perhaps, I wouldn't want to be treated in a similar way; I would prefer to exit tranquilly. I have already told my assistants that if something happens to me, not to jump all over me /taking exceptional measures/." (Malan 1975)

There are two types of incapacity: natural (as in the case of a minor) and pathological (as in the case of mental illness). Article 54 of the penal code states that in case of necessity, an intervention is permissible even against the will of the patient, to save the patient's life. This is now under discussion. Who decides the patient's competence? The family, according to Merli, although there are no laws to say so. The court intervenes only in the case of refusal: if the patient is deemed competent, even a court order cannot force treatment.

There are generally accepted procedures for deciding who takes responsibility for the incompetent patient: first the husband or wife, then father or mother (first-grade relations), but this is merely custom, not codified. If there is a conflict among them, they can go to court, but this is most rare (Merli).

In many cases, the physician will "consult" the patient's family, but in such a way that they virtually have to follow his advice (Mori).

The decision-making authority of the physician seems to be barely challenged. A Committee on Euthanasia of the Institute for Legal Medicine has been formed, announcing that it will meet...a year from now! They seem in no hurry to settle, or even discuss, the issues. They want clarification of
the transplant law, but not clarification of a euthanasia law, such as that proposed by Deputy Fortuna (see below). Limited hospital space, and a situation of wartime medicine, result in daily decisions to withhold or withdraw treatment from the terminally ill, but "it's nowhere written and no one discusses it." (Merli) There are no hospital committees to decide; the doctor decides, and then "advises the family; it is easy to get their acceptance of his decision." (Anon.) "Decisions are left to the good sense of the physician; if he sees that the patient is incurable, he will not massage the heart. The doctor is more afraid of tattletale nurses than of the patient's family." (Anon.)

6. Proposed Law on Euthanasia

Between the penultimate and this final draft, the father of the proposed euthanasia bill died (see Appendix D), which effectively kills the issue, according to most observers. Socialist deputy Fortuna's proposal was based on the 1976 recommendations of the Council of Europe (#779) which deal with reanimation, pain abatement etc. It does NOT deal with active euthanasia. It was intended to "assure dignity of life and regulation of passive euthanasia." It would dispense physicians from subjecting to life-sustaining technologies everyone in an irreversible terminal condition, unless the patient consciously consented to their use. Terminal condition was to be determined by a physician designated by the local health unit, and he should verbally communicate to the relatives of a patient over 16 or to a minister of his religion or to the patient himself or his direct or indirect line of antecedents or descendents (up to the second grade of relation); these persons should all be over 16. If any of these wants to oppose the termination of treatment, they should do so within 12 hours. Even in this case, the President of the Court, after hearing the reasons of the person opposed to suspension of treatment, and to the physician, can authorize suspension of therapy.

Only the Radical party seemed interested in moving the bill to discussion (not even Fortuna's own party, the Socialists, were eager to back it, as in the case of the divorce and abortion bills he previously sponsored, see Appendix D). Merli points out that law cannot go ahead of culture; while brain death as a concept has now entered the common culture in Italy, public opinion is still not "ready" even for a rational discussion of the issue.
In an opinion poll, the family of a paraplegic would answer differently from others in the general public, on questions regarding euthanasia (Merli).

In a recent poll, however, a large majority of Italians (see Appendix E) were found to favor what might be termed "passive euthanasia" and a similarly large majority were opposed to "active euthanasia," although support for the former was interpreted on the basis of responses to questions that did not actually use the term "euthanasia." (We might expect quite different response rates had the term been used, in fact.)

The strategy of the Fortuna bill was to introduce the proposal, then let it "cook" for a few years while public opinion is educated to the meaning of passive euthanasia, or while the issue is discussed in terms that omit the use of the tabu word, and only then reintroducing the bill to the legislature.

IV. LIABILITY

There seem to be differing perceptions as to whether there are few or many malpractice cases in Italy, and no way to determine just how many. Surely bringing suits is far less common than in the US. The Institute for Legal Medicine is involved in at least 100 a year, but they do not represent all Rome or all Italy, where Merli believes there may be "thousands" annually. (Common perception, however, is that there are virtually no such cases; an Italian medical sociologist stated categorically "There are practically none in Italy," and our informal contacts confirmed this public view, which may well explain why there ARE so few, it not being known to most people that malpractice suits can in fact be brought.) Our anonymous surgeon informant, for example, believes such suits are "very rare" and that physicians have "little to fear." He cites the case of a husband whose wife died in childbirth; the husband was accused by friends of being mercenary because he suggested a civil case to collect damages. He says it is difficult to find doctors willing to testify against other doctors, but Merli says it is not difficult at all. Mori says a case is brought only if a death is involved. (See Appendix F, the brief account of a physician who went to prison for a year for having refused a cesarean section to a woman whose neonate died — ostensibly from lesions suffered during delivery.) Most vulnerable to suit are orthopaedists and obstetricians.

Most malpractice cases that are brought do not involve overtreatment, but error in diagnosis and mistreatment. Nurses are also subject to suits, especially if they function outside their defined "sphere of competence." (A computer search in the Court of Assizes, using a variety of keywords, did not turn up any malpractice cases. The case list, however, when
consulted for cases on "omicidio del consenziente" — assisted suicide, or active euthanasia — turned out to be almost entirely all abortion cases.

While doctors may feel immune to threats of malpractice, institutions of health care are subject not only to legal prosecution but a veritable hailstorm of journalistic criticism. Our anonymous informant points out that the post office and trains are also in abominable condition, but that the health care system is an easier target for journalists, particularly those motivated by political considerations — although we have found biting criticism in papers from the far left to the far right. (Criticism of health care in Rome could, until recently, be interpreted as criticism of the former Communist government; it will be interesting to see if the current Christian Democrats can either improve the system or at least turn away journalistic accusations. One nurse of our acquaintance insists that everything worked better, especially the hospitals, under the Fascists.)

Apart from political considerations, and whether it sells more newspapers to attack the health care system or the way the post office treats its clients, it is widely acknowledged that the dream of universal free health care of a high standard is far from realization, and that practice within that system — with regard to the subject of this report, as well as more generally — departs widely both from the prescriptions of the legislature and from the official teachings of the Catholic Church.
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APPENDIX A: National Health Service

The national health service constitutes the entire health structure which the State, the regions, the localities place at the disposition of their citizens for the care of their health and prevention of disease. Inscription in the SSN (NHS) is automatic for all citizens already enrolled in mutual aid entities and thus in possession of a card. Citizens however who have never enjoyed any form of assistance, are enrolled in the SSN by choosing a doctor of choice. The citizen who needs a medical visit should go to his own doctor of choice — to his clinic/office or in case of need in a home visit. The ambulatorio (clinic) should be open for 5 days a week, with opening hours that assure adequate care. On Saturday it is not obligatory for the doctor to open the office, while he should deliver home visits until 2 PM. Home visits are also free, but subject to the following rules: if the request is made before 10 AM, the doctor's visit must be made during the day. In the case in which the request is made later, the visit must occur before noon of the following day. The doctor of choice is obliged to make a home visit, also on Saturday, if the request is made before 10 AM. From 8 PM until 8 AM weekdays and from 2 PM to 8 AM Saturdays and Sundays (i.e., till 8 AM Monday), for urgent cases a Service of Medical Guard is in operation in every area of the country. Also in these cases the care is absolutely free.

Hospital services: where the citizen needs hospital care, on the proposal of the caring physician and providing the enrollment card, he can obtain care without charge in: public hospitals, with just the referral by the attending physician; in institutes and licenced nursing homes (licenced by the Region) with the referral of the attending physician and the authorization of the USL (local health unit).

Private licensed Nursing Homes (not necessarily for aged): for these places the expense of a bed stay is the responsibility of the citizen and he can request partial reimbursement, in the degree established annually within his region. Users must go to the USL.

Specialist care: In case of specialist visits or diagnostic tests (analyses, X-rays) the citizen can go: to the polyclinics of the mutual entity (former entities, now USLs), to the specialist offices of all public hospitals, to the licensed specialty clinics. In the first two cases all that is needed is the request of the physician of choice and presentation of the enrollment card; no other authorization is necessary. The request of the physician is not necessary for the following specialist visits: pediatric (for those who do not already have a pediatrician of choice), obstetric-gynecologic, odontiatric. It is possible to report to licensed specialty clinics when other structures are not in condition to satisfy the request in a short time.

Medicines and pharmaceutical help: Only the doctor of choice and the specialist can prescribe drugs to the citizen who requests them or after a medical visit. The prescription should be placed on a form and can be used within 10 days in the pharmacies of the Region indicated on the prescription. Some of the drugs commercially available are furnished free to the citizen who presents a medical prescription. For other medicinal specialties, however, the user is obliged by law to pay a small sum directly, the so-called "ticket", in proportion to the cost of the medicine.
What is the USL (Unita Sanitaria Locale): USL means Unita Sanitaria Locale. It means a complex of buildings (policlinics, hospitals, consulting offices etc.) and personnel who work there (doctors, administrators, pharmacists, nurses, analysts etc.) who can furnish the citizen a complete, free assistance. The USL depends directly on the individual or associated Comune. All Italian citizens present in the territory of the Lazio (Rome) region have the right to be assisted by the Sanitario Servizio.

Choice of the Doctor of Choice (literally, doctor in whom you have trust): To obtain many of the services of the SSN the citizen must choose a doctor of trust.
Health: Goodbye Services; Nearly Everyone of Us Will Pay

Passe Sera  Monday 30 September 1985

From a full-page article on the Battle in the Senate, beginning Wednesday, including education, transport, health etc.

Dear Tienamocelc, our family doctor. Because his service will be one of the few free services that the state will offer to the citizen. The health sector in fact is the most hit by the spending cuts predicted for the 1986 budget. The State in fact, will limit its free intervention only to those patients in hospital, to the family doctor, and for those with a family income very low, at the limits of survival, that is 11 million lire a year (about 850 thousand a month). The certification of income, will be conducted by the city government which, will be called to a co-responsibility. Above 11 million, citizens will be asked to put their hand into the wallet: a prescription will cost 2000 lire (about double the present-day ticket), while tickets for medicine, analysis, and thermal cures and specialists will rise to 25%. But that's not enough, the health union and the regions, in fact will have the right to apply supertickets for the upper income category, for both direct and indirect services (the former currently receive services without paying, the latter pay and are then reimbursed).

SANITÀ’
Assistenza addio
pagheremo quasi tutto

TIENAMOCELC caro, il nostro medico di famiglia. Perché la sua assistenza sarà uno dei pochi servizi gratuiti che lo stato offrirà ai cittadini. Il settore della sanità è infatti il più colpito dai provvedimenti di taglio di spesa previsti con la finanza 86. Le spese infatti, limitate a un intervento gratuito solo ai ricoveri e prestazioni ospedalistiche, ai medici di famiglia, appunto, a cui concfroni di chi ha un reddito familiare basso, al limite della sopravvivenza, a cioè di 11 milioni l’anno (pari a poco più di 850 mila lire al mese). L’accesso al reddito, ai fin dei provvedimenti relativi all’assistenza, sarà deciso al Comune che, in tal modo, saranno chiamati a una corresponsabilità. Oltre gli 11 milioni, i cittadini saranno chiamati a mettere mano ai portafogli in riscossa costerà 2000 lire (in doppia il doppio dell’attuale ticket). Il titolare in medicina, analisi, e cure termali e specialistiche salirà al 25%. Ma non basta, Usi e Regole, infatti avvengono le faccende di applicazione «superticket» oppure tranche — per la fissa superiore di reddito — l’assistenza diretta in assenza indiretta. Lo stesso regime, del resto, previsto per la famiglia con reddito lordo annuo superiore ai 36 milioni, che saranno chiamati a pagare totalmente ogni prestazione, non ricevere un passato rimborso. Ancora saranno costretti i contribuenti mancati sia a carico del lavoro dipendente (l’1,75% delle ritenute imponibili per i lavoratori) e il 5,6% a carico dello stesso che è di quello assicurazione (l’9% del reddito lordo imponibile). Così tutte queste misure — che, di fatto, aumentano il Stato sociale, favorendo l’uno non-pagante a spese non-pagante — sono dannose per i redditori di 11 milioni l’anno.
By law, these are the duties of the Unita Sanitaria Locale (Rights of the Handicapped), from *La Repubblica* October 1985

With medical documentation, parents can request recognition of invalidism of a minor under 18, which carries the right to a) total exemption for payment of medicines and care of the sickness, b) free provision of prostheses, orthopedic shoes, wheelchairs, and whatever technology is currently available to stimulate the capacity for recovery or betterment of the quality of life. The law also guarantees: physiotherapy and specialist visits (home visits if the handicapped cannot walk), free summer trips. In case of total invalidity, the family has the right to a monthly check of about £250,000 ($150) until the child is 18, when it changes over to a social pension.
APPENDIX C: Therapeutic Tenacity: the Case of Calvino

In a recent example of the irreversible coma of a famous person (writer Calvino), public statements acknowledging the irreversible state nonetheless pointed out that "the medical team has never ceased an instant in its efforts to save him." (Italo Calvino is at the end of his life. His heart, effectively continues to beat, but the brain of the writer, at the end of another dramatic night, is sliding toward a sleep from which he will never reawake: "coma irreversibile," is the verdict of the doctors who, it is not rhetoric to say, have not ceased an instant to fight to save him.)

La Repubblica 18 September 1985

Silenzio, uno spasso cerebrale fa cadere le speranze di salvare lo scrittore.

Calvino in agonia.

Verdetto dei medici "coma irreversibile"
APPENDIX D: The Man of Civil Rights: Fortuna is Dead, Father of the Divorce Law

He never ceased to fight, to convince, to battle. Everyone will say of him, now that he's dead, that he was the father of divorce. True, but he was something more, he belonged to that faction of the Italian left which, after having taken up arms against fascism, then left he Communist Party with anger and bitterness following the Soviet repression of the workers' revolt in Budapest in 1956. Fortuna became a socialist and "nourished" the liberal-radical sector....Even in the socialist house he had his problems. The PSI remained apartly structured in the Marxist-Leninist style, aggravated by the same type of para-Catholic moralism that encumbered the Communist party....the left was frozen by rites of orthodoxy.

Thus to be in favor of dicroce, a layman, anti-clerical, was to live in a condition of terrible discomfort.

Fortuna was elected deputy in 1963 and the law which introduced divorce into Italy was approved in December 1970. Three years later he proposed the first law to legalize abortion. By then the door to civil rights was broken down and subsequent referenda to abrogate them failed. On the wave of the divorce victory of 1975 Italy experienced a turn to the left with the beginning of that tumultuous redistribution of consensus that redesigned the entire Italian political scene.

At the beginning Loris Fortuna was alone, or nearly so: intellectuals of the liberal left supported him. Divorce was seen negatively not only by the Catholics; many communists and a good aprt of the socialists also frowned on it. It was in style to justify this aversion by referring to the terrible danger that it would fracture the country. The major parties, however, had to recognize that the present-day country was galloping along by itself with the worker and student movements demonstrating how wide was the gap between represented and representative.

Thus it was that the divorce law passed, but as a product of negotiation, compromise, exchange and some underhandedness. The country did not break apart. The abortion law was no less dramatic; it raised different ethival issues, more agonizing but it also went along. The big parties of the masses stopped grumbling. Peasant-Mediterranean Italy became forever industrial-European Italy, also thanks a divorce and the nearly-solitary battle of Loris Fortuna and his few companions.

The article continues to outline his many other Parliamentary roles, but not a word with reference to his recent proposal on euthanasia.

La Repubblica 6 December 1985, p. 6.
APPENDIX E: Public Opinion on Euthanasia, Active and Passive

From "Unplug the tubes is an act of humanity": the majority of Italians and Germans are Convinced, Messaggero, Sunday 15 September 1985

(a half page on Euthanasia, complete with The Karen Ann Quinlan photo and the major article on the imminent bill in the Netherlands.)

Translation only of passages marked in pink.

The good death (literally "sweet" death). Every culture, since forever, has debated this problem which poses questions for the conscience. Then goes on to give examples of the Cuma in Panama, who kill their sick with poison, the old and sick Polynesians who are strangled, etc., and the Greek meaning of the word "euthanasia" — quick and easy death, the meaning of mercy death being a distortion. Professor Barni, president of the Italian Society of Legal medicine, elsewhere cited in this report, comments: "It's true, the laws of all countries and the medical associations condemn euthanasia as contrary to the principles of the medical profession, but the uncertainty of the legal and medical limits of treatment of the terminal patient remains unsettling for the medical profession and for society."

A Disturbance for the society. It is illustrated by the debate underway all of the world on two aspects of euthanasia — the passive which consists in interrupting medical care destined only to artificially prolong a life (illustrated by the example of a sick person who lives only because attached to an automatic respirator) and "active" which prevents the administration of particular medicine so as to accelerate the death of the incurably sick.

All over the world initiatives have been taken for a regulation of the "morte dolce" but have not arrived at an obligatory arrangement. The debate is in the phase in which it is concentrated mostly on passive euthanasia which finds public opinion ever more favorable, however with many reservations and cautions. It is illustrated by two polls, one in Italy and one in the German Federal Republic.

According to the poll of a research firm in Trieste (SWG), 7 Italians in 10 are opposed to the therapeutic continuation, that is are not in agreement with the doctor who continues to provide care for the sick even when there is no longer any hope. In practice, 7 Italians in 10 say yes to passive euthanasia, left to individual conscience. Six Italians in ten, in contrast, are opposed to active euthanasia, that is to give death to the sick one who asks for it....

All over the world initiatives to reach a regulation are being undertaken. In the USA and the Netherlands in particular. It is also being talked about in Italy where the socialist Loris Fortuna presented a proposed law on passive euthanasia. "Good death doesn't mean good homicide," Fortuna said, "no one wants to authorize killing, I only want to have forbidden the prolongation and persistence of therapy (extension of therapy). With my proposal I want to defend the dignity of every poor human in the terminal phase.

For the Catholic Church euthanasia is and remains unacceptable. Giovanni Paolo II, speaking to representatives of the Italian Society of Anesthesiologists, invited the doctors not to render themselves accomplices with those who practice "la morte dolce." The Church admits, however, that it is not necessary to maintain artificially alive a body which, by natural causes, is destined to be extinguished regardless of any care.
APPENDIX F: Processed for Maltreatment

Doctor Condemned for Having Denied Authorization of Cesarean Section

Como: a "primario" (chief of service in a hospital) in gynecology and obstetrics was condemned for having denied authorization for a Cesarean section. After five hours of discussion, the judges of the court of Como yesterday afternoon condemned to one year in prison the primario of gynecology of the hospital Saint Anna, professor Gino Grassi. The primario was accused of punishable homicide for the death of a neonate, Massimo Tagliabue. Professor Grassi, in fact, had denied authorization for the Cesarean section and the little one suffered severe lesions to the brain during the delivery.

Condannato medico
per aver negato
autorizzazione
al taglio cesareo

Como — Un primario di ginecologia a Como è stato condannato per aver negato l'autorizzazione al taglio cesareo. Dopo cinque ore di dibattito, i giudici del tribunale di Como hanno condannato a un anno di carcere il primario di ginecologia dell'ospedale Sant'Anna, il professore Gino Grassi. Il primario era stato accusato di omicidio colposo per la morte di un neonato, Massimo Tagliabue. Il professore Grassi, infatti, non aveva negato l'autorizzazione al taglio cesareo e il bambino è morto con gravi lesioni al cervello durante il parto.

Repubblica
Sat. 12 Oct. 85

BEST COPY AVAILABLE
«So che sei molto coraggioso»

Lettera di Reagan a un bimbo colpito da Aids

LOS ANGELES - A Los Angeles un bimbo di 9 anni è stato spedito da Reagan a un intervento di meditazione e successivamente al colloquio con lui è stato inviato un telegramma con la lettera scritta da Reagan. Viene anche presentato un libro intitolato "So che sei molto coraggioso". Il bimbo è stato curato in un ospedale storico, dove Reagan ha visitato, per un periodo di tempo non specificato, e ha incontrato il bambino. La lettera, nel testo, è stata scritta da Reagan alla sera, ma non è stata pubblicata in un giornale o in un'agenzia di stampa. Il bimbo è stato trattato con cura e attenzione, come è stato citato in alcune interviste. Il bimbo è stato messo in una situazione di cura e assistenza, con la possibilità di recarsi a ricevere cure mediche e assistenza, come è stato citato in alcune interviste. Il bimbo è stato messo in una situazione di cura e assistenza, con la possibilità di recarsi a ricevere cure mediche e assistenza, come è stato citato in alcune interviste. 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morte serena
APPENDIX G:

Notes from "The Patient's Bill of Rights", Corriere della Sera, Thursday 3 October 1985

How patients and their families are rebelling against the "hospital power." Liguria Region approved its new law which protects them; regions of Veneto, Piedmont, Puglia, Abruzzo, Campania guarantee the continual presence of parents next to their babies; But, notwithstanding this positive fact, the situation remains difficult and the statements of principle too often remain just words.

Someone has counted how many are the rights of the patient, in hospital and out. They are, in the present historical moment, 30 or 40. More or less...I have before me the Bill of Rights of the Patient in Liguria, passed 26 April 1985...There are many regions that have similar laws or in which they're in advanced state of discussion — naturally we're talking about Tuscany (Florence the capital), Piedmont (Torino), Emilia Romagna (communist-controlled Bologna) — all in the north.

The Elderly: In common in these laws is that they guarantee the presence of the parents next to sick children. Specific rights are spelled out for three other categories: women, elderly, and chronically ill. To be a woman, in a hospital, is in fact a permanent condition like a chronic sickness and of weakness like that of the elderly.

Where there are no regional laws, Patients' Bills of Rights are solemnly proclaimed, from the grassroots initiative; there are 30 such, many of them autonomously signed by the local authorities, such as in Lecce, Varese, ...Rome ...

We're talking about "Bills," laws and non-laws that are founded on the tough experience in wards and clinics, matured in the long lines in front of the USL (health union) window, waiting for the documents on principles of the most diverse international organizations, distilled by 60,000 letters which in the 5 years since its founding (in Rome 1980) the Court for the Defence of the Rights of the Patient has received, which in turn is part of the Federal Democratic Movement (NDF), which was founded by the sociologist Quaranta, Caroleo, present secretary general, and Giovanni Moro, son of the president of the Christian Democrats killed by the Red Brigades. Today the "Tribunal" (which is not a tribunal (although myths and rites please people, says Quaranta) are informal organisms for denouncing, are not concerned with following an isolated case as in transforming it into a case study, and example, "political" that is, thus into material for one of the Bills for the Patient, which may come together. The Movement believes that less and less, fearing a dangerous crystallization into a single national Bill, for which, in truth, a government commission in the ministry of Health has already been constituted.

9) If you see cockroaches, take them for hallucinations. In fact, they go away.

10) Comfort the moribund who invariably is placed in the bed next to yours.

11) Even if you are convalescing, keep your pyjamas on (if not, how would the nurse who pases know to give you orders?). It is also prohibited to leave the hospital for a brief Sunday vacation; you'll lose you bed place.

12) Get used to undressing in public, to using toilets on stilts, and to doors that don't exist.

13) Prepare yourself for the violent noises and the sudden, unjustified putting on of lights" (paraphrase from the "Bill" from the Umbria region, 1981). Luciano Girotto of the Russell Group for the Defense of the Citizen (who has an advisor in the city government) "My wife died of a brutal illness, screaming because of the atrocious pain, while under her windows the cars of the visitors were trumpeting and the motors of the nurses who were going off duty thundered ferociously."

14) Don't even try to ring the call bell, the night light, the visit light, or to set up the screen. (from the "Bill", Lazio — Rome, 1983)

15) Accept the distinction of gender, renouncing any respect as a woman (Council of Europe Recommendation 1984).

16) But above all, recounce the right to information. It is the most serious and common cause of discomfort for he who has to furnish it to you. From the information about why you are here, to when you will leave, of what they have administered to you, of the plan of the hospital. Keep quiet, better to know nothing. But this subject, for its importance, merits a discussion by itself.

Before closing, however, this section of our investigation, we must remember that even in this field there are noble exceptions, to whom go all our respect. The respect that is always due to the minority.
La garanzia dei diritti del malato

Gli amianti

Il disagio

I malati peregrinano nei corridoi dell'ospedale Maggiore a Bologna