論文

The Right to Die and Human Dignity:
The California Natural Death Act as a Case Study

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要　旨

本稿は、全米で初めて末期患者の意思表明である指示書に法的効力を与えたカリフォルニア州自然死法を事例に、アメリカにおける尊厳死をめぐる論争を考察する。1976年に成立したカリフォルニア州自然死法は末期患者の生命維持装置の取り外し、または不使用を要請する指示書を法的に認めた。法の反対派と交渉を繰り返し、修正を重ねた結果、非常に制約の多い法律となり、利用できる患者は限られていた。

従来の研究ではカリフォルニア州自然死法の限定的な側面が取り上げられてきたが、本稿がこの法を分析する上で着目するのは、人間の尊厳の概念、とりわけ自然死法の発案者であるカリフォルニア州下院議員のバリー・キーンの尊厳の解釈である。急速に進歩する医療技術や患者の意思が重視されない現状に危機感を抱いたキーンは、今まで難しいとされていた死の法制化に挑んだ。当時のアメリカでは延命治療の拒否権は存在していたものの、キーンはその権利を行使する手段が不明確であると考え、日々進化し続ける医療技術に対応する術を法的に確保する必要があると訴えた。

過度な治療を患者の尊厳に対する侵害と捉え、自己決定権を重要視したキーンの思想はカリフォルニア州自然死法に投影された。今まで提案された尊厳死法や自然死法は主に自己決定権と命の尊さという二項対立的な枠組みのもとで議論されていたが、カリフォルニア州自然死法は人間の尊厳を医療技術に結び付け、新たな軸を導入した。自然死法において急速に進歩する医療技術は人間の尊厳、すなわち患者が考える自分らしい生き方やあるべき姿を脅かす存在として位置づけられた。本稿は、カリフォルニア州自然死法が人間の尊厳という概念を現代の医療技術につなげ、尊厳死をめぐる議論の軸をより複雑なものにしたことを指摘した。

Introduction[1]

In 1976, with the passage of Assembly Bill 3060, California became the first state in the nation to recognize as legally binding a terminally ill patient's instructions to cease medical treatment. The bill, which would become the California Natural Death Act, marked a critical turning point in the history of the right-to-die debate in America because it was the first law to acknowledge the constantly expanding capacity of modern medicine and the necessity to

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[1] This paper uses the following abbreviations in the notes: USCCB for United States Conference of Catholic Bishops; CSA for California State Archives; NCCB for National Conference of Catholic Bishops.

defend human dignity from the possibilities of medical technology.

The California law was passed in a tumultuous period in which people were beginning to fear the possibilities of medical technology, courts were beginning to define and expand the right to privacy, and lastly, individual rights and choice were starting to be emphasized in many fields. It is against this backdrop that Barry Keene, a Democratic assemblyman, introduced the California Natural Death Act in 1976. The act, which recognized the right of an adult patient to make a written directive instructing physicians to withhold or withdraw life-sustaining treatment in the event of a terminal illness, was the first of its kind in the nation.2) After Keene introduced the bill in February, a fierce battle ensued over the content of the bill: legislators, legal experts, ethicists, the clergy, and the public all participated in scrutinizing the bill and analyzing its benefits and harms. Proponents of the bill evoked the horrors of medical technology and stressed the need for individual autonomy in order to protect the dignity of patients. Opponents, headed by the Roman Catholic Church and various Right to Life groups, framed their arguments around the sanctity of life and the dangers of slipping into the realm of active euthanasia.

Previous studies on the California act have acknowledged the significance of the law as the first to recognize advance directives, but they have either focused on the restrictive nature of the act or linked the law to the Quinlan case, a landmark court decision handed down in 1976.3) These studies have also overlooked the complexity of the debate over the law, presenting the debate as a dichotomous clash between proponents who favored patient autonomy and opponents who stressed the sanctity of life. This paper aims to unravel the complex debate over the right to die by focusing on the concept of human dignity, a key component of the law. It suggests that the California Natural Death Act introduced a new strand of analysis in the right-to-die debate by connecting human dignity to modern medical technology.

In the following section, this paper analyzes the content of the California Natural Death Act and the factors that made its passage possible. In the second section, it examines the principle actors involved in the debate over the law. Lastly, it explores how the California law made a direct connection between the loss of human dignity and medical technology. This paper also incorporates excerpts of personal correspondence with Barry Keene, the author of the California Natural Death Act.

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2) Natural Death Act, ch. 1439, 1976 Cal. Stat. 6479.

3) Although there are many studies which analyze the California Natural Death Act from a legal and political perspective, relatively few studies examine the significance of the law using a historical approach. For studies that examine California law, see Robert Veatch, *Death, Dying, and the Biological Revolution: Our Last Quest for Responsibility* (New Haven, CT: Yale University Press, 1989); Peter Filene, *In the Arms of Others: A Cultural History of the Right-to-Die in America* (Chicago: Ivan R. Dee, 1999); Ian Dowbiggin, *A Merciful End: The Euthanasia Movement in Modern America* (New York: Oxford University Press, 2003); Henry Glick, *The Right to Die: Policy Innovation and Its Consequence* (New York: Columbia University Press, 1992).

1. The California Natural Death Act

In the last hours of September 30, 1976, Governor Jerry Brown signed the California Natural Death Act into law, making the Golden State the first in the nation to grant legal, binding force to the instructions of individuals to withhold or withdraw life-prolonging treatment. Although the governor claimed that he did not agonize over the decision to sign the bill, it was evident that the measure dealt with a highly emotional and controversial topic.[4] The law had been heavily debated before it reached the desk of the governor, but his imprimatur would not mean the end of the debate — rather, it signaled a new step in the right to die movement, where death would be placed within the realm of legal language.

The California Natural Death Act gave legal recognition to written directives, which are documents that indicate the patient's directions to withhold or withdraw life-sustaining procedures in a terminal condition.[5] In order for a written directive to be valid, a patient must be deemed a "qualified patient," which the act defines as "a patient diagnosed and certified in writing to be afflicted with a terminal condition by two physicians, one of whom shall be the attending physician, who have personally examined the patient."[6] A "terminal condition" is broadly defined as "an incurable condition caused by injury, disease, or illness" which would lead to death "within reasonable medical judgment."[7] In addition to these requirements, the law stipulates that the patient must also be an adult, competent, and diagnosed with a terminal condition at least 14 days before the execution of the directive.[8] To minimize the possibility of coercion, the directive must be signed by the patient in the presence of two witnesses that are not related to the patient and would not benefit from the patient's death.[9] The directive is valid only for five years after it was executed, and patients can revoke it at any time either by destroying the document or issuing a written or verbal revocation.[10]

To prevent abuse, the California law contained strict safeguards, such as limiting its use to patients who have been diagnosed with a terminal condition, and stopping treatment only when

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[4] Nancy Skelton, "Brown's Office Quiet At Last As Bill-Signing Time Ends," *Sacramento Bee*, October 2, 1976.

[5] Natural Death Act, ch. 1439, 1976 Cal. Stat. 6479 (enacting Cal. Health & Safety Code §§7185-7195). A "life-sustaining procedure" is defined in the law as "any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician, death is imminent whether or not such procedures are utilized."

[6] Id. §7187.

[7] Id. §7187.

[8] Id. §7191(c). If the patient executes a directive prior to being diagnosed with a terminal condition or within the first fourteen days after being so diagnosed, the directive is not binding. The patient must reexecute the directive in order for it to be valid; if not, the statute provides that the attending physician may consider the directive as one factor in the decision to withhold or withdraw life-sustaining procedures.

[9] Id. §7187.

[10] Id. §7188-7189.

death is imminent. The law also excluded pregnant women and patients in skilled nursing facilities from its definition of a qualified patient.[11] Lastly, the law expressly forbade mercy killing or euthanasia, stressing that only the “natural process of dying” is permitted under the act.[12]

The California Natural Death Act was grounded in the philosophical premise that adult individuals have the fundamental right to make decisions regarding their own bodies, including the decision to have life-sustaining procedures withheld or withdrawn in cases of terminal illness. The law begins by noting that modern medical technology has made it possible to artificially prolong human life beyond natural limits, and that this prolongation of life for terminally ill patients may cause “loss of patient dignity and unnecessary pain and suffering, while providing nothing medically necessary or beneficial to the patient.”[13] The law also notes that, under the status quo, medical and legal professions are uncertain about the actions to take when a patient requests that life-sustaining procedures be withheld or withdrawn.[14] As a solution to these problems, and taking note of the fundamental right of adult persons to control their medical destinies, the law recognizes the right of an adult person to execute a written directive that instructs his or her physician to withhold or withdraw life-sustaining treatment in the event of a terminal illness.[15]

The main purpose of the California act was to protect the autonomy of terminally ill patients, but the law also provided protection for physicians, licensed health professionals, and health facilities that withheld or withdrew life-sustaining procedures. They were protected from civil and criminal liability of withholding or withdrawing life-sustaining treatment if they followed the provisions of the act.[16] In addition, physicians who refused to withhold or withdraw treatment on moral or professional grounds were given the choice to opt out; however, they were required to transfer the qualified patient to another physician who would effectuate the directive.[17]

The passage of the California Natural Death Act was made possible through many factors. Firstly, the 1970s were marked by a rising fear of the possibilities of medical technology, the expansion of the right to privacy, and an increasing emphasis placed on individual rights and choice. Robert Veatch, a prominent medical ethicist, described the 1970s as being in the midst of a “biological revolution,” where new technologies could control biological processes such as life and death.[18] The biological revolution forced Americans to directly grapple with

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[11] Id. §7188-7188.5.

[12] Id. §7195.

[13] Natural Death Act, ch. 1439, 1976 Cal. Stat. 6479, §7186.

[14] Id. §7186.

[15] Id. §7186.

[16] Id. §7190.

[17] Natural Death Act, ch. 1439, 1976 Cal. Stat. 6479, §7191 (b). This provision has led to suggestions that the California act provides more protection for the physician than for the patient. Margaret W. Randall, “The Right to Die a Natural Death: A Discussion of *In re Quinlan* and the California Natural Death Act,” *Cincinnati Law Review* 46, no. 1 (1977): 192-206.

death and grasp the idea that the nature of death was shifting along with the technological innovations of the day. Innovations such as artificial respirators, artificial cardiac pacemakers, and kidney dialysis made it possible for people to prolong their lives, but many of these procedures resulted in overzealous attempts to sustain lives at all costs, which was a steep price for patients to pay. Veatch also suggests that the revolution has raised new ethical and social issues that could no longer be debated solely by doctors.19) The controversial nature of these new issues led to the inclusion of lawmakers, ethicists, clergy, and members of the public in the process, as evident in the case of the California Natural Death Act.

The rapid advancement in technology coincided with a movement stressing patient rights, on the one hand, and the expansion of the right to privacy to encompass issues involving the body on the other.20) Prior to the mid-1960s, physicians almost exclusively made the important decisions at the bedside of the patients, such as decisions regarding birth and death; by the mid-1970s, this paternalistic framework had collapsed and the authority in decision-making shifted to give patients more say in decisions involving their bodies.21) This shift in the patient-physician relationship and the emphasis placed on the rights of patients was prompted by the decline of trust in physicians and the growing disillusionment with the medical profession. Spurred by the various rights movements of the 1960s, interest in the principle of respect for autonomy and individualism increased, leading to patient demand for control over medical decisions.22) The doubts cast over excess medical treatment and the uneven distribution of power in the doctor-patient relationship were then brought to the courts, which had recently established the right to privacy in *Griswold v. Connecticut* (1965). This right to privacy was then applied to cases involving life and death, such as *Roe v. Wade* and *In re Quinlan*.23) In these cases, the courts ruled that the right to privacy encompassed the right of individuals to

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18) Veatch, *Death, Dying, and the Biological Revolution*, 11-12.

19) Ibid., 2.

20) David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1992), 390.

21) Rothman, *Strangers at the Bedside*, 1-2.

22) Paul Starr, *The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry* (New York: Basic Books, 1984), 388-89; Rothman, *Strangers*, 108, 128-29. Rothman attributes the shift in authority to the loss of the relationship between physicians and patients, and the abuse of authority by physicians. Faden and Beauchamp describe this change as a shift from trust to commerce as the main theme of the relationship between doctors and patients. Ruth R. Faden and Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986), 94.

23) In *Griswold v. Connecticut* (1965) the United States Supreme Court found the right of privacy to exist under the United States Constitution, and this right of privacy has been used as the legal basis for many corollary rights, such as abortion and the right to die. *Griswold v. Connecticut*, 381 U.S. 479 (1965). *Roe v. Wade* (1973) is a landmark decision by the United States Supreme Court ruling that the right to privacy encompasses a woman's right to choose to have an abortion. *Roe v. Wade*, 410 U.S.113 (1973). In the Quinlan case, the New Jersey Supreme Court found that the right of privacy encompasses a patient's decision to decline medical treatment under certain circumstances: *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

make choices about their own bodies, such as abortion and refusal of life-sustaining treatment. The California Natural Death Act was thus a challenge to the longstanding premises in American medicine that the more medical care the public received, the better off it was, and that patients should entrust medical decisions to professionals.[24] Viewed more broadly, it was a product of the intersections among the development of medical technology, the loss of faith in medical professionals, and the desire to reclaim rights involving the body.

Secondly, on the more practical side, the rising cost of medical care and increases in medical malpractice insurance premiums provided additional impetus for the passage of the California act. As more Americans were dying in hospitals and other institutional care facilities than in their own homes, the expense of terminal care became a pressing issue. Studies revealed that 73 percent of adult Americans dying in 1964 or 1965 had received some hospital or institutional care in the 12 months before death, and that 38 percent had bills of $1000 or more.[25] A nationwide study also showed that the percentage of Americans dying in institutions had increased from 49.5 percent in 1949 to 60.9 percent in 1958.[26]

In addition to the institutionalization of death and mounting costs of treatment, the medical malpractice insurance crisis of 1974-1975 also shaped the backdrop of the California law. That crisis caused sharp increases in insurance premiums, with premiums surging as much as 500 percent in some states. Soaring premiums led to threats of strikes or refusals to provide services by health care professionals, and Congress quickly debated the need for a federal insurance program.[27] The crisis abated with most states enacting new laws that ensured the availability of malpractice insurance, and while supporters of the California Natural Death Act did not particularly emphasize these practical issues, they nonetheless contributed to the backdrop that allowed its passage.

2. The Debate Over the Natural Death Act

(1) Assemblyman Barry Keene

The principle architect of the California Natural Death Act was Barry Keene, a Democrat

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[24] Starr, *The Social Transformation of American Medicine*, 379.

[25] Elaine J. Timmer and Mary Grace Kovar, *Expenses of Hospital and Institutional Care During the Last Year of Life for Adults Who Died in 1964 or 1965 United States*, Vital and Health Statistics 22, no. 2 (1966): 2, accessed August 7, 2015, http://www.cdc.gov/nchs/data/series/sr_22/sr22_011.pdf. For analysis of the data, see Anna A. Scitovsky, "'The High Cost of Dying': What Do the Data Show?" *Milbank Quarterly* 83, no. 4 (2005): 825-41; John C. Fletcher, "Ethics and the Costs of Dying" in *Genetics and the Law II*, eds. Aubrey Milunsky and George J. Annas (New York: Plenum, 1980): 187-209.

[26] Halbert L. Dunn, *Vital Statistics of the United States 1958 Vol.1*, National Vital Statistics Reports (1960), tables 6-L and 6-M, accessed August 7, 2015, http://www.cdc.gov/nchs/data/vsus/VSUS_1958_1.pdf.

[27] Patricia M. Danzon, *Medical Malpractice: Theory, Evidence, and Public Policy* (Cambridge, MA: Harvard University Press, 1985): 1-3, 98-99.

who represented the politically liberal 2nd District of California. Keene's personal commitment to right-to-die legislation predated his election to office, and he began crafting a natural death law in 1974.[28)] His first attempt at a natural death law, which would have guaranteed "the right of any person to die without prolongation of life by extraordinary means," failed to pass in the legislature.[29)] His second attempt, which would become the California Natural Death Act, managed to pass after lengthy negotiations and numerous amendments. For Keene, there was a clear problem in the status quo, where the wishes of patients to refuse treatment were not recognized by the physicians or hospitals. He explained that "out of some misplaced benevolent custodialism, the dying have been systematically and deliberately stripped of their autonomy," and saw a need to remedy the situation.[30)] Keene reiterated his position in personal correspondence, noting,

> There existed a huge disparity between the theoretical *legal empowerment* and the *actual circumstances* confronting a terminally ill individual often in a state of mental and physical deterioration. The complexities included potential resistance to ending extraordinary care by a physician trained to extend life; a family member ridden with guilt (and possibly threatening a lawsuit if life were to be terminated); a clergyman with religious opposition applying pressure; and hospital policies formulated to avoid a malpractice lawsuit, justified or not, alleging a legally inappropriate termination of life. In the law, it is often said that "a right without a remedy" is meaningless.[31)]

Although the right to refuse medical treatment had already existed under common law, Keene argued that patients were often unable to exercise this right, rendering it "meaningless."[32)] The Natural Death Act, which gives legal recognition to the wishes of the

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[28)] Keene was motivated to create a natural death act law after witnessing two events in which individuals were unable to refuse unwanted medical treatment. Barry Keene, "The California Natural Death Act: A Well Baby Check-Up on Its First Birthday," Box 51, LB 311: 1755, File AB3060: Advisory Task Force (1 of 2), Barry Keene Papers, 2-3.

[29)] California Assembly Committee on Health, *Interim Hearing on Rights of Terminally Ill* (Sacramento: California State Assembly, 1974), 3.

[30)] Keene, "Well Baby Check-Up," 3.

[31)] Barry Keene, e-mail message to author, July 20, 2015.

[32)] The rights to informed consent and to refuse medical treatment can be traced back to *Union Pacific Railway Company v. Botsford* (1891) and *Schloendorff v. Society of New York Hospital* (1914). In *Union Pacific*, the United States Supreme Court declared that "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others." *Union Pacific Railway Company v. Botsford*, 141 U.S. 250 (1891). In *Schloendorff,* the New York Court of Appeals established the principle of informed consent. Justice Benjamin Cardozo's famous opinion, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body," has often been used in support of bodily autonomy. *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (1914).

patients, would be the remedy to this situation. Keene also emphasized that the legislature was the best forum to address the problem in the status quo and to guarantee the rights of patients because as the embodiment of societal diversity, the legislature could "balance the sensitive legal questions, the potential stress on the medical relationship, the theologian's ethical concerns, and the public's clear concern about the dying process."[33) This unique nature of the legislature made it possible for Keene to pursue a comprehensive law that would guarantee the rights of terminally ill patients.

While acknowledging that court cases recognized the right to bodily autonomy and the right to refuse unwanted medical procedures, Keene contended "the decision of when to impose dehumanizing medical technology and when to withdraw life-support systems is at best chaotic, and at its worst, a gross infringement upon human dignity," and that there was an absence of a clear legal framework that would protect patients from this chaotic process.[34) Utilizing words such as "horror" and "nightmare" to describe the effect of excessive medical technology on patients, Keene deftly illustrated the plight of terminally ill patients:

> The ultimate horror, for many dying persons, is not death, but the possibility of being maintained in limbo and often in continuous pain in a hospital bed, with wrists restrained by leather bonds so that the tubes cannot be removed, and accompanied not by family and friends, but by the indignity of machines controlled by strangers. . . . They do not want to be placed on a medical roller coaster — the ultimate technological nightmare — over which they have no control and on which they must ride until the track runs out.[35)

By designating medical technology as the clear enemy of patients, Keene was able to demonstrate the necessity of his bill as well as gather support from a wide variety of groups, such as coalitions of senior citizens and individual churches in California.[36) The California Medical Association (CMA) also expressed their support for the bill, noting that existing law fails to provide a basis for individuals to determine their medical destinies, and that Keene's would allow "physicians to make a judgment based on the individual's wishes where such a wish is positively expressed."[37) This wide coalition of supporters facilitated the passage of the act in the state legislature.

[33) Barry Keene, "Well Baby Check-Up," 9.

[34) Barry Keene to Edmund G. Brown, Jr., September 13, 1976, Box 52, LP 311: 1766, File AB3060: Correspondence (2 of 4), Barry Keene Papers.

[35) Ibid.

[36) Supporters of the California law included the Retiree's Action Coalition, the Senior Citizens League, and the Gray Panthers. According to a list prepared by Keene, over 30 churches expressed their support for his bill. "Who Supports AB 3060," n.d., Senate Committees Judiciary, microfilm MF 1:5 (4), CSA, Sacramento, California. Keene contacted leaders of organizations and often held meetings to discuss his bill.

[37) E. Kash Rose to Edmund G. Brown, Jr., September 9, 1976, Box 52, LP 311: 1766, File AB3060:

(2) The California Pro-Life Council

The organization which mounted the strongest opposition to the California Natural Death Act was the California Pro-Life Council (CPLC), the California affiliate of the National Right to Life Committee, a pro-life organization dedicated to opposing abortion and euthanasia. The CPLC consistently opposed the California law on the basis that it was “unnecessary, unwise, and dangerous.”(38) The organization mainly framed their arguments around practical issues, pointing out that the harms brought by the law would far outweigh any benefits it might provide. It argued that patients already had the right to make living wills under current law and that physicians were generally required to follow the wishes of the patient, thus negating the need for natural death legislation. The CPLC also voiced its concern about attempting to legislate a right to select death, noting that there were “simply too many complexities in this matter, too many ambiguities and uncertainties, for the Legislature to successfully draft precise, reasonable language that is not subject to misinterpretation or abuse.”(39) These complexities included the facts that physicians are given immunity from civil liability even if they do not act in good faith, that patients may not fully understand the ramifications of executing an advance directive, and that certain terms in the bill such as “death” and “terminal illness” were open to interpretation.(40) This view directly clashed with Keene’s claims that a law would best clarify the rights of terminally ill patients.

In addition to concerns over the legislation of death, the CPLC linked the California bill to euthanasia and warned that it would be the first step toward its legalization. Although the law included provisions against mercy killing or active euthanasia, the CPLC argued that giving legal recognition to advance directives “unleashes a whole array of legal machinery” that would place the state in the position of favoring death over life.(41) The CPLC displayed heavy distrust in the ability of the proposed Act’s capability to protect the rights of patients and looked to the state to protect individuals from the dangers of euthanasia. Charles Heatherly, the President of the CPLC, wrote that regardless of the exact language of the bill or the intentions of Keene, the law would “inevitably be interpreted by proponents of Euthanasia as a first step in their quest for Euthanasia legislation” because it prioritized patient choice over life.(42)

Correspondence (2 of 4), Barry Keene Papers. Henry Glick, who examined the California Natural Death Act from a policy-oriented perspective, claims the CMA was receptive to Keene’s bill because it saw the concept of the advance directive as a solution to the mounting problems of medical malpractice insurance premiums and incidents of medical liability in the 1970s. Glick, *Right to Die*, 97.

(38) Charles Heatherly to Barry Keene, July 19, 1976, Box 52, LP 311: 1771, File AB3060: Correspondence – Opposition and Support (2 of 3), Barry Keene Papers.

(39) Ibid.

(40) “Arguments Against AB3060 (Amended June 24, 1976),” LP 311: 1771, File AB3060: Correspondence – Opposition and Support (2 of 3), Barry Keene Papers, 4-11.

(41) California Pro-Life Council, “California Pro-Life Council Action Alert,” July 1976, Box 52, LP 311: 1771, File AB3060: Correspondence – Opposition and Support (3 of 3), Barry Keene Papers.

(42) Charles Heatherly to Barry Keene, July 19, 1976, Box 52, LP 311: 1771, File AB3060: Correspondence – Opposition and Support (2 of 3), Barry Keene Papers.

Despite numerous negotiations over a six-month period, the CPLC and Keene were unable to reach an agreement over the bill. Keene had made numerous amendments to the California bill in an attempt to accommodate the demands of the opposition, such as setting a five-year limitation on the directive and excluding pregnant women from qualified patients.43) Although the CPLC conceded that the amendments addressed some of its concerns, it concluded that the bill was "an unwise innovation" and refused to withdraw its opposition.44) Keene was clearly frustrated by the lack of cooperation from the CPLC, and accused the organization of ignoring the voices of the patients in their commitment "to a single-minded philosophy that, in the case of the terminally ill, is far removed from the realities of those who are suffering."45)

(3) The National Conference of Catholic Bishops

The National Conference of Catholic Bishops (NCCB), the official assembly of American bishops in the United States, also saw the Natural Death Act as unnecessary, vague, and susceptible to condoning euthanasia. The NCCB presented the Catholic Church with a cohesive, collective voice that allowed them to enter the political arena and engage in discussions concerning problems of the nation.46) Although it was mostly focused on opposing abortion during the 1970s, especially after *Roe v. Wade*, the NCCB steadfastly opposed natural death laws, including the California law.

The stance of the NCCB in regards to natural death laws is based upon the address of Pope Pius XII to the International Congress of Anesthesiologists in 1957, in which he declared that dying patients are not obligated to use extraordinary means to prolong their lives, and that doctors are not bound to go beyond ordinary means to save the patient if they are given permission to refrain by the patient.47) The Office of Health Affairs of the NCCB, which was originally in charge of dealing with matters concerning euthanasia, reiterated the stance of the Pope in its research paper, noting that the Church "endorses death with dignity, both the withdrawal of extraordinary means and administering pain-relieving drugs under certain circumstances."48)

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43) Keene amended the bill nine times. Barry Keene, "Can We Make the Natural Death Act a Better Law?" March 19, 1978, LP 311: 1756, File AB3060: Advisory Task Force (2 of 2), Barry Keene Papers.

44) Thomas F. Payne to Gary Hart, July 13, 1976, Box 52, LP 311: 1771, File AB3060: Correspondence – Opposition and Support (2 of 3), Barry Keene Papers.

45) Keene sent out a letter to senators and assemblymen to criticize the actions of the CPLC. Template letter from Barry Keene to Members of the California State Legislature, July 21, 1976, Box 52, LP 311: 1771, File AB3060: Correspondence – Opposition and Support (2 of 3), Barry Keene Papers.

46) Timothy A. Byrnes, *Catholic Bishops in American Politics* (Princeton, NJ: Princeton University Press, 1991), 49.

47) Pope Pius XII, "The Prolongation of Life: An Address of Pope Pius XII to An International Congress of Anesthesiologists," in *Death, Dying, and Euthanasia*, eds. Dennis J. Horan and David Mall (Washington, D.C.: University Publications of America, 1977), 281-87.

48) NCCB Office of Health Affairs, "Theological and Legislative Outline for Euthanasia, Death with Dignity

The position taken by the NCCB reveals that the Catholic Church is not inherently opposed to the concept of death with dignity, which the California Natural Death Act aimed to provide; in fact, Keene and the Catholic Church shared a common disdain and fear of medical technology unnecessarily prolonging the dying process. However, the two parted ways on how to deal with this problem: Keene and his supporters claimed that a natural death act would be the remedy, while the Catholic Church argued that such a law would cause more harm than good. Like the CPLC, the NCCB saw a clear connection between natural death acts and the legalization of euthanasia, and warned against the danger of attempting to codify death. Monsignor James T. McHugh, the director of the NCCB Office of Pro-Life Activities, argued that living wills, or advance directives, may be seen by the public as a "teaching mechanism to condition the public opinion to accept positive termination of life in cases of senility or incurable illness."[49] The vague wording and ambiguous nature of the law would allow those who support active euthanasia to interpret the California act in their favor, posing greater danger for vulnerable individuals such as the terminally ill.

Compared to the non-denominational CPLC, the NCCB opposed the California bill by incorporating Catholic doctrine in its arguments. In its Resolution on Euthanasia, the NCCB Ad Hoc Committee on Pro-Life Activities affirmed that as life is a gift from God, society has a moral obligation to provide protection for the life of every person. While recognizing that individuals are not obliged to undergo extraordinary measures to sustain life, the committee disagreed with the very nature of natural death laws because they considered the laws to be "inappropriate substitutes for the co-operative decision making efforts of the patient, the family and the physician."[50] Unlike Keene, who valued the autonomy and choice of patients above other factors, the Catholic Church and NCCB regarded life to be within the dominion of God, and situated death within a web of relationships rather viewing it as an isolated, private experience of the individual. While dying is an intensely personal experience, it also involves family, friends, and society who care for the individual, and the death of that individual will affect those who were involved in the process.[51] The NCCB considered natural death acts to sever these bonds between the dying individuals and the community surrounding them, and argued against the legislation of death as the best option:

> But dying cannot be reduced to legislative procedure, and the needs of dying persons will not be adequately met unless society, the family and friends of the patient and the

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& Other Health Legislation," 1975, Box 65, File NCCB: Ad Hoc Committee: Pro-Life Activities: Euthanasia 1976-1979, USCCB Records, 33-34.

[49] James T. McHugh, "Report on Euthanasia Trends," November 19, 1976, Box 63, File NCCB: Ad Hoc Committee Pro-Life Activities 1977 Jan.-Mar., USCCB Records, 3.

[50] NCCB Ad Hoc Committee, "Guidelines Concerning 'Death/Dying Legislation," February 1977, Box 63, File NCCB: Ad Hoc Committee Pro-Life Activities 1977 Jan.-Mar., USCCB Records, 8.

[51] NCCB Ad Hoc Committee, "Guidelines," 4.

> patient's physicians are all participants with the dying person in this most important phase of his or her life.[52]

The NCCB was not as involved in the debate over the California act as the CPLC, but its arguments contributed to the debate by offering insight into the possible ramifications of legislating the right to choose death and the nature of human death.

3. The New Strand in the Debate: Human Dignity and Medical Technology

In an oral history interview conducted twenty years after the passage of the California Natural Death Act, Keene admitted that his law was "limited in certain ways, and operationally not all that effective."[53] Its restrictive nature had been noted when the bill was introduced in 1976, and scholars have relentlessly dissected the law since its passage, pointing out major constitutional deficiencies. Although the law was passed on the basis of recognizing the dignity and privacy of patients, its definition of qualified patients meant that patients who are unconscious or have lapsed into a permanently non-cognitive state were excluded from the protections afforded by the act. The law also relies on terms such as "imminent," "terminal condition," and "life-sustaining procedure," which are open to interpretation. Scholars have voiced their concerns about whether physicians could accurately determine a terminal condition and the imminence of death, and have raised the possibility of misdiagnosis or failure of diagnosis. The amount of discretion given to physicians has also alarmed the scholars, who point out that physicians are given the power to determine whether the patient is "qualified," whether the directive complies with the requirements listed in the act, and whether the directive should be honored if the patient becomes qualified after executing it.[54] In addition, according to a survey conducted by the CMA a year after the passage of the Act, only six of the 112 physicians who took the survey answered that the Natural Death Act had changed the way in which they practiced medicine, and scarcely more than half of the respondents answered

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[52] Ibid., 3.

[53] Barry Keene, Oral History Interview, conducted 1994 by Carole Hicke, Regional Oral History Office, University of California at Berkeley, for the CSA State Government Oral History Program, accessed July 25, 2015, https://archive.org/details/barrykeeneoral00keenrich.

[54] For a legal analysis of the California act, see Chris Beraldo, Comment, "Give Me Liberty and Give Me Death: The Right to Die and the California Natural Death Act," *Santa Clara Law Review* 20, no. 3 (1980): 971-91; Ellen J. Flannery, "Statutory Recognition of the Right to Die: The California Natural Death Act," *Boston University Law Review* 57, no. 1 (1977): 148-77; Marc I. Steinberg, "The California Natural Death Act: A Failure to Provide for Adequate Patient Safeguards and Individual Autonomy," *Connecticut Law Review* 9, no. 2 (1977): 203-26; William J. Winslade, "Thoughts on Technology and Death: An Appraisal of California's Natural Death Act," *DePaul Law Review* 26, no. 717 (1977): 717-42.

that the Act had been useful to them.[55] Despite this harsh assessment, however, the California Natural Death Act remains a significant and revolutionary achievement in the history of the right-to-die movement in America because it was the first law to directly connect the concept of human dignity to modern medical technology. Having analyzed the California Natural Death Act and the key actors involved in the fierce debate over the law, this section will examine how it linked together the concepts of human dignity and medical technology with legislative action, thus introducing a new strand in the debate over death with dignity laws.

The concept of human dignity is intricately intertwined with the field of bioethics, especially with matters concerning life and death. However, despite being recognized as an important concept, there is no clear consensus on the definition of the term “human dignity.” Philosophers, bioethicists, legal theorists, theologians, politicians, and the public have wrangled over the concept and have brought their own interpretations to the table; as a result, their efforts to clarify the term have both illuminated and clouded it. Human dignity has played a significant role in the right-to-die debate in America, with both proponents and opponents weaving it into their arguments. The actors involved with the California Natural Death Act were no exception.

For Keene, the preservation of human dignity was a central component of his argument in favor of the California act, and he often evoked the image of medical technology depriving terminally ill patients of their dignity in order to demonstrate the necessity of his bill. In his letter to Governor Brown, Keene argued that his bill recognized the need of terminally ill patients to be freed from the “tyranny of medical technology” and would provide patients with measures to preserve their sense of bodily autonomy.[56] He also claimed that artificial prolongation of the moment of death “cheapens the quality of life and personal dignity” instead of enhancing a terminally ill patient’s final days.[57] These statements reveal that Keene’s argument on behalf of human dignity was twofold: medical technology that artificially prolonged the moment of death violated the human dignity of terminally ill patients, and the fact that these patients could not exercise their rights to refuse treatment or effectuate their wishes also violated their dignity. In addition, it is possible to glean from his word choices that Keene interpreted human dignity as something that would allow an individual to retain an intact self, or more precisely, the self a patient sought to maintain. Before the Assembly voted to pass the bill, Keene asked his fellow assembly members whether patients will “spend their last few days in a manner befitting human dignity or be kept alive with respirators, pumps on

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[55] California Medical Association, “Survey Results Following One Year’s Experience with the Natural Death Act, September 1, 1976 – August 31, 1977,” Box 51, LP 311: 1755, File AB3060: Advisory Task Force (1 of 2), Barry Keene Papers.

[56] Barry Keene to Edmund G. Brown, Jr., September 13, 1976, Box 52, LP 311: 1766, File AB3060: Correspondence (2 of 4), Barry Keene Papers.

[57] Barry Keene to Charles Heatherly, May 17, 1976, Box 52, LP 311: 1771, File AB3060: Correspondence – Opposition and Support (2 of 3), Barry Keene Papers.

their hearts, pumps on their lungs, pumps on every part of their body?"[58] The state of being kept alive artificially through excessive medical means against one's will prevented the patient from achieving the self he or she sought to preserve, thus infringing the dignity of the patient.

Keene's emphasis on human dignity and his efforts to ground his law in this concept sets the California Natural Death Act apart from previous attempts to legislate death. Prior to the California act, there had been attempts to codify the right to die, and the notion of death with dignity had been discussed in the United States Senate Special Committee on Aging. For example, in 1906, the state of Ohio considered "An Act Concerning Administration of Drugs etc. to Mortally Injured and Diseased Persons," a bill that would have legalized euthanasia. The debate over the bill concentrated on the collective welfare of society and made little or no reference to patient autonomy and human dignity, which was repeatedly stressed in the California bill.[59] Walter W. Sackett, a member of the Florida House of Representatives, had introduced passive euthanasia bills in the Florida legislature each year, beginning in 1969. His 1976 bill called for any person above the age of eighteen and mentally competent to be able to "execute a document directing that medical treatment designed solely to sustain his life processes be discontinued."[60] Sackett's bill was similar to the California act in that it aimed to give legal recognition to written directives, but its main concerns were the expenditures involved in treating the terminally ill and the protection of medical personnel from malpractice suits stemming from the practice of passive euthanasia.[61] Although his bills introduced prior to 1973 had included a provision basing the legislation on a right to die with dignity, Sackett chose to emphasize the practical benefits of legislation rather than delving into the specifics of human dignity.[62] Asserting that as much as $100 million was being spent per year in Florida keeping patients alive, Sackett argued that the state "must stop the waste."[63] In 1972, the United States Senate Special Committee on Aging held hearings on the concept of death with dignity after recognizing the high level of public interest in the subject. Senator Frank Church, who chaired the hearings, acknowledged that the nation was facing a series of problems, such as the increasing costs of treatment, the threat posed to patients by medical technology, and

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[58] George Anastasia, "Fatally Ill in California Win Right to Die," *Philadelphia Inquirer*, October 2, 1976, Box 52, LP 311: 1762, File AB3060: Articles (4 of 4), Barry Keene Papers.

[59] For analysis of the 1906 Ohio bill, see Jacob M. Appel, "A Duty to Kill? A Duty to Die? Rethinking the Euthanasia Controversy of 1906," *Bulletin of the History of Medicine* 78, no. 3 (2004); Ezekiel J. Emanuel, "The History of Euthanasia Debates in the United States and Britain," *Annals of Internal Medicine* 121, no. 10 (1994).

[60] H.B. 3703, 1976 Leg., Reg. Sess. (Fl. 1976).

[61] Walter W. Sackett, Jr., "Foresight Vs. Hindsight," n.d., Box 52, LP 311: 1766, File AB3060: Correspondence (1 of 4), Barry Keene Papers; Walter W. Sackett, Jr., "I've Let Hundreds of People Die. Shouldn't You?" *Medical Economics* 50, no. 7 (1973): 92-97.

[62] Meta Calder, "Chapter 765 Revisited: Florida's New Advance Directives Law," *Florida State University Law Review* 20, no. 2 (1992): 291-365.

[63] Sackett, "I've Let Hundreds of People Die," 96.

the struggle to provide humane care for terminally ill patients. However, he declared in his opening statement that the country "has a long way to go before we can even begin to think about changes in public policy, if indeed such changes should prove to be desirable."[64] The committee understood the need to face the issues related to death and dying but refused to take governmental action to solve them.

In contrast to the previous bills or the Senate hearings on death with dignity, the California act sought to solve the issue of the needless prolongation of life by creating a law that was grounded in the protection of human dignity. Calling his bill "a commitment to life," Keene stressed that "the quality of life and personal dignity for the terminally ill person" were the paramount concern.[65] The California Natural Death Act was the first law to confront what Eric J. Cassell calls "dying in a technological society." According to Cassell, death in the United States shifted from a moral to technical matter, where the death of a patient became "a failure of technology in rescuing the body from a threat to its functioning and integrity."[66] He blames the institutionalization of death and the depersonalization of care for changing how death is viewed in society, suggesting that "there seems to be more concern for the disease than for the dying person, more concern for life as a succession of heartbeats, than life as meaning" in a technological society.[67] The California act attempted to reclaim the human dignity that modern medical technology and the technological society had taken away from terminally ill patients, and it relied on legal means to achieve this objective. Previous debates over the right to hasten death had focused mainly on the clash between patient autonomy and the preservation of life, but the Act introduced a new layer, which was the impact of medical technology on human dignity. When discussing the law, Keene and his sponsors also considered health care economics such as the growing costs of medical treatment and malpractice insurances, which accompany modern medical technology.[68] This also helped to make the debates more intricate and multilayered, though the foundation of his argument for the act rested on an appeal to human dignity.

Conclusion

"If human beings, as said for example in our Declaration of Independence," Keene wrote, "are entitled to 'life, liberty, and the pursuit of happiness, should that not apply to a

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[64] U.S Senate, Special Committee on Aging, *Death with Dignity An Inquiry Into Related Public Issues*: *Hearings before the Special Committee on Aging*, 92th Cong., 2nd sess., 1972, 1, accessed August 3, 2015, http://www.aging.senate.gov/imo/media/doc/publications/871972.pdf.

[65] Press Release, May 24, 1976, microfilm MF 3:4 (27), CSA, Sacramento, California.

[66] Eric J. Cassell, "Dying in a Technological Society," *Hastings Center Studies* 2, no. 2 (1974): 31.

[67] Ibid., 36.

[68] Barry Keene, e-mail message to author, July 20, 2015; Barry Keene, e-mail message to author, July 21, 2015.

determination not to extend one's life, a power to shape the circumstances of one's precious final days, and the pursuit of an end to the torture of unrelenting mental or physical pain?"(69) These questions lie at the heart of Keene's interpretation of human dignity, and they are what guided him on his journey to codify the rights of patients.

The California Natural Death Act was crafted in response to innovations in medical technology and the inability of terminally ill patients to exercise their right to refuse unwanted medical treatment. Scholars, while pointing out the limitations of the law, agree that its significance transcends its effectiveness. Keene states that his law served as a symbol of the possibility of legislating death, which had previously been thought to be impossible, and that it catalyzed similar legislation throughout America.(70) He also suggests that the law "sparked a conversation" on the profound issue of death and dying, which eventually paved the way for more operationally effective laws such as the Oregon Death with Dignity Act, the introduction of more comprehensive directives, and progress in both the hospice movement and the patient-physician relationship.(71) Even the NCCB, which had continuously opposed attempts to legislate death, remarked that the enactment of the California act had changed the nature of the right-to-die debate by providing concrete concepts such as advance directives and death with dignity legislation, which could be discussed and scrutinized.(72)

Viewed in its wider context, then, the novelty of the California Natural Death Act becomes clear. It introduced a new strand of analysis to the right-to-die debate by connecting human dignity to medical technology, and suggests that the significance of the law lies in its adding this additional layer to the debate. Though its effectiveness was limited and its impact on subsequent death with dignity legislation underrated, the California Natural Death Act helped to highlight the many layers of the debate over the right to die and to define the contours of human dignity. Today, the debate over right-to-die legislation has widened its scope and shifted from the legal recognition of advance directives to the legalization of physician-assisted suicide.(73) Revisiting the California act in light of these recent developments is an important step in understanding the historical context and the challenging complexities of the ongoing right-to-die debate.

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(69) Barry Keene, e-mail message to author, July 20, 2015.

(70) Keene, "Well Baby Check-Up," 9; Barry Keene, Oral History Interview, conducted 1994 by Carole Hicke, Regional Oral History Office, University of California at Berkeley, for the CSA State Government Oral History Program, accessed July 25, 2015, https://archive.org/details/barrykeeneoral00keenrich.

(71) Barry Keene, e-mail message to author, July 25, 2015.

(72) NCCB Ad Hoc Committee on Pro-Life Activities, "Resource Papers on Death and Dying," April 28, 1977, Box 65, File NCCB: Ad Hoc Committee: Pro-Life Activities: Euthanasia, USCCB Records, 8.

(73) In 1994, Oregon became the first state to legalize physician-assisted suicide. The Oregon Death with Dignity Act went into effect in 1997. The state of Washington passed the Washington Death with Dignity Act in 2008. In 2013, Vermont became the third state to enact a death with dignity law. In October 2015, Governor Jerry Brown signed the End of Life Options Act, making California the largest state to allow physician-assisted suicide.