Deciding with Dignity: The Terminally Ill Patient’s Right to Information About the California End of Life Option Act

by CHRISTINE SUNG*

Introduction

“Goodbye to all my dear friends and family that I love. Today is the day I have chosen to pass away with dignity in the face of my terminal illness... I even have a ring of support around my bed as I type... Goodbye world.” On November 1, 2014, Brittany Maynard ended her life in her home in Oregon after posting this quote on her Facebook account. After suffering for months from glioblastoma, an aggressive brain cancer, Maynard and her husband moved from California to Oregon and established residency there shortly after being informed that she only had six months to live in order to access Oregon’s Death with Dignity law, which was not yet passed in California at the time. Although Maynard was able to utilize the rights afforded by the Oregon law, she was required to move away from her home to do so. Maynard’s death made international headlines and re-invigorated the right to die movement across the country.

In October 2015, California Governor Edmund “Jerry” Brown signed the End of Life Option Act (“California Act”) into law, which legalized

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2. Id.
3. Id.
4. Id.
physician aid-in-dying for competent residents who are terminally ill with less than six months to live. Governor Brown stated that his decision was swayed by his reflection on what he himself would want if he were put in a situation facing death. He continued saying, "it would be a comfort to be able to consider the options afforded by this bill and [he] wouldn’t deny that right to others."

The California Act grants California residents the ability to have a peaceful and autonomous death, by being able to die on their own terms through the aid-in-dying drug. The requirements of the California Act are similar to that of other states in many aspects, such as only permitting terminally ill, competent residents to utilize physician aid-in-dying and requiring the physician to obtain informed consent from the patient prior to prescribing the aid-in-dying drug. To date, every version of the End of Life Option Act ("EOLO Act") includes a provision that protects health care providers who refuse to participate in the EOLO Act for reasons of morality, conscience, and ethics by exempting them from liability. These immunity provisions, also referred to as conscience clauses, allow physicians and health care providers to refuse to participate in the California Act. In the Oregon and Washington Acts, there is no guidance on whether the word "participation" includes providing information. In the Vermont Act, there is a specific provision that requires physicians to disclose information about aid-in-dying and explicitly excludes the act of


8. Id.


11. For the purposes of this Note, the "EOLO Act" refers to similar Acts from other states, such as Oregon, Washington, and Vermont; and the "California Act" refers to the End of Life Option Act in California.

12. OR. REV. STAT. § 127.885(4) (2016); WASH. REV. CODE § 70.245.190 (2016); VT. STAT. ANN. § 5285 (2016).

13. Id.

14. For Healthcare Providers, DEATH WITH DIGNITY, https://www.deathwithdignity.org/learn/healthcare-providers (last visited Mar. 30, 2016) (This website provides links to materials that each state has published to assist health care providers with navigating their respective acts. None of the materials on this website set forth guidance on what the scope of the term "participation" covers in the given state.).
giving information from the definition of "participation."  However, the California Act defines participation to include informing a patient about his or her rights under the California Act and referring the patient to a participating physician in the definition of "participation." Under certain circumstances, this broad definition of "participation" in the California Act may lead to a violation of the state constitutional right to privacy and more specifically the right to bodily autonomy and the doctrine of informed consent. It may also lead to conflicting obligations on the part of the physician brought about by the California Terminally Ill Patient’s Right to Know End-of-Life Options Act ("Right to Know Act"). This Note will assess whether the current California Act violates the California Constitution and/or the doctrine of informed consent by allowing physicians to refuse to give information about the act to their patients.

Part I of this Note will discuss the history and development of the right to die in California and the history and rationale of conscience clauses, which have affected the development of the right to die in many ways. Part II of this Note will lay out the requirements of the California Act. Part III will analyze whether the conscience clause of the California Act violates the patient’s California constitutional right to privacy. This Part will focus on the patient’s right to make his or her own medical decisions through the right to privacy in the California Constitution and how, out of necessity, this may grant the patient the right to information about aid-in-dying. This Part will also set forth defenses that the physician may have, as part of the balancing test required in examining privacy claims. Then, Part IV will explore an alternative route and establish the patient’s right to information about aid-in-dying through the patient’s rights under the doctrine of informed consent. Lastly, Part V will examine potential solutions to the apparent conflict between the patient’s rights and section 443.14(e)(2) of the California Act ("conscience clause of the California Act") and the feasibility of revising this section of the California Act to comply with the requirements of the California Constitution and the doctrine of informed consent.

15. VT. STAT. ANN. § 5282 (2016).
18. The term “right to die” in other contexts may encompass the right to various acts such as active suicide, passive suicide, euthanasia, and palliative sedation. However, for the context of this Note, it will only apply to physician aid-in-dying, which has also been referred to as “physician-assisted death.”
I. Background

In Anglo-American jurisprudence, the idea of the right to die was historically not only strongly opposed, but also seen as too taboo to even discuss. In most states, physicians who assist patients in dying are deemed to commit manslaughter—a felony charge. Given the compelling moral and legal concerns behind aid-in-dying, it took multiple attempts and revisions, along with providing a method for physicians to opt out through the inclusion of a conscience clause, to pass the California Act.

California has a rich history with respect to the aid-in-dying movement. The movement began in 1980 when Derek Humphry founded the first right to die organization in the United States, the Hemlock Society, in Santa Monica, California. The Hemlock Society assisted those who were terminally ill in obtaining a peaceful death. The Hemlock Society also distributed information to terminally ill patients on how to die. A decade later in 1990, Dr. Jack Kevorkian helped several patients die and, as a result, was convicted of second-degree murder for one of the deaths in 1999.

In 1986, the Americans Against Human Suffering launched a campaign for the introduction of a physician-assisted suicide ballot initiative in collaboration with the Hemlock Society. This campaign later produced the 1992 California Death with Dignity Act, which would have legalized physician aid-in-dying by permitting physicians to either administer medication to terminally ill patients or prescribe medication for terminally ill patients to administer themselves. However, the proposition was defeated in a fifty-four to forty-six percent vote by California voters.

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21. The Hemlock Society later evolved into End-Of-Life Choices, which merged with Compassion in Dying in 2005 to form Compassion & Choices, an organization that works towards protecting patients' rights in end-of-life care.
23. Id.
26. DEATH WITH DIGNITY, supra note 22.
27. Id.
Similar bills were reintroduced in 1995, 1999, 2005, and 2007, all of which ultimately failed.²⁸

In January 2015, California Senators Lois Wolk and Bill Monning introduced the End of Life Option Act.²⁹ After a series of hearings and amendments, the Act passed in June 2015 and Governor Brown signed it into law in October 2015.³⁰ Soon after, in November 2015, opponents gathered to collect signatures to have the law overturned.³¹ In January 2016, opponents announced that the ballot referendum to overturn the law failed to garner enough signatures.³² As a result, the law became effective on June 9, 2016.³³ The law will sunset on January 1, 2026, unless the Legislature extends it.³⁴

Prior to the passage of the California Act, many health care providers, religious groups, and California residents strongly opposed it. For objecting health care providers, the concern lies within the Hippocratic Oath that physicians must take and the apparent conflict with the duties specified in the Oath.³⁵ The argument stands on the presumption that assisting a terminally ill patient with ending his or her life prior to the end of their natural life is performing a “harm,” rather than a “benefit” to the patient. However, the modern version of the Hippocratic Oath does not include the specific clause often cited as a conflict, that the physician will “be of benefit, or at least do no harm” to the patient.³⁶ For religious groups,
such as Christian organizations, aid-in-dying is viewed as suicide. In the United States, after the Supreme Court's decision in *Roe v. Wade*, Congress and a number of other state legislatures, including California, began enacting conscience clauses, which allow exemption from participation in a law for reasons of religion or conscience. In the context of aid-in-dying and the California Act, the conscience clause permits the physician to refuse to assist the patient in procuring the aid-in-dying drug for reasons of conscience. The rationale behind conscience clauses is the protection of health care providers’ freedom of religion rights under the First Amendment of the United States Constitution and article 1, section 4 of the California Constitution.

However, the conscience clause in the California Act broadly extends to permitting the physician to withhold information about the Act from the patient. Although terminally ill patients are now legally able to receive physician aid-in-dying, this right can easily be overlooked if the patient is not properly informed about it. The physician’s refusal to inform the patient of his or her rights under the California Act may be anticipated in certain circumstances, given that until recently, it was still considered a crime. However, the patient’s right to the information about the California Act should still be afforded some protections.

41. U.S. CONST. amend. I.
42. CAL. CONST. art. I, § 4.
44. CAL. HEALTH & SAFETY CODE § 443.14(e)(2) (2016) (Physicians are not subject to liability for “refusing to participate in activities authorized under this part, including, but not limited to, refusing to inform a patient regarding his or her rights under this part, and not referring an individual to a physician who participates in activities authorized under this part.”).
II. The Requirements of the California Death with Dignity Act

The California Act has requirements for both eligibility and actions that must be taken prior to obtaining the aid-in-dying drug. For eligibility, the patient requesting the aid-in-dying drug from the physician must be an adult with the capacity to make medical decisions, who has a terminal disease diagnosis from his or her attending physician.\textsuperscript{46} The California Act defines a "terminal disease" as an incurable and irreversible illness that will result in death in less than six months, as confirmed by reasonable medical judgment.\textsuperscript{47} The California Act requires that the patient be a California resident.\textsuperscript{48} He or she must also have the ability to self-administer the aid-in-dying drug.\textsuperscript{49} The request must come from the patient him or herself and cannot come from an agent, conservator, or surrogate.\textsuperscript{50} If a patient meets the aforementioned criteria, he or she is deemed a "qualified individual."\textsuperscript{51}

The main concern of the California Act is section 443.14(e)(2), which may effectively rule out any guarantees of a physician obtaining informed consent, if utilized. Section 443.14(e)(2) states:

\begin{quote}
Notwithstanding any other law, a health care provider is not subject to civil, criminal, administrative, disciplinary, employment, credentialing, professional discipline, contractual liability, or medical staff action, sanction, or penalty or other liability for refusing to participate in activities authorized under this part, \textit{including, but not limited to}, refusing to inform a patient regarding his or her rights under this part, and not referring an individual to a physician who participates in activities authorized under this part.\textsuperscript{52}
\end{quote}

As stated above, the California Act explicitly states that the physician is not required to inform the patient of the Act and the rights it affords. The Act allows the physician or health care provider\textsuperscript{53} to determine whether

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\item \textsuperscript{46} CAL. HEALTH & SAFETY CODE § 443.2(a).
\item \textsuperscript{47} ld. at § 443.1(q).
\item \textsuperscript{48} ld. at § 443.2(a)(3).
\item \textsuperscript{49} ld. at § 443.2(a)(5).
\item \textsuperscript{50} ld. at § 443.2(c).
\item \textsuperscript{51} CAL. HEALTH & SAFETY CODE § 443.1(o) (2016).
\item \textsuperscript{52} ld. at § 443.14(e)(2) (emphasis added).
\item \textsuperscript{53} ld. at § 443.1(h) (defining "health care provider" to be: "any person licensed or certified pursuant to Division 2 (commencing with Section 500) of the Business and Professions Code; any person licensed pursuant to the Osteopathic Initiative Act or the Chiropractic Initiative Act; any
they want to provide the information or participate in the act by making it optional—rather than mandatory—so long as the physician or health care provider abstains for reasons of conscience, morality, or ethics.\(^{54}\)

It is also important to note that the California Act distinguishes the reach of the word “participation” in cases where the physician decides to opt out of the California Act from cases where the health care provider decides to opt out of the California Act, but its employees do not.\(^{55}\) The term “participation” is used again in section 443.15, which prohibits physicians from participating in the California Act on the premises owned or managed by the prohibiting health care provider, or while acting in the scope of employment.\(^{56}\) However, “participation” under these circumstances does not include “providing information [about the California Act] to a patient [upon the request of the individual]”\(^{57}\) or “providing an individual, upon request, with a referral to another [participating physician].”\(^{58}\) Soon after the bill passed, the California Medical Association (“CMA”) released guidelines on how the California Act should be applied.\(^{59}\) The guidelines clearly lay out what is required of both the physician and patient involved, and reiterate much of what is stated above.\(^{60}\) The CMA guidelines reaffirm the application of the conscience clause of the California Act.

**III. The Patient’s Rights Under the California Constitutional Right to Privacy**

Because the California Act does not ensure that a qualified patient will be able to obtain information about aid-in-dying, the patient must establish that he or she is entitled to the information in order to receive it from physicians who refuse to participate in the California Act. Although

person certified pursuant to Division 2.5 (commencing with Section 1797) of this code; and any clinic, health dispensary, or health facility licensed pursuant to Division 2 (commencing with Section 1200) of this code,” which includes physicians).

54. *Id.* at § 443.14(e)(1).

55. *Compare* section 443.14(b) (explaining that participation includes the refusal to inform a patient of his or her rights and not referring an individual to a physician who participates in activities authorized under this part), with section 443.15(f)(3) (explaining that participation does not include “providing information to a patient about this part” or “providing a patient, upon the patient’s request, with a referral to another health care provider for the purposes of participating in the activities authorized by this part”).


57. *Id.* at § 443.15(f)(3)(B).

58. *Id.* at § 443.15(f)(3)(C).


60. *Id.*
California courts have refused to extend the right of privacy and bodily autonomy to mean that the individual has a state constitutional right to physician assisted suicide, this refusal does not rule out whether the individual has a state constitutional right to the information regarding the newly passed California Death with Dignity Act. Historically, the right to privacy grants the patient the right to make his or her own medical decisions through the right to bodily autonomy. The right to privacy stems from both the United States Constitution and the California Constitution. However, under both constitutions, the right to privacy is not absolute and must be balanced against the interests of the entity that is violating such right, regardless of whether it is the state or, under the California Constitution, a private entity. Thus, if the countervailing interests outweigh the privacy interests, the violation of the right to privacy may be justified, depending on the means used to further the countervailing interests. In the circumstance of the patient's right to know about his or her right to aid-in-dying, the countervailing interest is the physician's right of conscience. Then, we determine whether allowing the physician to refuse to give the patient information about aid-in-dying is an appropriate and justified means of protecting the physician’s right of conscience. Prior to conducting this balancing test, we must first establish the patient’s right to know about the right to aid-in-dying as a right that stems from the patient’s right to privacy.

Under the United States Constitution, the Supreme Court has held that the right to privacy can be interpreted in the word “liberty” of the Due Process Clause of the Fourteenth Amendment and in the Ninth Amendment. In Griswold v. Connecticut, the Court created the

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62. See Bartling v. Superior Court, 163 Cal. App. 3d 186 (1984) (holding that competent patients with serious illnesses have the right to withdraw from life-support treatments, even if it will hasten death); see also Bouvia v. Superior Court, 179 Cal. App. 3d 1127 (1986) (holding that patients who are mentally competent and understand the risks involved have the right to refuse treatment).
63. Griswold v. Connecticut, 381 U.S. 479, 504 (1965) (stating that if the statute is "reasonably necessary for the effectuation of a legitimate and substantial state interest, and not arbitrary or capricious in application, [it is] not invalid under the Due Process Clause [of the United States Constitution]"); (citing Zemel v. Rusk, 381 U.S. I (1996)).
64. Hill v. Nat'l Collegiate Athletic Ass'n, 865 P.2d 633, 655 (Cal. 1994) (An “invasion of a privacy interest is not a violation of the state constitutional right to privacy if the invasion is justified by a compelling interest.”).
66. See Griswold, 381 U.S. at 487.
Peripheral Rights Doctrine on the basis of the Ninth Amendment—also referred to as the "penumbra" theory—reasoning that the Bill of Rights creates "zones of privacy" in many of the Amendments in the Bill of Rights, thus meaning that the right to privacy granted by the Constitution is not an explicit right but is granted through another enumerated right and thus is specific to the action or thing that is in question.\(^\text{67}\) Many subsequent cases have followed the "penumbra" theory that \textit{Griswold} created.\(^\text{68}\) However, the right to privacy under the United States Constitution only applies to government action and holds less force than the California constitutional right to privacy because it is implied, rather than explicit.\(^\text{69}\) We turn to the right to privacy under the California Constitution, which is not only broader and more protective, as it applies to both state and private actors, but is also explicitly stated.\(^\text{70}\)

\textbf{A. The California Constitutional Right to Privacy and Its Elements}

In contrast to the right to privacy under the U.S. Constitution, the right to privacy, also known as the Privacy Initiative,\(^\text{71}\) is explicitly stated in the California Constitution as an inalienable right.\(^\text{72}\) Under article I, section 1 of the California Constitution, the inalienable rights include "enjoying and defending life and liberty . . . and pursuing and obtaining safety, happiness, and privacy."\(^\text{73}\) In determining whether the state interest justifies a violation of the right to privacy under the California Constitution, California courts hold that the state must show that it has a "compelling interest" that is furthered by the invasion of the individual's privacy.\(^\text{74}\) Because the California Constitution classifies the right to privacy as a fundamental liberty, "it is protected even from incidental encroachment," unless the violating party can show that there is a compelling interest that is

\begin{itemize}
  \item \textit{Id.}
  \item \textit{Hill v. Nat'l Collegiate Athletic Ass'n}, 865 P.2d 633, 641 (Cal. 1994).
  \item \textit{CAL. CONST. art. I, § 1}.
  \item \textit{Id.}
\end{itemize}
both “legitimate and overriding.” In the case at hand, the violating party could potentially be either the legislature that enacted the conscience clause of the California Act or the physician who failed to disclose the necessary information. The countervailing interests weighed in the balancing test will differ depending on whom the violation of privacy claim is against. Furthermore, even if the violating party can prove that there is a compelling interest, the violation must also be the least intrusive means of furthering said interest.

The elements required in proving a claim for violation of the right to privacy under the California Constitution are as follows: (1) the plaintiff must have a legally protected privacy interest; (2) society must be prepared to recognize that there is a reasonable expectation of privacy under the circumstances; and (3) the conduct of the defendant must amount to a serious invasion of the protected privacy interest of the plaintiff. These elements are deemed to be “threshold components of a valid claim,” rather than a “categorical test,” which are structured to act as a gatekeeper to exclude cases with only de minimis intrusions.

B. Application of the Elements of the Right to Privacy

1. The Patient Has a Legally Protected Privacy Interest in Obtaining Information About Aid-in-Dying

The patient must first show that he or she has a specific and legally protected privacy interest in obtaining information about aid-in-dying. Recognized legally protected rights generally fall into one of two categories: (1) informational privacy, which prohibits the distribution of personal confidential information, or (2) autonomy privacy, which protects one’s interest in making personal intimate decisions and in conducting personal activities without surveillance. The patient’s interests in choosing his or her own preferred course of medical treatment would fall within the latter of the two: autonomy privacy.

76. Id. (citing Fults v. Superior Court, 88 Cal. App. 3d 899 (1979)).
78. Leonel v. Am. Airlines, 400 F.3d 702, 712 (9th Cir. 2005) (citing Loder v. City of Glendale, 927 P.2d 1200, 1230 (Cal. 1997)).
79. Hill, 865 P.2d at 654.
80. Id.
81. Id. at 651 (quoting Whalen v. Roe, 429 U.S. 589, 598–600 (1977) (The right to privacy contains interest in having the “independence in making certain kinds of important decisions.”)).
Autonomy privacy has been frequently referred to as the right to bodily autonomy, the right of self-determination, or the right of control over bodily integrity. California courts interpret these rights to mean that the right to privacy "guarantees to the individual the freedom to choose to reject, or refuse to consent to, intrusions of his [or her] bodily integrity." In doing so, the law is aiming to preserve the "inviolability of the person."

Though a majority of cases brought on the basis of the right to bodily autonomy have focused on the right to refuse medical treatment rather than the right to die specifically, they introduce the "idea of the competent patient's right to make medical decisions." Also, the patient's right to make his or her own medical decisions can be "effectively exercise[d] only if the patient possesses adequate information to enable an intelligent choice." In other words, if the information is required for the patient to make a medical decision, then the patient's state constitutional right to privacy is not fully exercised until the patient has the required information. So, it follows that in a situation where a qualified patient is deciding what end-of-life option to choose, he or she has the right to know about the California Act as a possible option. By withholding this information, the physician is inhibiting the patient's ability to fully exercise his or her right to bodily autonomy. Under this analysis, the patient is deemed to have a legally protected privacy interest.

3. The Patient Has a Reasonable Expectation of Privacy

After establishing that the patient has a legally protected interest, the patient must then prove that he or she has a reasonable expectation of privacy under the circumstances that society is prepared to accept. An objective analysis based on "widely accepted community norms" is used to show a reasonable expectation of privacy. The analysis of reasonableness may consist of a discussion of the "customs, practices, and physical settings

83. Bartling, 163 Cal. App. 3d at 195 (citing Superintendent of Belchertown Sch. v. Saikewicz, 370 N.E.2d 417, 427 (1977)).
84. Id. (citing Saikewicz, 370 N.E.2d at 427).
87. Hill v. Nat’l Collegiate Athletic Ass’n, 865 P.2d 633, 655 (Cal. 1994) (citing RESTATMENT (SECOND) OF TORTS § 652D, cmt. e (AM. LAW INST. 2016) (“The protection afforded to the plaintiff’s interest in his privacy must be relative to the customs of the time and place, to the occupation of the plaintiff and to the habits of his neighbors and fellow citizens.”).
surrounding [the] particular activit[y]" and any other circumstances that may limit or expand the patient's reasonable expectation. For example, if advance notice was given to the patient regarding the privacy intrusion, it may reduce the severity of the intrusion. Thus, if the patient was notified initially that his or her provider objected to participation, then this fact will weigh against the patient having a reasonable expectation of privacy in this particular situation.

When a patient goes to a physician and gets diagnosed with a terminal illness, the patient can expect the physician to disclose recommended treatments, along with any feasible alternatives. Traditionally, physicians were permitted to, and often did, overrule patients' preferences and decisions. This paternalistic approach to medical decisions has since evolved into the modern day autonomous approach, in favor of the patient's choice. The American Medical Association ("AMA") states, "The patient has the right to make decisions regarding the health care that is recommended by his or her physician." The purpose for this right is to help physicians foster a partnership with the patient "by providing information and allowing for autonomous decision-making."

Accordingly, the patient's right to make his or her own medical decisions should be a reasonable expectation of privacy, given the current customs and practices that guide the physician-patient relationship in making medical decisions. Modern health care practices also indicate that physicians should provide the information needed for the patient to make a medical decision. So, a qualified patient making a medical decision on an end-of-life treatment can reasonably expect that he or she will get the information necessary to facilitate such a decision. The difficulty arises when determining whether the patient has a reasonable expectation to obtain the information about aid-in-dying specifically. Given the strong opposition to the California Act and aid-in-dying within the medical field, the physician may argue that health care customs dictate that there is no reasonable expectation to the information about aid-in-dying, since aid-in-dying is not widely accepted. However, the patient may argue that the

88. Id.
89. Id. (citing Ingersoll v. Palmer, 743 P.2d 1299, 1316 (Cal. 1987)).
90. See Loder v. City of Glendale, 927 P.2d 1200, 1232 (Cal. 1997); Leonel v. Am. Airlines, 400 F.3d 702, 713 (9th Cir. 2005).
92. Id.
94. Id.
information about aid-in-dying is necessary to making a complete decision, because it is an option that he or she can legally choose. Therefore, the patient has a reasonable expectation to obtain the information.

3. Defendant's Conduct Amounts to a Serious Invasion of Patient's Rights

The last threshold component to establish a claim to privacy is a showing that the defendant's conduct amounts to a serious invasion of the patient's rights. The defendant in this situation could be either the legislature or the physician. The patient may have a claim against the legislature, arguing that the broad reach of the conscience clause violates the patient's constitutional right to make medical decisions. The patient may also have a claim against the physician, as a private entity, who chooses to exercise this conscience clause and thus fails to fulfill his obligation to the patient to give assistance in making a medical decision. For the purpose of this Note, the focus will be on showing that the physician has an obligation to the patient to give him or her this information, though the patient may also have a claim against the legislature. Both claims require the patient to establish that the information the physician is permitted to omit is essential to the patient being able to adequately exercise his or her right to make a medical decision.

A serious invasion of the right to privacy must be something that amounts to "an egregious breach of the social norms." Evaluating "the extent and gravity of invasion is an indispensable consideration in assessing an alleged invasion of privacy." This must be evaluated in light of how vital the information withheld from the patient is to the patient's right to make a medical decision. If the patient can show that knowing the information is essential to making a full and informed medical decision, then the nondisclosure of the information may amount to an egregious violation of social norms. The purpose of this element is to essentially rule out any de minimis invasions of privacy. This third element can be considered very closely tied with the second element of having a reasonable expectation of privacy. Although the third element is more

96. See, e.g., Am. Acad. of Pediatrics v. Lungren, 940 P.2d 797, 806 (Cal. 1997) (Plaintiffs sought declaratory and injunctive relief against the state claiming that the legislation in dispute violated the state constitutional right to privacy.).
97. See, e.g., Hill, 865 P.2d at 637 (Plaintiffs brought an action claiming that an intercollegiate athletic association's drug testing program was a violation of the state constitutional right to privacy.).
98. Id. at 655.
99. Id.
100. Loder v. City of Glendale, 927 P.2d 1200, 1231 (Cal. 1997).
focused on the violation on behalf of the physician, rather than what the patient can reasonably expect, both elements require an examination of customs and norms. Borrowing from the analysis in the second element above, the patient can argue that the customs in health care and in physician-patient relationships is for the physician to facilitate the patient’s autonomous medical decision by disclosing all the necessary information. Withholding vital information is an egregious breach of social norms, and not what is expected in the modern day physician-patient relationship.

4. Defenses to the Violation of the Right to Privacy: Weighing the Patient’s Right to Privacy Against the Physician’s Right to Freedom of Religion

As stated Hill v. National Collegiate Athletic Association, the right to privacy is not absolute and must be balanced against other countervailing interests. The three elements set forth in Hill are only threshold elements, which act as gatekeepers to keep out claims for only de minimis intrusions. After meeting these threshold elements, the final step of analyzing a privacy claim is weighing the defendant’s justifications for the privacy intrusion. In the application of a balancing test, the focus is on any interests that the physician may have in withholding the information. Just as the patient has the right to privacy and to bodily autonomy, the physician is also entitled to freedom of religion and freedom of speech.

After the Right to Know Act passed, many opponents raised First Amendment claims. In an article by W. Eugene Basanta, he wrote about whether a physician could still refuse to abide by the Right to Know Act claiming that it was a violation of his First Amendment rights. In regards to the freedom of religion, Basanta applied the rational basis test, which is afforded to statutes that are neutral on their face. He proposed that, because the purpose of the Act was to facilitate better communications between the patient and the physician, it will likely pass the rational basis test and is, thus, constitutional. Although Basanta’s analysis was primarily focused on the constitutionality of the Right to Know Act, the underlying purposes of the Right to Know Act demonstrate the importance of physician-patient communication. For the purposes of the conscience clause of the California Act, this would weigh strongly in the patient’s favor in balancing the patient’s right to the information against the

102. Loder, 927 P.2d at 1230.
103. Id.
104. Basanta, supra note 43.
105. Id. at 5–6.
106. Id.
physician’s right of conscience. Furthermore, conscience clauses typically protect the party from actions that would be against his or her religion or morals.\(^{107}\) By only requiring the physician to disclose information and not participate in the act of actually assisting the death, the patient can argue that this is requiring a lesser burden on the physician.

As part of the right to privacy analysis, courts have also considered whether there are alternative or less intrusive methods to fulfill the countervailing interests.\(^{108}\) The purpose of enacting conscience clauses is to protect the physician’s and health care provider’s constitutional freedom of religion.\(^{109}\) In doing so, other conscience clauses in EOLO Acts in other states do not broaden the scope of their coverage.\(^{110}\) As stated above, the conscience clause in the California Act is the only one of the four existing EOLO Acts that explicitly allows physicians to refuse to give information about the rights afforded by the California Act.\(^{111}\) As stated by the court in Bartling v. Superior Court, “[I]f the right of the patient to self-determination as to his [or her] own medical treatment is to have any meaning at all, it must be paramount to the interest of the patient’s hospital and doctors.”\(^{112}\) Though the California Act is more instructive on what the term “participation” means, the broad reach of the term leaves the patient with little or no recourse for utilizing his or her own right to bodily autonomy.

IV. The Patient’s Rights Under the Common Law Doctrine of Informed Consent

To further bolster the patient’s claim of possessing a right to the information about the California Act, this part of the Note will examine the patient’s rights under the doctrine of informed consent. The doctrine of informed consent is traditionally a doctrine of tort law, as well as an issue of medical ethics.\(^{113}\) Informed consent, though a common law doctrine, is

\(^{107}\) Marshall, supra note 39.


\(^{109}\) Marshall, supra note 39.

\(^{110}\) OR. REV. STAT. § 127.885(4) (2016); WASH. REV. CODE § 70.245.190 (2016); VT. STAT. ANN. § 5285 (2016).

\(^{111}\) CAL. HEALTH & SAFETY CODE § 443.14(e)(2) (2016).


grounded in the right of privacy, and more specifically, the right of bodily autonomy.\textsuperscript{114}

A. The History and Purpose of the Doctrine of Informed Consent

Justice A. Frank Bray coined the term "informed consent" in 1957 in his opinion for \textit{Salgo v. Leland Stanford Jr. University Board Of Trustees}, where he wrote that physicians have a duty to disclose "any facts which are necessary to form the basis of an intelligent consent by the patient to proposed treatment."\textsuperscript{115} Although not a purpose in the creation of the doctrine of informed consent, in practice, informed consent has been frequently offered as a defense to several torts.\textsuperscript{116} Originally, it was a defense to the torts of assault and battery.\textsuperscript{117} However in modern day, it has become a defense to the tort of negligence for physicians treating patients, which may offer immunity from liability.\textsuperscript{118} This transition occurred due to the statutory codification of the doctrine of informed consent in many states, including California,\textsuperscript{119} as a basis for a medical malpractice claim by arguing that the failure to obtain informed consent resulted in a breach of the physician’s fiduciary duty to disclose to the patient.\textsuperscript{120} It has also been referred to as a claim for "lack of informed consent."\textsuperscript{121} The California Supreme Court has distinguished the claim for lack of informed consent from the claim for battery, stating that they are separate causes of action: the former occurs when a physician does not "adequately disclos[e] the risks and alternatives" of the procedure prior to performance, while the latter occurs when the physician does not obtain any consent prior to performing a procedure.\textsuperscript{122} The former, the lack of informed consent, will be the focus of the discussion below.

\textsuperscript{114} TERRANCE MCCONNELL, INALIENABLE RIGHTS: THE LIMITS OF CONSENT IN MEDICINE AND THE LAW 65 (Oxford Univ. Press 2000).
\textsuperscript{116} FADEN, BEAUCHAMP, & KING, supra note 85, at 125–32.
\textsuperscript{117} \textit{Id.}
\textsuperscript{118} \textit{Id.}
\textsuperscript{119} CAL. CIV. CODE § 3333.1(c)(2) (2016).
\textsuperscript{120} FADEN, BEAUCHAMP, & KING, supra note 85, at 139–40.
B. The Components and Elements of Informed Consent

In general, the analytical components of informed consent are disclosure, comprehension, competence, voluntariness, and consent. The final component of consent may also be referred to as “authorization,” which is the formal aspect of informed consent, requiring the patient to sign an informed consent form. “Disclosure” requires that the physician give the patient the necessary information for the patient to make an autonomous decision. “Comprehension” and “competence” are closely related, but the former is referring to comprehension of the information disclosed, while the latter is referring to the competency of the patient to give informed consent. “Voluntariness” entails that the patient made the decision freely, in absence of fraud, duress, coercion, or undue influence by another person, including the physician.

According to California courts, consent is considered “informed” only after the physician has disclosed all material information necessary for the patient to consider in making a medical decision. “Material information” includes the chances of success and the risks of the procedure in language that the patient can understand. These risks include those that a reasonable person in the patient’s position would consider important, as well as any information a skilled physician would disclose to the patient, under similar circumstances. Essentially, the physician must give the patient as much information as needed for the patient to make an informed decision.

For the patient to make a claim against a physician for failure to obtain informed consent, the patient must prove that: (1) the physician performed a medical procedure on the patient; (2) the patient did not give his or her informed consent for the procedure performed; (3) a reasonable person in the patient’s position would not have agreed to the procedure if given full disclosure of the results and risks of and alternatives to the procedure; and

123. FADEN, BEAUCHAMP, & KING, supra note 85, at 274. See also McCONNELL, supra note 114, at 65.
124. McCONNELL, supra note 114, at 65.
125. FADEN, BEAUCHAMP, & KING, supra note 85, at 30.
126. Id. at 275.
127. Id. See McCONNELL, supra note 114, at 65.
(4) the patient was harmed by a result or risk that the physician failed to disclose prior to the performance of the procedure or treatment.\textsuperscript{131}

C. Application of the Elements of Informed Consent: The Materiality of the Information About the Patient’s Rights Under the California Act to the Patient Making an Informed Decision

After showing that the physician has performed a medical procedure, the patient must prove that he or she did not give informed consent for the procedure to be performed. This requires establishing the third and fourth elements of informed consent: (1) showing that a reasonable person in the patient’s position would not have agreed to the procedure if the physician gave full disclosure of the risks and alternatives to the procedure; and (2) establishing a causal relationship by showing harm to the patient as a result of the physician’s failure to inform.

To establish the third element, the test that the California Supreme Court uses to determine whether the information must be disclosed is the “materiality to the patient’s decision.”\textsuperscript{132} In evaluating this, California takes a patient-based approach, which uses an objective test of how a reasonable patient would have acted under the circumstances.\textsuperscript{133} However, it might be of consequence to note that some California courts have allowed the physician to use a subjective test as a defense, shifting the burden of proof to the physician.\textsuperscript{134} This subjective test is an inquiry into whether the particular patient at hand would have still consented in light of the omitted information.\textsuperscript{135}

To establish the fourth element, the California Supreme Court has held that the patient must establish that he or she would not have given consent, if the physician had disclosed the necessary information.\textsuperscript{136} In other words, even if the physician did not disclose enough information to the patient to obtain valid informed consent, it must be information that would have changed the patient’s decision regarding the medical procedure performed, in order for the patient to succeed on this claim in California courts. Given that the element of causation is subjective to the particular patient, this section will focus on establishing the materiality of the information to a


\textsuperscript{132} Cobbs, 502 P.2d at 11 (citing Canterbury v. Spence, 464 F.2d 772, 786 (D.C. Cir. 1972)).


\textsuperscript{134} See, e.g., Warren, 57 Cal. App. 2d at 583 (citing Truman, 611 P.2d at 907 n.5).

\textsuperscript{135} Id.

\textsuperscript{136} Cobbs v. Grant, 502 P.2d 1, 11 (Cal. 1972).
reasonable patient in making a medical decision on end-of-life options. This begins with a discussion of what California courts have generally held as material information, leading to a discussion of what is material information in the specific context of end-of-life decisions.

1. **The Duty to Disclose: How Much Disclosure Is Necessary**

As stated above, it is well established that physicians have the duty to disclose the necessary information to the patient in order for him or her to give informed consent to the medical procedure being performed, subject to exceptions. The information included in this duty consists of the benefits, risks, and alternatives related to medical procedures requiring informed consent. With regards to alternatives, *Cobbs v. Grant* held that the physician has the “duty of reasonable disclosure of the available choices with respect to proposed therapy and the dangers inherently and potentially involved in each.”

In *Hernandez ex rel. Telles-Hernandez v. United States*, the United States District Court, applying California law, stated that the level of disclosure necessary is “measured by the amount of knowledge a patient needs in order to make an informed choice.” In *Truman v. Thomas*, the California Supreme Court stated that this includes “all information material to the patient’s decision.” The standard for disclosure determines what the term “material information” encompasses. Both the *Hernandez* and the *Truman* courts applied a “reasonable person” standard, which required the physician to disclose all information that the physician knows or should know that a reasonable patient under similar circumstances would need to know in order to make an informed decision. However, in order for a fact to be “material,” it must also be a fact that is not commonly appreciated. Ultimately, the measure for how much the physician should disclose to fulfill his or her duty has primarily depended on what standard for disclosure the court applies. As stated above, California applies the

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139. *Cobbs, 502 P.2d at 10 (emphasis added).*


142. *Id.*

143. *Id.; Hernandez, 665 F. Supp. 2d at 1077.*

reasonable patient standard. In making end-of-life choices, the question is what a reasonable patient would want to know, after being diagnosed with a terminal illness with less than six months to live. Under the circumstances, a terminally ill patient would want to know about all options available to him or her, in order to weigh all the options and make a full and complete decision. Given the passage of the California Act, it is logical to infer that physicians should know about the California Act and should know that a reasonable patient would want to know about this Act in order to make such a decision.

2. The Duty to Disclose: Physician-Recommended Treatments or Procedures

The *Truman* court also rejected the argument that the duty to disclose only applies after a patient consents to the procedure that the physician recommends.\(^{145}\) The court’s rationale behind the purpose of the duty to disclose was to give patients the chance to “meaningfully exercise their right to make decisions about their own bodies.”\(^ {146}\) By rejecting a recommended procedure, the patient is not any more knowledgeable about the procedure than a patient who consents.\(^ {147}\) Furthermore, a patient’s rejection of a recommended procedure does not terminate the physician-patient relationship and fiduciary duties that come along with it.\(^ {148}\) Thus, the duty of disclosure is not discharged simply by the patient’s rejection of a procedure the physician recommends. The *Truman* decision also expanded the duty to disclose to include “recommended diagnostic as well as therapeutic procedures.”\(^ {149}\)

California courts have held that there is no general duty for a physician to disclose information regarding non-recommended procedures.\(^ {150}\) In *Vandi v. Permanente Medical Group, Inc.*, the patient-plaintiff urged the court to include information about non-recommended procedures as a necessary component in the physician’s duty to disclose.\(^ {151}\) The court rejected the patient’s argument for such a rule due to the difficulties in application. For example, one aspect requires the physician to defer to the patient’s desires, rather than the physician’s medical

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145. *Id.* at 906.
147. *Id.*
148. *Id.*
150. *Id.* at 1071 (citing Scalere v. Stenson, 211 Cal. App. 3d 1446 (1989)).
151. *Id.*
judgment. However, the court did not categorically exclude such a duty. To impose such a duty, the patient must show evidence that the physician should have disclosed the information concerning the non-recommended procedure. More specifically, the patient must show that a skilled physician in good standing within the medical community would have disclosed the information under similar circumstances.

While the patient is making a decision about which end-of-life option to choose, it is a possibility that he or she will refuse to choose one of the treatments that the physician recommends. However, as the Truman court explains, this does not discharge the fiduciary duties that the physician has to the patient, such as the duty to disclose. The physician must still fully disclose to the patient all of the material information in making an end-of-life decision. The physician may make an argument that aid-in-dying is a non-recommended treatment and accordingly, the physician has no general duty to disclose information about it. However, the holding in Vandi gives patients the opportunity to create such a duty by showing that a skilled physician in good standing within the medical community would have disclosed the information when counseling the patient about end-of-life choices. To do so, the patient must prove that a reasonable physician would disclose information about aid-in-dying to a terminally ill patient making an end-of-life decision. The argument in favor of this proposition is examined in the following section.

3. Material Information in Making End-of-Life Decisions: The Terminal Patients' Right to Know End of Life Options Act

In 2008, the California Legislature enacted the Terminal Patients' Right to Know End of Life Options Act. The Right to Know Act requires physicians to give terminally ill patients comprehensive information and counseling regarding legal end-of-life options upon the patient's request. The Right to Know Act lists a few end-of-life options, including palliative care and withdrawal of life-sustaining treatment, but
does not limit the coverage of information required to the options listed. Acknowledging the health care providers’ right of conscience, the Right to Know Act allows health care providers to opt out of these duties, so long as they refer or transfer the patient to another health care provider that will provide the information and inform the patient on the procedures of transferring to another health care provider. The Legislature stated in the legislative findings of the Act that terminally ill patients rely on their physicians to give them helpful information and without it, a host of problems may occur, including the “needless physical and psychological suffering to patients and their families.”

After the passage of the California Death with Dignity Act, aid-in-dying, now being a legal end-of-life option, should be included in the information that physicians are required to disclose to terminally ill patients. Otherwise, the physician would have to refer or transfer the patient to another health care provider that will provide the information. Therefore, unless the physician refers the patient to another participating provider, the Right to Know Act should be interpreted to require the physician to disclose the information about aid-in-dying to a terminally ill patient to comply with the Right to Know Act and remain in good standing with the medical community. Contrary to this inference, the California Act expressly exempts physicians from having to inform the terminally ill patient on his or her right to aid-in-dying and from referral and transfer to another health care provider that participates in the California Act. Consequently, the California Act violates the doctrine of informed consent by allowing physicians to forgo fulfilling the duty to disclose prior to performing a treatment or procedure on the patient.

V. Reconciling the Right to Privacy and the Doctrine of Informed Consent with the Conscience Clause of the California End of Life Option Act

The California End of Life Option Act permits physicians to opt out of participation in the act, including giving information to patients about their rights under the Act for reasons of conscience, morality, or ethics. However, the doctrine of informed consent and likely the California Constitution require the physician to disclose to the patient alternatives that

160. Id. at § 442.5(b).
161. Id. at § 442.7.
164. Id.
a reasonable patient would want to know, which can arguably include the right to aid-in-dying, prior to performing a procedure or treatment on the patient to avoid legal liability. The issue arises when a terminally ill patient requests end-of-life options from his or her physician, who chooses to opt out of participation in the California Act. Subsequently, the physician does not facilitate the transfer of the patient to another health care provider who participates in the California Act, and instead performs an alternative end-of-life option procedure. This physician may be liable for negligence for breaching his duty to disclose this information to the patient. Breaching this duty may likely be a violation of the patient's state constitutional right to privacy due to the lack of bodily autonomy and self-determination. In this situation, because the information about the California Act and aid-in-dying would be considered information that would be material to making an end-of-life decision, patients would have a state constitutional right to the information through the right to privacy.

A possible solution would be to require physicians to inform all their patients initially that they have opted out of the California Act. This would at the very least give terminally ill patients notice of aid-in-dying as a possible option when making end-of-life decisions. Under these circumstances, the patient would be on notice of the refusal of disclosure of the information about aid-in-dying, which may reduce the severity of the intrusion.\textsuperscript{165} To facilitate the flow of information about the California Act, in February 2016, the California Senate proposed the End of Life Option Telephone Number Act, which would provide information about the new End of Life Option Act through a toll-free line operated by the Department of Public Health.\textsuperscript{166} The Committee on Health approved this bill, but was ultimately voted down in the Appropriations Committee.\textsuperscript{167} However, the California Department of Public Health has a webpage that provides forms and information for both providers and patients.\textsuperscript{168} Beyond this source, many organizations have also been compiling resources for providers and patients to utilize.\textsuperscript{169} These efforts may ameliorate much of the problems caused by the current California Act by safeguarding the patient's right to

\textsuperscript{165} Ingersoll v. Palmer, 743 P.2d 1299, 1351 (Cal. 1987).
\textsuperscript{166} End of Life Option Telephone Number Act, S. 1002, 2015 Leg., Reg. Sess. (Cal. 2016).
\textsuperscript{167} California, DEATH WITH DIGNITY, https://www.deathwithdignity.org/states/california (last visited Aug. 27, 2016).
\textsuperscript{169} Organizations such as the Coalition for Compassionate Care of California, Hemlock Society of San Diego, UCSF/UC Hastings Consortium on Law, Science & Health Policy, and Death with Dignity have all produced resources that clarify the current California Act and assist both providers and patients with how to navigate and utilize the law.
the information about aid-in-dying, while still protecting the physician’s interests. However, it is important to note that while the outcome will essentially be the same, the physician still has an obligation to the patient to obtain informed consent prior to performing a medical procedure. This obligation still requires the physician to disclose information material to the decision, which—under end-of-life situations—includes all alternatives legally available to the patient (i.e., physician aid-in-dying).

Conclusion

As a vital inalienable act, the right to privacy grants the patient the right to make medical decisions affecting his or her body, requiring the patient to have the information necessary to make such a decision. The broad conscience clause of the California Act results in physicians violating patients’ right to privacy by allowing physicians to refuse to give the patient this material information. Similarly, as a matter of medical malpractice, this conscience clause will also lead to physicians violating their duty to obtain informed consent from the patient by not adequately educating the patient prior to performing the medical procedure. Though there are many resources that patients can utilize to get information on aid-in-dying, it should not take away the legal obligations of the physician. As a general policy matter, the courts should not shift the burden onto the patients, requiring them to go through alternative means to fully secure their rights. In doing so, the courts would impede the ever-important objective in the field of medicine—to encourage physician-patient communication.
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ROGER PATTON, B.S., J.D. .................. Assistant Professor of Law
RICHARD PEARL, B.A., J.D. .................. Assistant Professor of Law
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<th>Name</th>
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<td>James Pistorino, J.D.</td>
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