

MAKING DECISIONS ABOUT ARTIFICIAL VENTILATION AT THE END OF LIFE: DOES LAW AFFECT MEDICAL PRACTICE?

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Making decisions about life-prolonging treatment involves the consideration of moral values, bioethical principles and personal beliefs. Yet, physicians, patients and their relatives who are involved in these decisions operate within a legal framework that principally confines the decisions they make.

The purpose of this article is to examine the influence of the law on physicians who face decisions about ventilation at the end of life. Such an examination is hardly discussed in the existing legal discourse, so this article proposes to fill this gap.

To fulfill the purpose of the article, findings from an empirical study of qualitative interviews with Israeli physicians are presented. These findings are analyzed in relation to the position of the Israeli Dying Patient Act 2005, which regulates end of life.

The analysis shows that there are differences between the practice of physicians and the legal rules that set limitations on the withdrawal of ventilation. These differences are particularly evident when physicians have to deal with a patient's request to

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withdraw ventilation, when a decision has to be made on whether to provide ventilation to a dying patient in emergency circumstances, and when family members are involved in the decision-making process. These findings lead to a discussion about the reasons for these differences, their possible implications and the means to bridge the gaps between practice and law.

The discussion in this article has implications for jurisdictions that regulate end-of-life decision-making. The gaps detected between law and practice in this study and the methods physicians adopt when dealing with real-life situations within a legal framework that limits their professional judgment raise questions about how law- and policy makers should deal with discrepancies between law and practice. Furthermore, these gaps lead to a jurisprudential question regarding the role of law in society where end-of-life issues are subject to an ongoing public debate.

I. Introduction

Making decisions about life-prolonging treatment involves the consideration of moral values, bioethical principles, and personal beliefs. Yet, physicians, patients, and their relatives who are involved in these decisions operate within a legal framework that principally confines the decisions they make. The purpose of this article is to examine the influence of the legal framework on physicians when facing— together with the patient and the relatives—decisions about artificial ventilation at the end of life.

The literature in social science, bioethics, and law on withdrawal and withholding of life-prolonging treatment is voluminous. In health sociology, studies indicate that physicians distinguish between withholding and withdrawing artificial ventilation, reflecting the moral and emotional difficulties physicians experience when facing a request to withdraw treatment.¹ In bioethics, scholars discuss the main tenets of the debate, concentrating on the scope of autonomy of the dying patient and whether withdrawal of treatment is considered a permissible act of omission or a direct cause of the patient's death.² The sociological research and bioethical discourse influences the legal position and the way lawmakers structure the legal framework.³

1. See generally, David W. Frost et al., *Patient and Healthcare Professional Factors Influencing End-of-Life Decision-Making during Critical Illness: A Systematic Review*, 39 CRIT. CARE MED. 1174 (2011). See below for a detailed discussion.

2. See generally John Coggon, *The Wonder of Euthanasia: A Debate That's Being Done to Death*, 33 OXFORD J. OF LEGAL STUD. 401 (2013).

3. See generally *Bland v Airedale NHS Trust* [1993] [2002] EWHC 429 (Eng.); see also EMILY JACKSON, *MEDICAL LAW: TEXT, CASES AND MATERIALS* 898-908 (Oxford, 3rd ed. 2013) [hereinafter JACKSON].

However, what is hardly examined in the existing legal discourse is the impact of the legal framework and its rules on medical practice in the context of end-of-life decision-making, particularly when decisions about artificial ventilation are made. The article proposes to fill this gap. Its purpose is to examine whether and how clinicians who face decisions regarding the withholding or withdrawing of artificial ventilation apply the relevant legal rules.

This is important for several reasons. First, there are several potential factors, including the physician's views, beliefs, and moral convictions that influence physicians who make decisions about the provision of life-prolonging treatment to a dying patient. It is thus necessary to investigate how, if at all, the law affects physicians' decisions and actual conduct. Second, the law usually provides a framework for action but cannot address all the various situations that arise in practice. It is thus important to examine whether the law has a positive, negative, or neutral effect on real-life situations. Third, finding out that there are differences between the conduct of physicians on the one hand and the legal rules they have to follow on the other may require law and policy-makers to reconsider the current legal framework.

To fulfill the purpose of this article, we will present and discuss findings from an empirical study of qualitative interviews with Israeli physicians. These findings will be analyzed in relation to the position of the Israeli Dying Patient Act 2005, which provides the legal framework for end-of-life decision-making.⁴ The analysis will show that there are gaps and differences between the practice of doctors who generally adopt a Western liberal view in this context and the legal mechanisms that set limitations on withdrawal of artificial ventilation. The analysis will also show that a physician's views, family involvement, and the external circumstances beyond the physician's control make it difficult for the physician to apply existing legal rules. This analysis will lead us to consider legal and policy changes to the current position.

Despite the focus on a particular legal system, the discussion in this article has implications for all jurisdictions that regulate this complex area of end-of-life decision-making. The gaps detected between

4. See generally Avraham Steinberg & Charles Sprung, *The Dying Patient Act, 2005: Israeli Innovative Legislation*, 9 *ISR. MED. ASS'N. J.* 550 (2007).

law and practice in this study and the methods physicians adopt when dealing with real-life situations within a legal framework that limits their professional judgment and personal preferences raise the question of whether law- and policy-makers should strive to minimize these gaps and what methods they should use to deal with them. Furthermore, these gaps lead to a more jurisprudential question regarding the role of law in the context of end-of-life issues, which are the subject of an ongoing public debate.

In light of this introduction, the structure of this article will be as follows. The next part sets the bioethical scene. It discusses the leading bioethical approaches towards decision-making regarding withholding or withdrawing artificial ventilation at the end-of-life. This is followed by a review of findings from previous empirical studies regarding the views and experiences of physicians in the context of artificial ventilation. The fourth part describes the legal framework and rules that physicians in Israel have to follow. The fifth part of the article presents the findings from our empirical study, which examines the conduct of physicians when they face decisions about artificial ventilation. The sixth part provides a legal and bioethical analysis of the findings, and the last two parts discuss the main implications and the conclusions of the legal and empirical study.

II. The Bioethical Framework

The discussion regarding artificial ventilation is conducted in light of two main principles: autonomy and nonmaleficence. While the first focuses on the individual who wishes to make independent decisions, the second addresses the act itself and its moral implications. We will first deal with nonmaleficence, then with autonomy, and, lastly, with the interaction between them.

1. Nonmaleficence

The duty not to cause harm, whose origins go back to the Hippocratic Oath, is a central principle in modern bioethics.⁵ It is based on consequential moral theories that claim that the morality of acts should be determined according to the nature of their consequences.⁶

5. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 150 (Oxford U. Press, 7th ed., 2013) [hereinafter BEAUCHAMP].

6. *Id.*

Accordingly, an act or a decision that causes more harm than good should be considered immoral, and vice versa.⁷ Therefore, a harmful action might be morally justified if it provides a greater good than harm. For example, amputating a patient's leg is not a harmful act if it substantially prolongs the patient's life (assuming the patient views her life as worth living).⁸

A fundamental issue in this context is the definition of harm. Two American bioethicists, Beauchamp and Childress, argue that "X harmed Y" may practically mean that X causes a physical injury to Y, but it may also mean that X treated Y unjustly or that X's action compromised Y's interests.⁹ The two bioethicists explain that it may also mean that X violates Y's rights.¹⁰ The definition of harm raises a similar question: What aspects of the individual's life should be considered when deciding whether a specific course of treatment is harmful or beneficial? Should only medical factors be considered, or should other aspects of the individual's life (i.e., the patient's emotional well-being, personal values, style of living) be considered as well? Some scholars argue that physical health is only one of the goods that compose the individual's overall wellbeing and, therefore, should not be the decisive factor when considering the moral nature of a particular course of treatment.¹¹

In light of this discussion, it is clear why the debate about artificial ventilation is conducted in the context of the principle of nonmaleficence. Because withholding and withdrawing artificial ventilation can lead to the patient's death, a question arises of whether, in taking these courses of conduct, the physician breaches her duty not to cause harm.

Generally, the bioethical discussion about withholding or withdrawing life-prolonging treatment in the context of nonmaleficence is well-trodden.¹² However, as will be shown below, the debate has yet to end. Philosophers, bioethicists, and lawyers still discuss this issue

7. *Id.*

8. *Id.* at 153.

9. *Id.*

10. *Id.*

11. See STEPHEN WEAR, *INFORMED CONSENT: PATIENT AUTONOMY AND CLINICIAN BENEFICENCE WITHIN HEALTH CARE* 35-36 (2nd ed. 1998).

12. See generally Soren Holm, *The Debate about Physician Assistance in Dying: 40 Years of Unrivaled Progress in Medical Ethics?*, 41 *J. MED. ETHICS* 40 (2015) [hereinafter Holm].

today. To a substantial extent, the discussion revolves around the general distinction between acts and omissions and, more specifically, between killing, which is defined as a positive act, and letting die, which is considered an omission.¹³ The question examined is whether withdrawal of life-prolonging treatment, such as artificial ventilation, can be considered an omission, or as letting the patient die, and is hence morally permissible (because it does not infringe on the physician's duty not to cause harm), or whether it is a positive act that actively kills the patient and, hence, should be morally and legally prohibited (because it violates the duty not to cause harm).

The discussion about acts and omissions has yielded various viewpoints. From a linguistic perspective, British scholar Ian Kennedy argues that to define switching off a ventilator as an omission "does some considerable violence to the ordinary English usage."¹⁴ He adds that this definition is invoked to provide ethical and legal justifications for physicians when they switch off a ventilator.¹⁵ It appears that, to Kennedy, defining the withdrawal of life-prolonging treatment as an omission is a moral fiction.¹⁶ Without this fiction, some scholars argue, the physician kills the dying patient when switching off the ventilator, which in turn violates her duty not to cause harm to the patient.¹⁷

However, British bioethicist Jonathan Glover states that morally there might be no difference between withholding and withdrawing life-prolonging treatment.¹⁸ Although principally, acting positively (actively killing someone) is more reprehensible than doing nothing (i.e., letting someone die), this is not always the case.¹⁹ Glover gives the example of self-defense as a positive act that could end life but does not render the actor culpable and of the omissive act of starving a child to death, which amounts to murder.²⁰ Thus, according to this

13. See Raanan Gillon, *Euthanasia, Withholding Life-Prolonging Treatment, and Moral Differences between Killing and Letting Die*, 14 J MED ETHICS 115 (1988) [hereinafter Gillon].

14. See IAN KENNEDY, *TREAT ME RIGHT: ESSAYS IN MEDICAL LAW AND ETHICS* 349-51 (Oxford U. Press, 1988).

15. *Id.*

16. *Id.*

17. See Franklin G. Miller et al., *Moral Fictions and Medical Ethics*, 24 BIOETHICS 453, 454 (2010) [hereinafter Miller].

18. See generally JONATHAN GLOVER, *CAUSING DEATH AND SAVING LIVES* (1977).

19. *Id.*

20. *Id.* at 75.

view, the focus should not be on the moral implications of one's conduct (acts or omissions) but on the individual who faces a decision, her intention, and the scope of her moral responsibility.²¹ The implications of this position in the end-of-life context are that a physician who wants to help her dying patients relieve their suffering by letting them die through switching off the ventilator is either a criminal if she intends to end the patient's life or she is not if her mere intention is to relieve pain.²²

Other scholars focus on causation. Andrew McGee argues that unlike acts of euthanasia, such as injecting a lethal drug into a patient, withdrawing artificial ventilation is morally permissible because the main contributor to the patient's death is her underlying disease.²³ According to this view, by withdrawing treatment, the physician does not cause death or hasten its occurrence;²⁴ she merely lifts a barrier that postpones the inevitable.²⁵ Thus, the physician, by connecting the patient to a ventilator, prevents nature from taking its course.²⁶ Ultimately, disconnecting the patient from a ventilator does not cause death; it only influences its timing.²⁷

Miller, Truog, and Brock do not accept this analysis and argue that when the patient depends on the ventilator to continue living, then switching off the ventilator causes the patient's death.²⁸ They argue that what explains the death of a patient who depends on artificial ventilation is not the terminal illness but the "act of turning off the ventilator."²⁹ This is the proximate cause of death. They add that medical technology has a double effect: It enables physicians to prolong life but also to cause death.³⁰ McGee, in contrast, replies that technolo-

21. See John Coggon, *On Acts, Omissions and Responsibility*, 34 J MED ETHICS 576, 578 (2008); see also JAMES RACHELS, *THE END OF LIFE: EUTHANASIA AND MORALITY* 112 (1986).

22. See JOHN KEOWN, *EUTHANASIA, ETHICS AND PUBLIC POLICY* 14 (2002) (arguing that the main question is whether or not the doctor intends to produce the patient's death. If she does, this is morally wrong and it does not matter whether the patient died through acts or omissions).

23. See generally Andrew McGee, *Does Withdrawing Life-Sustaining Treatment Cause Death or Allow the Patient to Die?*, 22 MED. L. REV. 26 (2014) [hereinafter McGee].

24. *Id.*

25. *Id.*

26. *Id.*

27. *Id.* at 40.

28. See generally Miller, *supra* note 17.

29. *Id.* at 457.

30. *Id.*

gy provides the means to “hold death at bay,” and this should lead to the conclusion that physicians do not infringe their duty not to cause harm to their patients when they withdraw ventilation.³¹

The discussion between Miller, Truog, and Brock on the one hand and McGee on the other shifts the bioethical debate from causation to the physician’s moral responsibility. It shows that the line that distinguishes between permissible withholding of treatment and the contested act of withdrawal is thin.³² In supporting his view that there is no distinction between the two, McGee argues that if the patient is ventilated manually and not mechanically, then the physician’s decision not to re-inflate the oxygen bag is defined—strictly speaking—as the withholding of treatment, so the fact that the patient is connected to a machine that continuously provides oxygen does not essentially change the moral definition of the provision of oxygen to the patient.³³ Forty years ago, Glanville Williams made the same point, stating that switching off a ventilator is not an act of killing but a decision to stop saving the dying patient.³⁴

The discussion about causation and the physician’s moral responsibility is related to another aspect of the debate about the act-omission distinction in this context. It addresses the physician’s moral duty to treat the patient. This duty essentially relates to the physician’s duty not to cause harm in a wider sense, as was presented above by Beauchamp and Childress.³⁵

Arguably, a physician is morally responsible for the patient’s death (and thus causes the ultimate harm) only if she has an obligation to provide treatment or continue its provision and fails to do so.³⁶ If the physician has no duty to provide effective medical care, there is no causal link between her conduct and the death of her dying patient. In this context, the physician would not be morally responsible for the patient’s death regardless of whether she withholds or withdraws life-prolonging treatment, and she would not violate her duty not to cause harm. Thus, the question is whether the physician has a

31. See McGee, *supra* note 23, at 40; see also Andrew McGee, *Finding a Way through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia*, 13 *MED. L. REV.* 357, 383 (2005).

32. *Id.*

33. See McGee, *supra* note 23, at 39.

34. GLANVILLE WILLIAMS, *TEXTBOOK OF CRIMINAL LAW* 237 (1978).

35. See generally BEAUCHAMP, *supra* note 5.

36. *Id.*

moral duty to provide artificial ventilation when the patient is dying. The answer depends on one's view regarding the principles of autonomy, sanctity of life, and quality of life. For Beauchamp and Childress, physicians in principal have no moral duty to provide a futile treatment.³⁷ In other words, according to this view, physicians have no duty to provide treatment that does not improve the patient's health. If this view is accepted, then one might also accept that physicians have no duty to initiate ventilation (withholding of treatment) or continue its provision (withdrawal of treatment) when the patient is dying because the treatment is futile. It does not help the patient get over her illness or prolong her life substantially.³⁸

In any event, the discussion about the physician's duty does not end the bioethical discussion. Another aspect is related to the argument that letting patients die is valid and morally permissible only if it is authorized by the patient.³⁹ If withdrawal of artificial ventilation is not authorized by the patient, who then dies from natural causes (a terminal disease), the death might be defined as unjustified killing and not as a justified act of allowing the patient to die.⁴⁰ Thus, the validity of the authorization determines the morality of the physician's conduct, not whether it is an act or omission.⁴¹ This suggests that the discussion about the moral implications of withdrawal of treatment does not relate to nonmaleficence only but also involves the principle of autonomy.⁴² This principal is discussed next.

37. See BEAUCHAMP, *supra* note 5, at 169 (relating to curative treatment. Clearly, when the patient is dying and no curative treatment exists, the doctor still owes a duty to provide palliative treatment).

38. However, physicians who are influenced by religious or other personal convictions may not share the same view about medical futility. They may believe that life-prolonging treatments should be provided to dying patients even when death is near. If this is the policy in a particular medical center or jurisdiction, then the point about medical futility is no longer convincing. The inevitable conclusion in such a case would be that the physician owes a duty to provide a life-prolonging treatment and, hence, cannot withdraw artificial ventilation from the dying patient. See generally Sharon Reynolds et al., *Withdrawing Life Sustaining Treatment: Ethical Considerations*, 15 THORACIC SURGERY CLINICS 469 (2005) [hereinafter Reynolds]; Zev Schostak, *Jewish Ethical Guidelines for Resuscitation and Artificial Nutrition and Hydration of the Dying Elderly*, 20 J. MED. ETHICS 93 (1994).

39. Reynolds, *supra* note 38, at 470.

40. *Id.*

41. See BEAUCHAMP, *supra* note 5, at 175-177.

42. See generally Miller, *supra* note 17.

2. Autonomy

Despite the heated debate about the moral perception of withdrawal of ventilation, one should not forget that essentially, in many cases, the patient requests it be stopped.

At first glance, the physician should not have a dilemma: if the patient is legally competent and explicitly expresses a wish not to receive ventilation, or to stop it, then according to the principle of respect for autonomy, the physician has to respect the patient's request.⁴³ Although the scope of this principle is highly contested, it is widely agreed that every individual has a moral right to make an independent and voluntary decision, based on relevant information, as long as the individual does not cause significant harm to others and is not subject to undue influences by others.⁴⁴ One aspect of this right to autonomy is the right to refuse a proposed treatment (withholding) or a treatment that is already provided (withdrawal).⁴⁵ The same applies when the patient has no or diminished capacity to express her wishes. If the patient expressed wishes clearly and explicitly in the past, before loss of mental capacity, then the physician should respect these wishes, as long as there is no evidence to suggest that the patient has changed his or her mind.⁴⁶

However, things become complicated in this area. We will discuss three issues: (i) the potential conflict between patient autonomy and the physician's moral duty not to cause harm (nonmaleficence); (ii) the impact of family involvement on the decision, particularly when the patient has limited or no capacity to make decisions; and (iii) the physician's moral objection to respect the patient's wish.

43. *Id.* at 453.

44. For a comprehensive discussion, see BEAUCHAMP, *supra* note 5, at 101-149. For the centrality of this principle, see generally Raanan Gillon, *Ethics Needs Principles - Four Can Encompass the Rest - and Respect for Autonomy Should be 'First among Equals'*, 29 J. MED. ETHICS 307 (2003) [hereinafter *Ethics Needs Principles*]. For a recent discussion, see Raanan Gillon, *Defending the Four Principles Approach as a Good Basis for Good Medical Practice and Therefore for Good Medical Ethics*, 41 J. MED. ETHICS 111 (2015).

45. See generally *Ethics Needs Principles*, *supra* note 44.

46. See, e.g., BEAUCHAMP, *supra* note 5, at 189 (discussing the moral and legal aspects of advance directives is beyond the scope of this article.); RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA AND INDIVIDUAL FREEDOM* (1993) [hereinafter DWORKIN]; Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823 (2003) (assuming that advance directives are valid and reflect the preferences of a legally competent and informed patient).

(I) THE POTENTIAL CONFLICT BETWEEN AUTONOMY AND NONMALEFICENCE

As discussed above, physicians have a moral duty not to inflict harm on patients.⁴⁷ However, they also have a duty to respect a dying patient's request not to be connected to a ventilator or to be disconnected from it.⁴⁸ Miller, Truog, and Brock emphasize that what makes withdrawal of ventilation justifiable is the patient's request, or the "valid refusal of treatment."⁴⁹ They argue that the patient's request to stop ventilation leads to the conclusion that "the primary responsibility rests with the patient."⁵⁰

However, Miller, Truog, and Brock do not agree with the overriding impact the principle of autonomy has.⁵¹ They argue that bioethicists, in an attempt to resolve the conflict between respecting the dying patient's refusal of treatment and the physician's duty not to cause harm, developed a moral fiction that withdrawal of life-prolonging treatment is justifiable because the physician does not intend to cause death.⁵² Yet, as we already saw, the three scholars assert that withdrawal of ventilation does cause death.⁵³ In their view, if the ventilator-dependent dying patient prefers not to prolong their life by withdrawing the ventilator after reaching a decision that life is no longer worth living, a physician who is prepared to help him or her by withdrawing the ventilator intends not only to respect the patient's choice but also to cause death.⁵⁴ Thus, the three scholars argue, autonomy cannot morally resolve the problem the principle of nonmaleficence creates.⁵⁵ Ultimately, they assert, the responsibility for the patient's death is "shared by patients or surrogates and clinicians" who respect these wishes.⁵⁶

Other scholars, however, perceive autonomy as an overriding principle in this context. Emily Jackson, for example, is very clear when stating that when a legally competent patient refuses the continuation of life-prolonging treatment, the physician owes her an obli-

47. See BEAUCHAMP, *supra* note 5, at 169.

48. See generally *Ethics Needs Principles*, *supra* note 44.

49. See Miller, *supra* note 17, at 457.

50. *Id.* at 458.

51. See generally *id.*

52. *Id.*

53. *Id.*

54. *Id.*

55. See generally *id.*

56. *Id.* at 458.

gation to comply with this refusal.⁵⁷ Furthermore, in light of the patient's request, the physician has no duty to provide the particular life-prolonging treatment that the patient now wants to stop.⁵⁸ The British bioethicist John Harris presents a similar view. Relying on John Locke's account of personhood, Harris argues that the individual has the capacity to value *its own existence*.⁵⁹ Thus, the patient is also capable of morally assessing a situation when his or her existence is deprived by a terminal illness. According to Harris, a patient who wants to live is wronged by being killed because he or she is deprived of something valued, namely, life.⁶⁰ Similarly, a patient who does not want to continue living is respected by having the wish to die granted when physicians withdraw ventilation, because it is based on his or her voluntary decision and assessment of the quality of life.⁶¹

To sum up, the discussion about the potential conflict between the principles of autonomy and nonmaleficence has led some scholars to argue that despite the patient's independent request of switching off the artificial ventilator, the physician remains at least partly morally responsible due to the contribution of withdrawal of treatment to the patient's death. This stands in contrast to a more liberal view, expressed by other scholars, who impose the moral responsibility only on the patient who requested the withdrawal of treatment. Furthermore, it is also quite clear that the disagreement between those who classify withholding or withdrawing artificial ventilation under the same category of permissible conduct and those who do not is closely connected to the importance they give to the principle of autonomy on the one hand and sanctity of life on the other.⁶² We will see later how physicians view these two main principles and how their views affect their conduct.

57. *See id.*

58. *See JACKSON, supra* note 3, at 901.

59. *See generally* John Harris, *Consent and End of Life Decisions*, 29 J. MED. ETHICS 10 (2003).

60. *Id.* at 12-14.

61. *See id.* For another autonomy-based view, *see JACKSON, supra* note 3, at 911; Joseph Raz, *Death in Our Life* (2012) *Oxford Legal Studies Research Paper* no. 25/2012 <http://ssrn.com/abstract=2069357>.

62. *See generally* EMILY JACKSON & JOHN KEOWN, *DEBATING EUTHANASIA* (2011).

(II) RESPECTING PATIENT AUTONOMY AND FAMILY INVOLVEMENT

An issue that influences the scope of autonomy of the dying patient and the physician's conduct in end-of-life decision-making is family involvement.⁶³ The bioethical literature discusses both the positive and negative influences of family involvement when the patient is either legally competent or unable to make decisions. Essentially, when a patient has the mental capacity to make decisions, the principle of respecting autonomy means that the patient is free to lead life as he or she wishes as long as he or she does not significantly harm others and the decisions are made voluntarily and independently without external coercion.⁶⁴ This obviously imposes a duty on others not to unduly influence the patient to make a particular decision.⁶⁵ However, a relational approach to patient autonomy has been gaining scholarly attention recently.⁶⁶ This approach stresses that the patient's significant others, such as family and friends, nurture and support the patient's ability to make autonomous decisions and execute them.⁶⁷ Because end-of-life decisions are extremely difficult for the patient to make, it seems that family involvement can help the patient reach an informed and independent decision.⁶⁸

However, scholars also appreciate that family involvement can be detrimental to the patient's capacity to make autonomous decisions.⁶⁹ Arguably, some patients live in hierarchical families, or with dominant relatives who have great influence over the patient's life and decisions. When the patient is dying and capacity to assert his or her view regarding artificial ventilation is weakened in light of the patient's physical condition, the involvement of the family may become more influential, particularly when the relatives were dominant in

63. See generally ANDREW GRUBB, CHOICES AND DECISIONS IN HEALTH CARE 43 (1993) [hereinafter GRUBB].

64. See generally *id.*

65. See generally DWORKIN, *supra* note 46.

66. See CATRIONA MACKENZIE & NATALIE STOLJAR (EDS.), RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY AND THE SOCIAL SELF (2000).

67. See generally Jennifer Nedelsky, *Reconceiving Autonomy: Sources, Thoughts and Possibilities*, 1 YALE J. L. & FEMINISM 7 (1989).

68. See HILDE LINDEMANN-NELSON & JAMES LINDEMANN-NELSON, THE PATIENT IN THE FAMILY, 95-96 (1995) [hereinafter LINDEMANN-NELSON].

69. See Anita Ho, *Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-Making*, 22 SCAND. J. CARING SCI. 128, 128 (2008) [hereinafter *Relational Autonomy or Undue Pressure?*].

their relationship with the patient before the diagnosis of the terminal illness.⁷⁰

In the bioethical literature, it is possible to find various approaches that deal with the issue of family involvement in treatment decisions. Although these approaches deal with family involvement generally, they are relevant to the context of end-of-life decision-making when the patient is legally competent. There are those who provide an equal moral voice to the patient and the relatives in the resolution of conflicts and disagreements through family conferences.⁷¹ Others argue that the family's voice should be heard in the decision-making process but should give the patient the final word.⁷² For these scholars, the clinician is perceived as a mediator when there is a disagreement between the patient and the family or among the relatives.⁷³ Finally, there are those who accept the substantial involvement of dominant relatives, though they insist that a private sphere should be provided to the patient so he or she can express preferences to the clinician without the family's presence.⁷⁴

The issue of family involvement has gained scholarly attention in cases where the patient has diminished or no legal capacity to make decisions.⁷⁵ When the dying patient arrives at the hospital and has diminished or no legal capacity to make decisions, the family (if one does exist) and the medical team confer in an effort to reach a decision.⁷⁶ Although the autonomy of the patient in this context can potentially be fulfilled if he or she left an advance directive or verbally expressed their wishes before losing mental capacity,⁷⁷ this does not rule out the involvement of the family in practice,⁷⁸ as the findings presented in the next part show. There are two questions at this point: first,

70. See generally *id.*; Anita Ho, *Family and Informed Consent in Multicultural Settings*, 6 AM. J. OF BIOETHICS 26 (2006).

71. See JOHN HARDWIG, IS THERE A DUTY TO DIE? AND OTHER ESSAYS IN MEDICAL ETHICS, 29-44 (2000) [hereinafter HARDWIG].

72. See generally LINDEMANN-NELSON, *supra* note 68.

73. *Id.*

74. *Relational Autonomy or Undue Pressure?*, *supra* note 69, at 129-30.

75. See Katherine O'Donovan & Roy Gilbar, *The Loved Ones: Families, Intimates and Patient Autonomy*, LEGAL STUDIES 332, 332-33 (2003) [hereinafter O'Donovan].

76. *Id.* at 333-36.

77. *Id.* at 336-39. The assumption is that either the patient registered her directive so that the physician can access the registry to find out her wishes, or the relatives tell the medical team what the patient stated when she was still competent.

78. *Id.* at 338.

whether the family's personal views should be heard and respected by the physician, and second, whether the relatives should have the authority to make the decision. In this context, the physicians may perceive the involvement of the family with suspicion or hostility, especially if they do not agree with the relatives' view, or if they suspect that the relatives may have financial or other personal interests in a particular decision.⁷⁹

However, despite the physician's concerns, from the perspective of relational autonomy, relatives should have a voice in the decision-making process about artificial ventilation when the dying patient has diminished or no legal capacity to make decisions. The justifications for this view derive from the fact that the relatives know the patient as no one else does and from the close relationship between the patient and the family. The latter point should be elaborated. Familial relationships are based—to a substantial degree—on intimacy and emotional closeness, which create mutual responsibility and solidarity among family members.⁸⁰ Moreover, the intimacy and emotional closeness that exist in familial relationships lead to the perception that the family is part of the patient's identity, or even an extended part of the patient.⁸¹ As such, it significantly influences the decisions about life-prolonging treatment and is influenced by it.⁸² Not only does this justify family involvement in the form of active participation in the meetings with the medical team, but it also justifies the provision of authority to make a decision for the patient who has no or limited capacity to make decisions. Thus, convening the patient's close relatives and involving them in the end-of-life decision-making process is, from a relational perspective of autonomy, a sensible course of action.

Significantly, the various approaches to autonomy, even within the relational discourse, may lead not only to different decision-making processes, but also to different outcomes when artificial ventilation is considered. When the patient is legally competent to make decisions, holding a conference with the patient, the relatives, and the medical team to find out what each party prefers is different from holding a similar conference that is followed by a private meeting between the physician and the patient to find out whether the patient's

79. See generally GRUBB, *supra* note 63.

80. See LINDEMANN-NELSON, *supra* note 68, at 63-82.

81. See *id.*

82. See *id.*

interests differ from those of the relatives.⁸³ Concentrating on patients with no or limited capacity to make decisions, it is one thing to approach the family to find out the patient's wishes about life-prolonging treatments before she lost her legal capacity to make decisions, and it is another thing to approach the family to find out what *they* prefer in this situation. In this context, when there are only two parties to the decision-making process, namely, the physician and the family, a relational approach to autonomy that is based on communitarianism or ethics-of-care will ultimately give the family a voice, if not the final word.

(III) THE PHYSICIAN'S CONSCIENTIOUS OBJECTION

Another relevant aspect in the debate about withdrawal of artificial ventilation is the physician's conscientious objection. A preliminary question is why we need to consider the physician's view. A possible answer is related to the autonomy of the physician and professional integrity. Physicians, like other individuals, are moral agents, so they have a moral right to make independent decisions. Moreover, as individuals, physicians are driven, to an extent, by their moral values and principles. Thus, they might be reluctant to adopt the mainstream approaches in Western bioethics towards patient autonomy and nonmaleficence in particular cases or they might adopt a different interpretation of these principles than those employed by the hospital or the state in which they work. Another possible answer is that imposing a duty on physicians to provide treatments with which they do not morally agree carries extra costs that society may be reluctant to cover.⁸⁴

In light of this background, a request by a legally competent dying patient to stop an ongoing operating ventilator or a similar request in the form of advance directive may go unmet when asked of a physician who conscientiously cannot respect such a request. The question is what moral weight should be attached to this objection. On the one hand, some proponents of patient autonomy, such as Julian Savulescu, argue that the physician's moral view in these situations

83. *See id.*

84. *See* NILI KARAKO-EYAL, THE DOCTRINE OF INFORMED CONSENT AND PATIENTS RIGHT LAW 1996 (2008); Elizabeth Sepper, *Not Only the Doctor's Dilemma: The Complexity of Conscience in Medicine*, 4 FAULKNER L. REV. 385, 391-94 (2013); Elizabeth Sepper, *Taking Conscience Seriously*, 98 VA L. REV. 1501, 1507 (2012).

should not be taken into account.⁸⁵ They are perceived almost as technicians who provide the services the patient requires and should have no say on the matter of the preferred treatment.⁸⁶

Others, on the other hand, are more sympathetic to the physician's moral difficulty in respecting the patient's request to stop a life-prolonging treatment.⁸⁷ Emily Jackson, for example, presents a more nuanced approach. On the one hand, she admits that it is difficult to accept a situation where physicians would be permitted to conscientiously object to a request of a dying patient to withdraw ventilation, but on the other hand, she appreciates that it can be "difficult" for the physician to withdraw a life-prolonging treatment when it leads to the patient's death.⁸⁸ Thus, it appears that Jackson accepts the practical mechanism of transferring the patient to the care of another physician or another hospital that can respect the patient's request.⁸⁹

Ultimately, Jackson, like Savulescu, does limit the scope of the physician's moral objection to respecting the patient's request.⁹⁰ She argues that the physician's central duty is to provide care for the patient.⁹¹ This should be the case even when the physician morally disagrees with the patient's request for a lawful treatment.⁹² Jackson asserts that if the physician who morally objects to the patient's lawful request can transfer the patient to another colleague, it is ethically acceptable to do this.⁹³ However, if this is not possible in practice, then the physician must find the moral strength within herself to continue to provide care to the patient per his or her request.⁹⁴

The debate about the physician's moral objection is important because it brings us back to the discussion about the moral perception of withdrawal of life-prolonging treatment. Whereas many legal

85. Julian Savulescu, *Conscientious Objection in Medicine*, 332 BRITISH MED. J. 294, 294 (2006) [hereinafter Savulescu].

86. See *id.*; see also Christopher Meyers & Robert D. Woods, *An Obligation to Provide Abortion Services: What Happens When Physicians Refuse?*, 22 J. MED. ETHICS 115, 155 (1996).

87. See JACKSON, *supra* note 3, at 901.

88. See generally Emily Jackson, *The Relationship Between Medical Law and Good Medical Ethics*, 41 J. OF MED. ETHICS 95 (2015) [hereinafter *Relationship Between Medical Law and Good Medical Ethics*].

89. *Id.* at 97-98 (listing the facts of the seminal English case of *Re B*).

90. *Relationship Between Medical Law and Good Medical Ethics*, *supra* note 88, at 96-98.

91. *Id.* at 95.

92. *Id.*

93. *Id.* at 96.

94. *Id.*

scholars and bioethicists believe that there is no moral difference between withholding and withdrawing treatment, some physicians, as will be shown next, perceive them as morally different.

To sum up, the bioethical discussion proves that the ongoing disagreement among scholars about withdrawal of artificial ventilation has not been resolved. The application of principles such as autonomy and nonmaleficence, and values such as responsibility, care, and familial commitment, remain contested in this particular context. Beauchamp and Childress, for example, explicitly argue several times in their seminal book that the distinction between withholding and withdrawing treatment is "morally irrelevant and potentially dangerous."⁹⁵ Yet, Beauchamp and Childress, like other bioethicists, do not sufficiently acknowledge the physician's concerns, views, and modes of conduct in their daily practice.⁹⁶ Therefore, it is important to examine not only the physician's views but also their actual conduct when facing a decision about artificial ventilation. This is discussed next.

III. The Empirical Evidence

Clearly, empirical studies have examined the attitudes and conduct of physicians regarding withholding or withdrawing life-prolonging treatment. Here, we will follow the discussion in the previous part by examining the physician's views and attitudes towards the act-omission distinction, patient autonomy, the interaction between autonomy and nonmaleficence, and family involvement. We will also examine the physician's actual conduct when facing a decision to withdraw ventilation.

1. The act-omission distinction

Clinically, studies indicate that while ninety-nine percent of patients die a few hours after the withdrawal of treatment, eleven percent have survived when a decision to withhold treatment was followed, whereas for those who die, death occurred after fourteen

95. See BEAUCHAMP, *supra* note 5, at 159-160.

96. See Holm, *supra* note 12, at 42.

hours, on average.⁹⁷ This, as indicated next, has an impact on the views and conduct of physicians.⁹⁸

Studies in Western countries suggest that physicians view withholding and withdrawing life-prolonging treatment differently.⁹⁹ In a study conducted in North America, more than forty percent of 600 physicians stated that the withholding of treatment is more acceptable than its withdrawal, and approximately one-quarter stated that they are more disturbed by the option of withdrawal than by withholding treatment.¹⁰⁰ Similarly, a European study indicates that physicians are more willing to withhold treatment than to withdraw.¹⁰¹ In another U.S.-based study, two-thirds of the participating physicians stated that the withdrawal of treatment is ethically different from withholding it.¹⁰² A similar finding was reported in another study of American physicians and nurses.¹⁰³

When probing into the reasons for their views, physicians highlight the human agency required to withdraw life-prolonging treatment, an agency absent from the withholding of treatment.¹⁰⁴ This causes physicians to perceive the withholding of treatment as passive conduct and its withdrawal as active conduct that involves the physician in the process of death.¹⁰⁵ In one observational study undertaken

97. See Charles L. Sprung et al., *End-of-Life Practices in European Intensive Care Units: The Ethicus Study*, 290 JAMA 790, 792-94 (2003) [hereinafter *End-of-Life Practices*].

98. See Charles L. Sprung et al., *The Durban World Congress Ethics Round Table Conference Report: I. Differences between Withholding and Withdrawing Life-Sustaining Treatments*, 29 J. CRIT. CARE 890, 892 (2014).

99. This is also shared by physicians in other countries. See, e.g., Kaoruko Aita & Ichiro Kai, *Physicians' Psychological Barriers to Different Modes of Withdrawal of Life Support in Critical Care: A Qualitative Study in Japan*, 70 SOC. SCI. & MED. 616, 616 (2010).

100. See generally The Society of Critical Care Medicine Ethics Committee, *Attitudes of Critical Care Medicine Professionals Concerning Forgoing Life-Sustaining Treatments*, 20 CRIT. CARE MED. 320 (1992) [hereinafter Society of Critical Care Medicine Ethics Committee].

101. See Jean-Louis Vincent, *Forgoing Life Support in Western European Intensive Care Units: The Results of an Ethical Questionnaire*, 27 CRIT. CARE MED. 1, 2-3 (1999) [hereinafter Vincent].

102. See Mildred Z. Solomonat et al., *Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments*, 83 AM. J. PUB. HEALTH 14, 16-18 (1993).

103. See Donna L. Dickenson, *Are Medical Ethicists Out of Touch? Practitioner Attitudes in the US and UK Towards Decisions at the End of Life*, 26 J. MED. ETHICS 254, 256-58 (2000).

104. See Sharon Reynolds et al., *Withdrawing Life-Sustaining Treatment: Ethical Considerations*, 15 THORACIC SURGERY CLINICS 469, 470 (2005).

105. See Phillip D. Levin & Charles L. Sprung, *Withdrawing and Withholding Life-Sustaining Treatment Therapies Are Not the Same*, 9 CRIT. CARE 230, 230 (2005).

in an intensive care unit, causation explained the physicians' difficulty in withdrawing treatment.¹⁰⁶ It was discovered that unless the patient was very close to death, the physicians felt uncomfortable withdrawing life-prolonging treatments, despite the patient's poor prognosis.¹⁰⁷ The physicians felt that it is morally permissible to withdraw treatment only when it is obvious that death would occur regardless of any available treatment.¹⁰⁸ When this happens, there is no causative link between non-treatment and death.¹⁰⁹ Furthermore, other studies indicate that physicians feel that withdrawing life-prolonging treatment is more difficult psychologically than withholding treatment,¹¹⁰ because it requires that the physician reflect upon his or her role as a professional who helps patients improve their health (and not manage death).¹¹¹

The approach reflected in the above studies support those bioethicists who perceive withholding and withdrawing treatment differently.¹¹² The physician's approach does not reflect the more prevalent view in bioethics and law today that perceives these two patterns of conduct as morally equivalent.¹¹³ Yet, a recent study conducted in the U.S. reaffirmed the findings in the above studies, indicating that the majority of physicians (approximately sixty percent) find withdrawal of treatment psychologically and ethically more difficult than withholding it.¹¹⁴ It thus appears that there is a gap between the mainstream view in bioethics and the common view of physicians.¹¹⁵

106. See Jane E. Seymour, *Negotiating Natural Death in Intensive Care*, 51 SOC. SCI. & MED. 1241, 1241 (2000) [hereinafter Seymour].

107. *Id.* at 1249-50.

108. *Id.*

109. *Id.*

110. See generally Grace S. Chung et al., *US Physicians' Opinions about Distinctions Between Withdrawing and Withholding Life-Sustaining Treatment*, 55 J. RELIGION & HEALTH 1596 (2016) [hereinafter Chung].

111. See Seymour, *supra* note 106, at 1250.

112. See generally, Miller, *supra* note 17.

113. See BEAUCHAMP, *supra* note 5, at 159-60.

114. See generally Chung, *supra* note 110.

115. See generally Neil J. Farber et al., *Physicians' Decisions to Withhold and Withdraw Life-Sustaining Treatment*, 166 ARCHIVE INTERNAL MED. 560 (2006) [hereinafter Farber]. The common bioethical view that perceives withholding and withdrawing life-prolonging treatment as morally equivalent is supported by a study that found that some clinicians hold the same view; H. Hinkka et al., *Factors Affecting Physicians' Decisions to Forgo Life-Sustaining Treatment in Terminal Care*, 28 J. MED. ETHICS 109 (2002) [hereinafter Hinkka].

2. AUTONOMY

Studies indicate that respecting the wishes of the dying patient and collaborating with them at the end-of-life decision-making process is important for physicians in Western countries.¹¹⁶ In a recent U.S.-based study, ninety-three percent of the participant physicians agreed that they should always respect a request of a legally competent patient to withdraw life-prolonging treatment.¹¹⁷ Another study reveals that the most common ground for the physician's view that termination of life-supporting treatment is justified for dying patients is the right to autonomy, or in other words, the right to make independent decisions without coercion or undue influence.¹¹⁸

Similarly, when asking physicians in a study whether to continue with artificial ventilation of a dying patient, those who thought that ventilation should be discontinued stated that it accords with the patient's wishes (eighty-four percent of the responses).¹¹⁹ There was a similar response rate (seventy-two percent) in that study for withholding treatment.¹²⁰ In another study, the physicians expressed a preference for a shared decision-making process when the patient is legally competent to make decisions.¹²¹ Particularly, it was reported that physicians are more likely to propose withdrawal of ventilation when the patient is legally competent to make decisions than when he or she is not legally competent.¹²² In yet another study, conducted in Finland, it was indicated that a patient's advance directive decreases the number of decisions to provide life-supporting treatment.¹²³

116. See generally Chung, *supra* note 110.

117. *Id.*

118. See generally Anna Lindblad et al., *When Enough is Enough; Terminating Life-Sustaining Treatment at the Patient's Request: A Survey of Attitudes Among Swedish Physicians and the General Public*, 36 J. MED. ETHICS 284 (2010).

119. See generally Anders Rydvall & Neils Lynøe, *Withholding and Withdrawing Life-Sustaining Treatment: A Comparative Study of the Ethical Reasoning of Physicians and the General Public*, 12 CRIT. CARE 1 (2008) [hereinafter Rydvall]. However, the reason that treatment should be discontinued because it prolongs the death process received a higher response rate (ninety-two percent).

120. *Id.* The response rate for the argument that treatment should be avoided because its provision would compromise the patient's quality of life received a higher rate (eighty-three percent).

121. See generally Renata RL Fumis & Daniel Deheinzelin, *Respiratory Support Withdrawal in Intensive Care Units: Families, Physicians and Nurses Views on Two Hypothetical Clinical Scenarios*, 14 CRIT. CARE 235 (2010) [hereinafter Fumis].

122. *Id.*

123. See generally Hinkka, *supra* note 115.

These studies indicate that physicians who work in Western countries express a liberal approach that respects the right of dying patients to refuse life-prolonging treatment.¹²⁴ However, the question arises of whether this view is applied in practice, particularly in light of the review in the previous part, which indicates that physicians find it psychologically and morally difficult to withdraw a life-prolonging treatment.¹²⁵ In this context, at least one study indicates that physicians terminate a life-prolonging treatment in response to the patient's request.¹²⁶

Other questions that arise in this context are how important the principle of respect for patient autonomy is when physicians face a decision to withdraw artificial ventilation and what the impact of this principle is in light of other principles and values. These questions will be discussed next.

3. Autonomy and nonmaleficence

Interestingly, studies show that in justifying withholding or withdrawing life-prolonging treatment, the duty not to cause harm is more important for physicians than the duty to respect patient autonomy.¹²⁷ This was evidenced in a large study conducted in the U.K.¹²⁸ The 1,000 physicians taking part in the study who stated that their decision to withdraw treatment involved an expectation or intention to hasten the dying patient's death were asked to express their reasons for making such a decision.¹²⁹ The most prevalent reasons were no chance of improvement (seventy percent) and futility of treatment (sixty-six percent).¹³⁰ These reasons suggest that for the physicians who participated in the study, continuing with life-prolonging treatment was equivalent to causing harm and violating the principle of nonmaleficence.¹³¹ This conclusion is supported by another reason the study's participants expressed, namely, that the provision of treat-

124. See *id.*; Fumis, *supra* note 121; Rydvall, *supra* note 119.

125. See Farber, *supra* note 115.

126. See generally Reidun Førde et al., *Medical End-of-Life Decisions in Norway*, 55 RESUSCITATION 235 (2002) [hereinafter Førde].

127. See generally Clive Seale, *Hastening Death in End-of-Life Care: A Survey of Doctors*, 69 SOC. SCI. & MED. 1659 (2009) [hereinafter Seale].

128. See *id.*

129. *Id.*

130. *Id.*

131. *Id.*

ment causes or increases suffering (forty percent).¹³² Interestingly, respecting the patient's request was the least-common reason the physicians gave when providing reasons for their decision (twenty-two percent).¹³³

Similarly, in a study conducted in Sweden, physicians were asked whether to continue with the provision of artificial ventilation to a dying patient when neurosurgical treatment was unsuccessful.¹³⁴ Most physicians in that study supported withdrawal of ventilation.¹³⁵ The most prevalent reason (stated by ninety-two percent of the participants) was that continuing with ventilation would only prolong the death process.¹³⁶ This effectively indicates that the participants adhere to their duty not to cause harm and to maintain the patient's dignity.¹³⁷ Respecting the patient's wishes was high but less common (eighty-four percent) among the study's participants.¹³⁸ These findings correspond to a comparative study conducted between the attitudes of Israeli and U.S.-based physicians who work in intensive care units.¹³⁹ It was found that Israeli physicians attribute less importance to the patient's wishes in end-of-life decision-making than to other factors, such as poor prognosis and irreversibility of the disease.¹⁴⁰

Significantly, a study conducted in France indicates that physicians do not sufficiently involve the legally competent dying patients in the decision-making process, which leads to the finding that the medical team makes the decisions on their own in most cases.¹⁴¹ The main reason for this practice, as shown in the study, was lack of communication between the physicians and the patient.¹⁴² This accords with the findings in the Israeli-American study, where only approximately one-quarter of the physicians who participated in the study

132. *Id.*

133. *Id.* at 1664.

134. See *End-of-Life Practices*, *supra* note 97, at 792.

135. *Id.*

136. *Id.*

137. Similar findings were also shown in other studies. See, e.g., Edouard Ferrand et al., *Withholding and Withdrawing Life Support in Intensive-Care Units in France: A Prospective Survey*, 357 LANCET 9, 13 (2001) [hereinafter Ferrand].

138. See Rydvall, *supra* note 119, at table 3.

139. See *id.*

140. See generally Ethan Soudry et al., *Forgoing Life-Sustaining Treatments: Comparison of Attitudes Between Israeli and North American Intensive Care Healthcare Professionals*, 5 ISR. MED. ASSOC. J. 770 (2003) [hereinafter Soudry].

141. See generally Ferrand, *supra* note 137.

142. *Id.*

stated that they discussed Do Not Resuscitate (DNR) orders with the patient or the family.¹⁴³ The conclusion inferred from these studies is that the principles of nonmaleficence and beneficence—rather than the principle of respect for patient autonomy—in this complicated process dominates the set of values of physicians who face end-of-life decisions.

4. The impact of family involvement

Empirical studies have not reflected a uniform attitude towards family involvement. There are studies that indicate a high rate of family involvement when end-of-life decisions are made, but there are other studies that show a relatively low rate.¹⁴⁴ In addition, not all studies distinguish clearly between the involvement of relatives when the patient is legally competent to make decisions and when the patient is not. There are studies that report on family involvement in the physician's decision-making process when some of the patients in the study are legally competent and others are not.¹⁴⁵

In a study conducted in France, physicians who worked in intensive care units (ICUs) reported a significant rate (forty-four percent) of family involvement in cases of end-of-life decisions.¹⁴⁶ In that study, only twenty-seven percent of the patients were legally competent to make decisions.¹⁴⁷ In a U.S.-based study conducted in the ICUs of two hospitals, a high rate of family involvement (ninety-three percent) was found in this context.¹⁴⁸ Notably, only four percent of the patients in the study were legally competent.¹⁴⁹

143. See generally Soudry, *supra* note 140, at 774 (However, this particular finding does not fit findings from the US and Europe that indicated that physicians discuss DNR orders with their patients. See Vincent, *supra* note 101; Society of Critical Care Medicine Ethics Committee, *supra* note 100. However, discussing DNR orders does not necessarily mean that physicians discuss with their patients' other end-of-life options, such as withdrawal of artificial ventilation.)

144. See GRUBB, *supra* note 63. But see LINDEMANN-NELSON, *supra* note 68.

145. See GRUBB, *supra* note 63.

146. See Ferrand, *supra* note 137.

147. *Id.* at 12.

148. See Nicholas G. Smedira et al., *Withholding and Withdrawing of Life Support from the Critically Ill*, 322 N. ENGL. J. MED. 309, 311 (1990) [hereinafter Smedira].

149. *Id.*; see also Fumis, *supra* note 121, at 3 (In a study from Brazil, it was indicated that most physicians would like the patient's family to be involved in discussions about withdrawal of ventilation, regardless of whether the patient is legally competent).

Other studies reflect not just involvement in the decision-making process but also actual impact on the decision made. In one study, physicians stated that when the patient has lost his mental capacity, relatives' request "to do everything possible to save the patient" or prolong his life produced a significant reduction in withdrawal and withholding of treatment.¹⁵⁰ Other studies have reported similar findings.¹⁵¹ In another study conducted in Norway, it was reported that about forty percent of the physicians who participated in the study made a decision to terminate a life-prolonging treatment based on the relatives' wishes.¹⁵² It was unclear whether the patients in that study were legally competent.¹⁵³

However, studies indicate that there are differences between physicians' actual practice and their attitudes. Despite evidence that suggests that relatives are involved in end-of-life decisions, particularly when the patient is no longer competent to make decisions, studies suggest that the influence of the family in making a particular decision is limited.¹⁵⁴ For example, a study conducted in the UK examined, inter alia, the reasons behind physicians' decisions to withhold or withdraw life-prolonging treatment.¹⁵⁵ The study focused on the physicians who stated that they either expected or intended their decision to hasten the patient's death.¹⁵⁶ Among the eight reasons the participants addressed, relatives' request was among the least common (together with the patient's request).¹⁵⁷ Furthermore, a study conducted in Sweden indicates that a high rate of physicians prefer to be the sole decision-maker when the patient is legally incompetent to make decisions, thus expressing a preference to exclude relatives from the process.¹⁵⁸ This accords with another Swedish study that showed that only ten percent of the physicians who participated in the study thought that

150. See Hinkka, *supra* note 115, at 112.

151. See generally Vincent, *supra* note 101; Henry S. Perkins et al., *Impact of Legal Liability, Family Wishes and other 'External Factors' on Physicians' Life-Support Decisions*, 89 AM. J. OF MED. 185 (1990). 152. Førde, *supra* note 126, at 235.

152. Førde, *supra* note 126, at 235.

153. *Id.*

154. Seale, *supra* note 127, at 1665.

155. *Id.* at 1659.

156. *Id.*

157. *Id.* at 1663.

158. Peter Sjøkvist et al., *Withdrawal of Life Support- Who Should Decide? Difference in Attitudes Among the General Public, Nurses and Physicians*, 25 INTENSIVE CARE MED. 949, 951 (1999).

ventilation should be discontinued due to a request made by the patient's son.¹⁵⁹

However, the divergence in the practice and attitudes towards family involvement might depend on the physician's social background. In the comparative Israeli-U.S. study mentioned above, it was shown that Israeli ICU physicians tended to listen less to relatives than their American counterparts and to avoid the withdrawal of respiratory support or discontinuation of ventilation when the patient was legally incompetent.¹⁶⁰

5. Conclusion

The studies reviewed in this part do not cover the voluminous empirical research examining the attitudes and modes of conduct of physicians in this context. However, the studies covered here nevertheless suggest the following: (1) overall, physicians distinguish between withholding and withdrawing life-prolonging treatment, and they find it emotionally and ethically difficult to withdraw ventilation; (2) respecting the wishes of a dying patient is relevant when physicians consider withholding or withdrawing treatment; however, (3) poor prognosis, irreversibility of the disease, futility of treatment and avoidance of suffering are more important for physicians in justifying the withdrawal of treatment than respecting patient autonomy; (4) relatives are, overall, involved in the decision-making process, though they do not have a determining voice; and (5) the physician's religious and cultural backgrounds have an impact on their decision to withhold or withdraw life-prolonging treatment.

Taking into account these empirical findings, together with the mainstream approach in Western bioethics reviewed above, it is clear that legislators and judges face a complex task when shaping a legal framework in this area. In the next part, we will examine the Israeli legal framework.

159. Rydvall, *supra* note 119, at 3.

160. See Soudry, *supra* note 140, at 772. For studies that show how physicians' cultural and religious background affect their decisions to withhold and withdraw life-prolonging treatments, see Farr A. Curlin et al., *To Die, to Sleep: US Physicians' Religious and Other Objections to Physician-Assisted Suicide, Terminal Sedation and Withdrawal of Life Support*, 25 AM. J. HOSP. PALLIAT. CARE 112, 115 (2008); Charles Sprung et. al., *The Importance of Religious Affiliation and Culture on End-of-Life Decisions in European Intensive Care Units*, 33 INTENSIVE CARE MED. 1732, 1733 (2007); see also Fumis, *supra* note 121.

IV. The Legal Framework

End-of-life decision-making is regulated in Israel by the Dying Patient Act 2005.¹⁶¹ The Act applies only to patients who suffer from a terminal illness and are expected to die within six months, even with treatment.¹⁶² The Act is based on several principles that guide its interpretation and implementation. First, the aim is to regulate the treatment of the dying patient while striking a balance among sanctity of life, patient autonomy, and quality of life.¹⁶³ Second, the Act is based on democratic and Jewish religious values, as well as on fundamental principles of morality and ethics.¹⁶⁴ Third, the patient's medical condition, her wishes and her degree of suffering are the only considerations that should guide decision making.¹⁶⁵

The Act prescribes a detailed and comprehensive decision-making process regarding the treatment of the dying patient.¹⁶⁶ The fundamental presumption of the Act is that every person wishes to continue living, unless it is proved otherwise beyond any reasonable doubt.¹⁶⁷ This presumption can be refuted.¹⁶⁸ When the patient is legally competent to make decisions, the presumption can be refuted according to the patient's explicit and expressed wish.¹⁶⁹ This requires that the physician approach the patient and find out her preferences regarding withholding or withdrawing treatment.¹⁷⁰ When the patient is incompetent, the presumption can be refuted according to one of the following options: advance directives, a power of attorney, or a decision of an appointed physician who concludes that the dying patient does not wish to prolong her life.¹⁷¹ In making this conclusion, the

161. See The Dying Patient Act 2039-2005, SH No. 2039, arts. 3, 8 (Isr.) (A Patient whose life expectancy is of two weeks is defined by the Act as a dying patient in the final stage) [hereinafter The Dying Patient Act].

162. *Id.*

163. *Id.*

164. *Id.*

165. *Id.* at arts. 1, 2.

166. See generally *id.*

167. *Id.* at art. 4.

168. *Id.* at art. 5.

169. *Id.* According to Article 3, a patient is competent if she fulfills all the following conditions: she is seventeen, capable of expressing her will, was not declared legally incompetent and was not found to be incompetent by an appointed physician. Article 6 sets a presumption of competence according to which every person who is seventeen or over and was not declared legally incompetent is assumed to be legally competent to make decisions.

170. *Id.* at art. 15(a).

171. *Id.* at art. 5.

physician has to take into account a declaration given by the patient's close relative who states that the patient—had she been competent—would not have wanted to continue living.¹⁷²

In addition, the Act sets several rules regarding the provision of end-of-life medical treatments. First, under certain conditions, a patient's refusal to a life-prolonging treatment should be respected.¹⁷³ If the patient is legally competent, reasonable efforts should be made to persuade him or her to receive oxygen, nutrition, and fluids as well as routine treatments and palliative care, but he or she should not be coerced into receiving these treatments.¹⁷⁴ If the patient is legally incompetent, the withholding of nutrition and fluids, routine treatments, and palliative care is prohibited, notwithstanding her wish not to receive these treatments.¹⁷⁵ Second, while the withholding of life-sustaining therapies is principally permitted, deliberate killing, assisted suicide, and any other action that intentionally and actively shortens the dying patient's life are prohibited, even when they accord with the patient's will or are motivated by the physician's sense of compassion.¹⁷⁶

The third rule in this context is highly relevant to this article. The Act states that stopping a continuous medical treatment that is likely to cause the patient's death (e.g., disconnecting a dying patient from a ventilator) is forbidden, regardless of the patient's wishes.¹⁷⁷ On the other hand, if a continuous medical treatment was unintentionally or not unlawfully stopped (e.g., due to a power cut), the Act permits one to avoid its renewal if this accords with the patient's wishes.¹⁷⁸

Fourth, cyclic life-sustaining treatments (e.g., hemodialysis) can be discontinued or not renewed when the patient wishes so.¹⁷⁹ This rule also applies to treatments that by their nature are continuous but were planned in advance, through technological means, as a cyclic treatment.¹⁸⁰ This would be the case when a timer is installed on a ventilator and is set to stop at a particular point in time. This would ena-

172. *Id.*

173. *Id.* at arts. 15(a), 16(a).

174. *Id.* at art 15(b).

175. *Id.* at art. 16(b). Notably, different rules apply to dying patients in their final stage.

176. *Id.* at arts. 19, 20.

177. *Id.* at art. 21.

178. *Id.* at arts. 3, 21.

179. *Id.* at art. 21.

180. *Id.* arts. 3, 21.

ble the medical team to follow the legal rules set by the Act and not renew the ventilator when it automatically stops. This is considered permissible withholding of treatment.

Fifth, in a situation of medical emergency, a physician can provide a life-saving treatment to a dying patient without the patient's consent if it is impossible to obtain consent due to the emergency circumstances.¹⁸¹ However, if the physician knows that the wish of the dying patient—as determined according to the Act—is that life-saving treatments will be withheld under these circumstances, the physician should refrain from providing these treatments to the patient.¹⁸² It follows that when an emergency situation occurs, for example, when the patient faces serious breathing difficulties, the physician can connect the patient to a ventilator to eliminate imminent and immediate risk to the patient's life unless the physician knows in advance that the patient refuses such a treatment. A different rule applies to a dying patient in a final stage. In this case, the physician can withhold life-saving treatments, unless she knows that the patient has already expressed a wish to receive treatment in this situation.¹⁸³

Finally, the Act states that a physician is not obligated to provide a dying patient a specific medical treatment or to refrain from providing the patient a particular treatment if such action stands in contrast to the physician's values, conscience, or professional medical discretion.¹⁸⁴ In such a case, the physician should refer the patient to a colleague in the same medical institution who is willing to accommodate the patient's request.¹⁸⁵

The review of the legal position so far indicates that, unlike the position taken in American law, Israeli law distinguishes between withholding and withdrawing life-prolonging treatment.¹⁸⁶ While American law generally does not differentiate between withholding and withdrawing life-prolonging treatment and permits both if it is in accordance with the patient's wish,¹⁸⁷ this distinction is central to the existing Israeli legal framework.

181. *Id.*

182. *Id.* at art. 18 (a).

183. *Id.* at art. 18 (b).

184. *Id.* at art. 56.

185. *Id.*

186. *See generally* Gillon, *supra* note 13.

187. *See generally* Cruzan v. Missouri Dept. of Health, 497 U.S. 261 (1990); Bouvia v. Superior Court, 225 Cal. Rptr. 287, 302 (Cal App. 1986); Alen Meisel & Kathy

The theoretical roots of this distinction, as discussed in Part II, are based on the distinction between acts and omissions and, hence, between killing and letting die. It is based on the view, discussed in length above, that an active intervention (i.e., switching off a ventilator) directly creates a causal link between the physician's physical conduct and the patient's death and is considered the proximate cause of the patient's death.¹⁸⁸ This is in contrast with a passive course of action (i.e., not connecting the patient to a ventilator), which contributes less to the materialization of death.¹⁸⁹ Therefore, the first should be morally and legally prohibited, whereas the latter should be permitted.

Creating a distinction in the Act of 2005 between permissible withholding of artificial ventilation and prohibited withdrawal of this therapy was a significant change in Israeli law. Prior to this Act, Israeli courts did not explicitly rule that there is a relevant difference between withholding and withdrawing life-sustaining treatment.¹⁹⁰ Moreover, in the cases dying patients brought to courts to withdraw artificial ventilation, the Israeli district courts accepted the requests.¹⁹¹ The legal position that permits both withholding and withdrawing artificial ventilation was also supported by guidelines issued by the Israeli Ministry of Health¹⁹² and by the Israeli Patient Rights Act 1996, which indirectly addressed end-of-life decision-making before the 2005 Act came into force.¹⁹³

L. Cerminara, *The Appropriate Forum for End-of-Life Decision-Making: Courts or Clinical Setting?*, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISION-MAKING 3.32-3.35 (3rd ed., 2004); Lois L. Shepherd, *The End of End-of-Life Law*, 92 N.C. L. REV. 1693, 1698-1703 (2014).

188. Felicia Cohen & Joanne Lynn, *Vulnerable People: Practical Rejoinders to Claims in Favor of Assisted Suicide*, THE CASE AGAINST ASSISTED SUICIDE 247 (Kathleen Foley ed., 2004).

189. See *infra* Part II.

190. See Roy Gilbar, *Breathless: On Israeli District Court's Decision to Allow Doctors to Switch off a Terminal Patient's Ventilator*, 42 THE LAW ON THE NET: HUMAN RIGHTS 35, 47-49 (2015) [hereinafter Gilbar].

191. *Id.*

192. See MINISTRY OF HEALTH, HEAD OF PUBLIC HEALTH SERVICES, THE TREATMENT OF DYING PATIENTS (Jan. 31, 1996), http://www.health.gov.il/hozer/mk02_1996.pdf.

193. The Patient Rights Act does not specifically address the issue of end of life care. However, Article 13 holds that no medical treatment would be given to a patient unless she gave her informed consent. This rule supported the liberal approach adopted by the Israeli district courts prior to the Act, namely, that a patient's request to be disconnected from a ventilator should be respected. See Gilbar, *supra* note 190.

Adopting a distinction between withholding and withdrawing life-prolonging treatment by the Israeli legislator was not only a precedential change in Israeli law, but it also yielded disagreements and tensions among Israeli scholars.¹⁹⁴ The reasons for these disagreements derive from the two different approaches existing in this area. On one side stand those who criticize the distinction between continuous and cyclic life-prolonging treatments from a liberal perspective, arguing that the patient's fundamental right to refuse treatment should be respected and protected, especially in circumstances where there is no curative treatment and the prognosis is very poor.¹⁹⁵ In addition, these scholars generally do not agree that there is a relevant distinction between acts and omissions in this context.¹⁹⁶ Lastly, they argue that the legal prohibition on withdrawal of ventilation both contradicts the courts' decisions given prior to the Act and stands in contrast to the policy of the Ministry of Health and the spirit of the Patient Rights Act 1996.¹⁹⁷ On the other side stand those who adopt a more conservative approach, or a religious-based approach, highlighting the importance of the principle of sanctity of life when the patient is dying.¹⁹⁸ In addition, they emphasize the differences between withholding and withdrawing artificial ventilation with regards to causation and the physician's moral responsibility.¹⁹⁹

A report produced by a public committee and used by the Israeli Parliament, i.e., the Knesset, to legislate the Dying Patient Act reveals the reasons behind the legislators' distinction between withholding and withdrawing ventilation.²⁰⁰ A central motive for adopting this distinction was the need to reach an agreement between the proponents of the liberal approach (mainly the secular members of the public committee and of the Knesset) and supporters of the conservative/religious-based approach (in the committee and the Knesset).²⁰¹

194. *Id.*

195. See generally Amos Shapira, *Law and Bioethics in Israel: Between Liberal Ethical Values and Jewish Religious Norms*, 17 J. INT. BIOETHIQUE 115 (2006).

196. See Gilbar, *supra* note 190, at 52-53.

197. *Id.*

198. See Avraham Steinberg, *What is it to Do Good Medical Ethics? An Orthodox Jewish Physician and Ethicist's Perspective*, 41 J. MED. ETHICS 125, 126 (2015).

199. *Id.*

200. See MINISTRY OF HEALTH, THE NATIONAL COMMITTEE REPORT ON THE DYING PATIENT (Jan. 2002), http://www.health.gov.il/PublicationsFiles/steinberg_committee.pdf [hereinafter NATIONAL COMMITTEE REPORT].

201. *Id.*

Applying the Halachic approach that there is no obligation to actively prolong life (which also prolongs the pain and suffering of the dying patient) enabled the majority members of the committee and the Knesset to adopt a rule—in the form described above—that strikes a balance between the secular approach to autonomy and the Halachic approach to sanctity of life.²⁰² However, it appears that the need to reconcile these contrasting approaches was not the only reason for adopting a distinction between withholding and withdrawing life-prolonging treatment. Another explanation, which appears in the committee's report, lies in physicians' attitudes towards each course of action.²⁰³ The report states that physicians differentiate between withholding and withdrawing life-prolonging treatments, finding the latter more emotionally and ethically difficult to perform.²⁰⁴ This, as we saw in Part III, is reflected in empirical studies. The committee's report also acknowledged that actively withdrawing life-sustaining treatment contradicts the physician's essential task of healing patients and saving their lives.²⁰⁵

Discomfort with a comprehensive prohibition on withdrawal of continuous medical treatment was also expressed—though not explicitly—in a decision recently handed down by an Israeli district court.²⁰⁶ In the *John Doe* case, a request of a competent patient in an advanced stage of Amyotrophic Lateral Sclerosis (ALS) to be disconnected from a ventilator was supported by his treating physician and was submit-

202. See John Loike et al., *The Critical Role of Religion: Caring for the Dying Patient from an Orthodox Jewish Perspective*, 13 J. PALLIAT. MED. 1267, 1268 (2010); Avraham Steinberg, *The Halachic Basis of the Dying Patient Law* (2011) <http://98.131.138.124/articles/JME/JMEM12/JMEM.12.3.asp>; see generally Avraham Steinberg & Charles Sprung, *The Dying Patient Act, 2005: Israeli Innovative Legislation*, 9 ISR. MED. ASSOC. J. 550 (2007) [hereinafter Steinberg]. The majority of the committee members were aware of the negative ramifications of the distinctions they created for ALS and other patients who initially decide to have artificial ventilation at the early stages of their illness but then express a wish to be disconnected from it once their condition deteriorates. The solution the committee set, which is echoed Article 21, is to set a timer on the ventilator that stops the ventilator at particular point in time. This makes an act of withdrawal a passive act of withholding treatment.

203. See NATIONAL COMMITTEE REPORT, *supra* note 200.

204. *Id.*

205. *Id.*

206. Since it came into force, The Dying Patient Act has been discussed in a few courts' decisions. One of them was the John Doe case. See CA (TA) 16813-11-14 *John Doe v. Attorney General of Israel* (2014) (Isr.) [hereinafter John Doe Case]. The other decisions are not relevant to the discussion, as they discuss patients in PVS or minors.

ted to the court.²⁰⁷ The patient was fully aware of his condition, of the nature of his request, and of the expected consequences, i.e., that he would die within several minutes if disconnected from the ventilator.²⁰⁸ Nevertheless, taking into account his mental and physical pain and suffering and the fear that he would lose the ability to communicate with his family, friends, health care professionals, and nursing staff, he stated that he wished to be disconnected from the ventilator.²⁰⁹ Medical opinions indicated that if given appropriate medical treatment, the patient might continue living for many years.²¹⁰ Therefore, it was clear that he did not meet the definition of a “dying patient” set in the Act, which includes patients whose prognosis is up to six months.²¹¹ That being the case, the court had to decide which rule applies to the petitioner: either the legal position the district courts applied in their decisions prior to the Act, according to which withdrawal of artificial ventilation was permitted, or the principles set in the Act, including the prohibition on disconnecting patients from a ventilator.²¹²

Interestingly, the court did not address this issue, which was at the heart of this case and is relevant to approximately 700 ALS patients who currently live in Israel.²¹³ The judge was able to avoid this issue due to the declaration given in court by the Attorney General (AG), who acted as the respondent in this case.²¹⁴ Based on the “spirit of the Act” and the special circumstances of the case, the AG stated that while switching off a ventilator is prohibited, gradually reducing the ventilator’s oxygen level to that of open air is legally permitted.²¹⁵ The AG explained that this solution strikes the appropriate balance between the prohibition on disconnecting a dying patient from a ventilator that keeps them alive and the principle of patient autonomy

207. *Id.*

208. *Id.*

209. *Id.*

210. *Id.*

211. *Id.*

212. This alternative needs an explanation. The Attorney General argued that while The Dying Patient Act does not apply to the petitioner, its spirit, and the principles of the law it sets, including the prohibition on withdrawal of ventilation, should apply to this case.

213. The issue of what legal rules apply to patients with incurable and terminal diseases, with life expectancy of more than six months, goes beyond the scope of this article.

214. See John Doe Case, *supra* note 206.

215. *Id.*

that supports their right to refuse a treatment.²¹⁶ Moreover, it seems that the AG's opinion was that gradually reducing the ventilator's oxygen level is not morally equivalent to actively disconnecting a dying patient from a ventilator, which is prohibited by the Act.²¹⁷ Therefore, the AG argued that the solution he proposed should be approved by the court.²¹⁸ The court fully adopted the solution suggested by the AG without any substantive discussion.²¹⁹ It follows that the district court approves the use of a medical procedure that, in fact, enables physicians to stop a continuous life-sustaining treatment, despite the prohibition set in the Act. It should also be noted that the court did not express any objection to the concept that a gradual reduction in the ventilator's activity and the level of oxygen it produces are different from actively disconnecting a ventilator and, therefore, should be permitted.²²⁰

To sum up, this part shows that unlike the mainstream approach in bioethics and the position taken in most U.S. jurisdictions, Israeli law distinguishes between withholding ventilation, which aims to prolong the life of a dying patient, and its withdrawal, at least formally. Notably, this legal position is closer to the findings from the empirical studies reviewed above, which show that, overall, clinicians distinguish between the two. At the same time, the decision of the district court in the *John Doe* case reflects the complexity of the issue as well as the ongoing debate in Israeli law and bioethics regarding an adequate balance between the liberal principle of respect for autonomy and the Halachic principle of sanctity of life.

The following study was conducted in light of this legal background and the social-legal view that it is necessary to see how law works in practice. Its main aim was to examine whether, if at all, existing legal rules influence the practice of physicians who face—together with patients and their relatives—decisions about artificial ventilation at the end of life and whether there are gaps and differences between the legal rules and daily medical practice.

216. *Id.*

217. *Id.*

218. *Id.*

219. *Id.*

220. *Id.*

V. The Study

1. Aims

The central aim of the study was to examine whether the rules set by the Act for making decisions about ventilation are applied by physicians who provide treatment to dying patients. Answering this question would enable us to critique the legal position, examine the impact the law has on medical practice, identify barriers that make it difficult to apply the law, and consider whether the law should be amended.

This study is part of a larger project that examines the application of the Act in medical practice. This project focuses on the following questions: (1) Do the different stages set in the Act regarding the decision-making process accord with the practice of physicians in hospitals, and if so, what is the level of correspondence? (2) How do physicians determine in practice whether the dying patient is interested in life-prolonging treatment? (3) What is the level of influence physicians and relatives have on the process of determining the patient's wishes and on the decision made? (4) What do physicians think about central moral issues such as withholding or withdrawing treatment?

2. Methods

The study was based on qualitative and quantitative methods. In this article, we present findings from the qualitative, semi-structured interviews we conducted with twenty-two physicians. These physicians were asked about their decision-making process concerning withholding or withdrawing ventilation with dying patients and their relatives. The study was conducted in four different hospitals across Israel. The participants came from various specialties and professional ranks. They treat dying patients on a daily basis. Their characteristics are provided in Table 1.

Data were collected once institutional ethics approval for the study was granted. The interviews were based on an interview guide attached to this article as Appendix B. Data analysis included several stages and was based on a framework approach that suits a study whose aims are selected in advance and whose research questions are

specific and relatively narrow.²²¹ For a detailed account of the study's methods and process, see Appendix A.

3. Findings

Throughout the interviews, the participants addressed a number of topics related to the legal mechanisms the Israeli Act established. This article focuses on physicians' views and modes of conduct regarding the provision of artificial ventilation to dying patients. The findings address the following themes: (1) Do physicians withhold treatment and do they actively withdraw treatment? (2) How do physicians practically deal with the prohibition on withdrawal of ventilation? (3) How do physicians deal with the need to make urgent decisions about provision of artificial ventilation to dying patients? (4) What makes physicians connect patients to a ventilator, contrary to their own professional view? Finally, (5) what are the physician's views regarding the distinction between withdrawal and withholding of treatment?

A. DO PHYSICIANS WITHHOLD TREATMENT AND DO THEY ACTIVELY WITHDRAW TREATMENT?

Generally, the physicians who participated in the study refrain from connecting dying patients to a ventilator when they believe the circumstances justify it. M, a female physician who specializes in internal medicine and nephrology, described a case of an incompetent male patient with no family or appointed guardian who was diagnosed as a dying patient. M commented that in light of the patient's multiple organ failures and her lack of knowledge regarding his wishes, the decision was hers. She added that "we will not insert an endotracheal tube because there is no chance of reversing his condition and we do not want him to suffer."

In addition, physicians know that they are not allowed to disconnect a dying patient from a ventilator. Their comments suggest that they act accordingly. H, a male neurologist, stated: "We had a case of a patient. . . the family wanted us to disconnect [the ventilator]. . . and then I stated the Act, which held that we cannot disconnect

221. See Jane Ritchie & Liz Spencer, *Qualitative Data Analysis for Applied Policy Research*, 9 ANALYZING QUALITATIVE DATA 173 (Alan Bryman et al. eds., 1994); see also Aashish Srivastava & S. Bruce Thomson, *Framework Analysis: A Qualitative Methodology for Applied Policy Research*, 4 JOAAG 72 (2009).

but that if the patient is disconnected unintentionally, it is possible not to reconnect him." Q, the head of an ICU department, stated unequivocally that "in Israel, you do not take the endotracheal tube out." Although this last statement does not necessarily suggest that Q refrains from disconnecting his patients from a ventilator when they request this, the overall message he, as well as other participants, delivered in the interviews was that they do not actively and intentionally switch off a ventilator.

B. HOW DO PHYSICIANS DEAL WITH THE LEGAL PROHIBITION ON WITHDRAWAL OF VENTILATION?

A substantial number of the participants would prefer that the legal prohibition on disconnecting dying patients from a ventilator not exist. O, a female intern in an oncology department, said, "I think that I would have wanted the option of disconnecting patients."²²² S, a male physician who specializes in nephrology, commented that "I would have preferred that the prohibition (on withdrawal of treatment) not exist." M, a female physician who specializes in internal medicine and nephrology explained her preference: "[T]here are people, and you see that the machine provides ventilation to half a corpse."

The physicians expressed a preference to have the option of withdrawal of ventilation available to them. This preference is related to situations when the patient is connected to a ventilator contrary to her wishes (usually, because the physician was unaware of the patient's wishes), as expressed before losing mental capacity. It also addresses situations where the patient expresses a wish to be disconnected from a ventilator when he or she is already connected to it (this is the case, for example, with ALS patients).

Because the Israeli Act does not allow withdrawal of ventilation,²²³ the physicians who want to go along with the patient's request develop methods to deal with this prohibition. Q, the head of an ICU department, said that in these situations, "[W]e do not add treatments; we even reduce treatment and let the patient die." Q added that "we decide not to renew antibiotics, or not to give blood transfusion. We reduce the level of decisions to a minimum regarding unnecessary

222. However, O stated that if withdrawal of artificial ventilation had been legally allowed "in most cases [physicians] would not have disconnected [their patients from the ventilator]."

223. See generally The Dying Patient Act, *supra* note 161.

medications that do not help to the patient's current condition. We also stop treatments that do not affect the course of illness. We do not stop hydration, palliative treatment, or artificial ventilation."

U, who treats patients with congestive heart failure, explained his course of conduct: "If the patient is connected [to a ventilator] and there is nothing you can do, I will not engage [in] acts that would make the ventilator inefficient. I will give him fluids and that's it. So, he would not die of thirst. And then it is slowly faded . . . he will slowly stop . . . or you need to raise the ventilation indexes and you do not touch it. Stopping giving medications requires you to improve the ventilation indexes, so you do not touch [the indexes]. So, he is lying there for a short period of time, and it does not take a long time."

M, who specializes in internal medicine, described a different method: "If the patient takes the endotracheal tube out by accident, because he is restless and because we did not tie his hands [to the bed], we can tie the patient's hands so he won't take the endotracheal tube out. But we won't tie the hands of some patients. If a patient took the endotracheal tube out, we may not intubate again. If we see that the patient's condition really improves and we can successfully take the endotracheal tube out, and his condition deteriorates after a few hours, we will not resuscitate him."

F, a female oncologist, expressed a more active mode of conduct: "You do as if you are weaning them [from the ventilator], you give them more sedation . . . you do as if they are breathing. Ok, now he is suitable for weaning, you wean him, and you take the endotracheal tube out." She continues and explains: "You do not turn off the machine. You take the endotracheal tube out as if [the patient] can breathe independently, and then he cannot deal with it."

These comments reflect the methods the physicians adopted in dealing with the legal prohibition on withdrawal of ventilation when they find out that the patient or the patient's relatives are interested in this option. Whereas some physicians, like Q and U, act passively and refrain from acts that can improve the effectiveness of mechanical ventilation, other physicians, like M and F, take a more active approach that helps the patient and her family stop ventilation indirectly by, for example, weaning her from the machine when they can appreciate that the chances of success are remote. The findings suggest that the physicians found creative ways to overcome the legal prohibition set in the Act. The findings also suggest that when these physicians

found out, even in retrospect, the dying patient's wish to withdraw ventilation, precedence was given to her right to autonomy.

C. URGENT DECISIONS

In light of the legal prohibition on withdrawal of ventilation, the question of whether to connect a dying patient to a ventilator is crucial. The data indicates that one of the most common situations encountered when the dilemma arises of connecting a patient to a ventilator is when a dying patient arrives at the hospital late at night and her condition suddenly deteriorates in the emergency room or in the ward. The deterioration in her breathing requires a quick decision between two options: put the patient on a ventilator, knowing that it might be impossible to wean them from it, or not resuscitate and watch them die.

In this situation, the legal prohibition on withdrawal of artificial ventilation creates a dilemma. When facing the decision of what course of action to take, the physicians know that if they connect the patient to a ventilator and later on it is discovered that the patient expressed a wish in the past not to be connected to it, then it would be impossible to take the patient off the ventilator and respect his or her wishes. The dilemma stems from the inability to determine—due to the emergency circumstances—what the patient's wishes are when a decision is required. The reason is that the patient in this situation often lacks the mental capacity to express her wishes and make decisions, and due to a lack of time, it is impossible to inquire whether she already expressed a preference when she was legally competent.

The interviews conducted for this study indicate that in this situation, the physicians tend to connect the patient to the ventilator. O, an intern who specializes in oncology, explained: "In the emergency room . . . you have to decide, and then they will insert the endotracheal tube. . . The physicians who do not work in oncology, if in doubt, will insert the endotracheal tube. You first and foremost save the patient. Worst case, you mistakenly saved the patient and you did not mean it." O described such a case when she was a young physician: "The most traumatic episode I have ever had was when I was on duty in the ward, and an old lady arrived with a history of heart disease. She was not a cancer patient, and she was deteriorating, and I put her on a ventilator. An old lady. I would not have wanted my grandfather to be connected to a ventilator in such a situation, yes? But this was

the situation, and then the family came to me and complained because she had a will that stated that she did not want to be put on a ventilator.”

Q, the head of an ICU department, described a similar case: “The patient had apnea . . . she was eighty-eight years old. What do you do? Resuscitate or not resuscitate? What do you do? What will you do? This is the central question, right? She wrote that she did not want resuscitation . . . The treating physician in the ward decided that he cannot deal with a situation where a patient stopped breathing because of him . . . and inserted the endotracheal tube and sent her to us [to ICU]. What do we do? Her son arrived in a fury. ‘What have you done? She wrote that she does not want this.’ Now, do you take the endotracheal tube out?”

The physicians who addressed this situation in the interviews explained why dying patients who arrive at the hospital at a late hour would be intubated. First, the physician in the emergency room or in the ward does not know the patient and the details of her medical condition. O, a young intern in oncology, explained: “The emergency room is the worst. In the ER, you do not have the time to get to know the patient well. The patient is deteriorating in front of you. Now, go figure out what his medical condition is now . . . and if you do not know the disease, and you do not know how many lines of treatment he has already received, you do not know if he responded [to treatment] or did not respond. You cannot make a decision on the spot.” She added: “. . . and in the ward, often, physicians are helpless. They do not really know what the patient’s condition is and if he really stands a chance to survive [the disease]. . . .”

Second, the physician on duty who faces the decision of whether to insert the endotracheal tube has no time to gather information and ask the treating physician and the relatives what the patient wants. The reason is that the physician on duty has only a few minutes to make a decision. C, a male physician who specializes in nephrology, stated: “The patient needs resuscitation, the patient needs ventilation. He is not breathing. This is the scenario: [two A.M.] in the morning, emergency room, the patient is suffocating. He is blue, oxygen saturation is [seventy percent] . . . now, there is a matter of time here. If the physician does nothing in the next two minutes, three minutes, the patient dies. So, what do you want him to do? Shall he approach the family?”

Third, in many cases, when there is no conclusive evidence that shows that the patient already expressed an explicit wish not to receive artificial ventilation, the physician will connect the patient to a ventilator. B, a young physician who specializes in internal medicine, explained: “. . . if I don't have a document, and I have nothing, so with a heavy heart we put the patient on the ventilator, and at least he would not suffer for a long time, because his prognosis was very poor.” N, a neurologist, stated: “As long as the patient is deteriorating at night, in terms of his breathing. . . the only thing I can do is to put him on a ventilator. I can't sit like [and do nothing] . . .” She added: “I have no right to decide, when the patient did not express his wishes and when I do not have any evidence or documentation, not to put him on a ventilator.”

Another reason that came up in the interviews is that in these emergency circumstances, young physicians are the ones who face the dilemma of whether to put the patient on the ventilator or not. Some young physicians have difficulty dealing with such a situation. P, a female physician who specializes in internal medicine, stated: “What happens is that often, and this can happen, when a young physician at night is on duty, and even if the senior physician on call [who is at home] tells him ‘I think you don't [need to put the patient on the ventilator],’ if the young physician is in doubt, and if the decision [not to put the patient on the ventilator] is difficult for him, he has a right to put the patient on the ventilator. It happens a lot.”

N, a female neurologist, summed it up and stated that from the perspective of the health care system, it is nearly impossible not to put a dying patient on a ventilator in an emergency when there is no advance directive, even when the relatives notify the physician that the dying patient expressed a wish not to be artificially ventilated: “I, as I see the health care system today, we have no option today not to resuscitate when a patient gets into acute stress, and it doesn't matter what the family says. The family can tell me that he did not want to be connected to a ventilator, that he did not want to be disabled, that he did not want to depend on others. But, at the moment of truth, I am the one who needs to make the decision, and I have no right not [to connect the patient to a ventilator]. In the ward, this is the situation.”

D. WHEN PHYSICIANS CONNECT PATIENTS TO VENTILATORS CONTRARY TO THEIR OWN PROFESSIONAL VIEW

Another type of case is when a physician acts contrary to their professional view and connects a patient to a ventilator due to the relatives' request when the patient is either legally incompetent or when it is difficult—due to their weakness and physical condition—to find out what they want. O, an intern in oncology, admitted that “[U]ltimately, if there is a situation where [the family] insists on ventilation, the patient would receive ventilation.” L, a male oncologist, added that “there were cases where we intubated the patient due to the family’s pressure. There were such cases.” M, who specializes in internal medicine and nephrology, commented that “there are families who want you to do everything. If they are the legal guardians, we will do everything.” She explained: “If a family tells me to connect the patient to a ventilator, I will explain to them, for example, a dementia patient who is ninety-five years old, disabled, with pneumonia, I will explain to them that the chances of weaning him are very low. The chances that the inserted endotracheal tube would be taken out are very low and would cause him pain . . . many times we give people time to think, even if it is for a few minutes. And if they say put the patient on the ventilator, then we put them on the ventilator. There’s nothing I can do about it. My set of values does not reflect the set of values of all people.” H, a senior neurologist tried to explain: “The patient is unconscious and you need to put him on the ventilator and keep him unconscious, so it’s only the family and the patient. So . . . it is of interest to you what the patient thought and what the family thinks. This is not written in books. You know that according to the law, the family has no standing. But we always listen to the view of the family. If there is a family that wants [ventilation], if the patient is in a coma and he is dying and the family says ‘no, treat him,’ then we treat.”

Interestingly, going along with the family’s request stands in contrast with the physician’s principal view of artificial ventilation. The majority of the study’s participants believe that dying patients should not be connected to a ventilator when there is no clinical justification for it. M, who specializes in internal medicine and nephrology, said: “My personal view is that there is no need to die with an endotracheal tube in the mouth, and there is no need to be artificially

ventilated." She explained that there is no need to put a dying patient on a ventilator when the sole purpose is to alleviate his pain: "Is there any significance in putting someone on a ventilator and giving him oxygen when you know that you are not going to cure him, because you know that he has a metastasis tumor in his lungs? So, only to give him oxygen? What is the purpose of ventilation? To give him oxygen or to ease his pain? If it's to ease the pain, we have other means."

Other physicians emphasized that there is no need to connect a dying patient to a ventilator when it is not medically beneficial. O, an intern in oncology, admitted that "I really don't like to put patients on the ventilator when I think that it is not beneficial." O added that from her perspective, this "causes suffering" to the patient. Other physicians described the provision of futile artificial ventilation to dying patients with strong words. I, a male physician in an ICU department, perceived this as "abuse." F, a female oncologist, commented that "if [the patient] had secondary growths in his lungs, and all treatments have failed, and this is why he is not breathing, it is clear that there is no point in putting him on a ventilator because you are not going to wean him. So, what's the purpose? There is no point in artificial ventilation. . . it's abuse, not medicine."

Some physicians stated that they will not raise the issue of artificial ventilation in the discussion with the dying patient or with her relatives if they believe there is no clinical justification for it. F, a female oncologist, commented: "I am not raising issues concerning artificial ventilation at all, never. To me, it's absolutely idiotic . . . [i]t's a medical act that has indication. Artificial ventilation has an indication to be used as a bridge to a patient who suffers from congestive breathing and it is possible to substantially prolong his life." L, a male oncologist, agrees: "I am not always telling them 'it is possible to use artificial ventilation.' No, I am not telling them this if I don't think it is an option."

In light of this professional approach to artificial ventilation, the next question is why the physicians go along with the relatives' request to put the dying patient on a ventilator. The interviews suggest that there are several reasons for this. First, the physicians want to avoid conflicts with the relatives. This, for example, was echoed in the comments of I, a senior physician in an ICU department, and J, a head of an ICU department, who stated that "we do not want to start wars with the families." Another reason is the physician's assumption that

the relatives know the patient better than them, and therefore, it is morally justifiable that the relatives would act on behalf of the patient. In addition, the physicians perceive the relatives as a means to understand the patient's true wishes. M, a female physician who specializes in internal medicine, commented: "[relatives], I can't help it, know [the patient] better than me, and my set of medical considerations is not the only one that decides the case in some situations. So, yes, their set of considerations would be more important than mine." M was aware that when the relatives discuss the patient with her, they may express their personal views and not the patient's wishes. Nevertheless, she respects their position: "When the patient is not communicative, I think, in my view, when it concerns a disabled dementia patient, your father, your mother . . . my assumption is that you know him better than me, what happened throughout his life, that he wished and hoped that you would act now for his benefit. Therefore, I will go along with you, despite the fact that I think differently. The reason for this is that you are probably expressing what he would have wanted, and that's it."

Another reason is the empathy the physicians feel towards the relatives and their awareness that their decision to connect the patient to a ventilator has emotional implications for the relatives. A, a head of a hospital ward, explains: "I will go along with the family. You know why? Because to me, she is ill . . . but she is their mother and they will live with their guilt all their lives. You always need to go to the side that is more amicable. I don't need to win the argument. I don't need to be the one who is right here. Even if there is disagreement, and in the end the patient is put on the ventilator, and the patient survives for several more days, I think it creates less rifts than if you do nothing and the patient dies within the same number of days. It doesn't matter. Because then [the relatives] say '[Y]ou see? If we would have acted, the results would have been this and that.' Therefore, I think that it's not my place to say: 'I am telling you, there is no need [to put the patient on the ventilator] and that's it.' I don't think so."

In addition, L, a male oncologist, explains that going along with the family's pressure stems from his understanding that the relatives are sometimes emotionally unprepared for the news about the patient's condition. Replying to the interviewer's assumption that he goes along with the relatives' wish because they are the ones to bear

the emotional burden after the patient's death, L agreed and elaborated: "This is because [the relatives] came unprepared, because they perceive the situation totally differently than how I perceive it. I will try to talk to them, and explain where we stand. In most cases it works, but there are [other] cases. I can tell you that I had cases where you go along with the family's pressure because it is clear to you that if you do otherwise it's going to be bad. It would be bad for them, it would be bad for me . . ."

Moreover, the physicians said that they go along with the relatives' wish in order to give them a sense of closure. B, an intern in internal medicine, said: ". . . in the end, we want, in saying goodbye to the patient, for there to be a proper farewell . . . the family won't go home with 'perhaps we could have done more', or they will take it on them, or 'why we did not say and why we did not do this and the other'. . . the patient will die in the most respectful and holistic way. So . . . they will leave with a better feeling, because in the end, the patient dies, while they stay alive."

Furthermore, a few physicians stated that concern that the relatives might file a lawsuit against them led them to collaborate with the relatives and go along with their request. M, a female physician who specializes in internal medicine, said: "Part of it is paranoia. Part of it is the possibility that a relative would come and say you kill the patient one way or the other, and you don't know if the judge's value system tells him that dying patients must be artificially fed. I don't believe it would go that far, but it is part of [the physician's concerns]." When the interviewer asked M whether fears from legal claims are a central reason for going along with the family's request, she said: "It is a dominant reason. You do not want to get into trouble when the family's lawyer would say, '[Y]ou killed the patient because you did not give him proper treatment.' And [the family] can always obtain a professional medical opinion that would state that you did not feed [the patient], so he died, or you did not put him on the ventilator, so he died. You can always find a specialist who will support such a claim."

The direct implication of going along with the family is providing futile treatment to a dying patient. M, who specializes in internal medicine and nephrology, admitted that "I put people on the ventilator that [professionally] I did not have to resuscitate, [in circumstances] where I would not let anyone connect me to a ventilator, or to connect any of my relatives in this situation, and the patient insisted, or

his family insisted and he has dementia, for example. Yes, we'll connect him to the ventilator. What can we do? . . . Yes, we put them on the ventilator. Yes, there is nothing we can do." M continued: "We have a technology that can save life but [also] complicates our lives as physicians. And there are lots of cases where the artificial ventilation is futile. . ." C, a male physician who specializes in nephrology, addressed the issue of futile resuscitations and said: "I think it happens every day in Israel."

E. ATTITUDES TOWARDS WITHHOLDING OR WITHDRAWING ARTIFICIAL VENTILATION

Interestingly, the participants distinguish between a decision not to connect a patient to a ventilator and a decision to turn it off. A, a female physician who specializes in internal medicine, said: "From my perspective, from my view of the world, I cannot do something that intentionally and unequivocally ends [the patient's] life." When the interviewer asked whether she perceives disconnecting the patient from the ventilator as an act and a DNR order as an omission, A agreed and said: "It may seem like fine lines with no real difference, but at least in my view . . . I do something that is really active. I take out the tube, and he dies because he can't breathe on his own. I have not yet crossed this line." F, a female oncologist, echoed this, stating that there is a difference between not connecting a patient to a ventilator and disconnecting him or her from it, explaining that the latter is "active" and that it is "like similar to killing someone."

This attitude, which strikes a clear distinction between withholding and withdrawing artificial ventilation, raises the question about its reasons. M, a female physician who specializes in internal medicine and nephrology, admitted that the distinction is related to the physician's emotions and feelings. She said: "There is a difference. The fact is that between being passive and active, there is a difference in terms of feeling." She then elaborated: "In my view, there is a difference . . . there is a difference, you can call it, conceptual, or based on feelings and awareness . . . A patient is alive simply because he has a pacemaker. If I am asked to turn it off and I know that he would die within 30 seconds, I will definitely have a problem here, but to tell you logically why? I do not have a logical reason, only that I, as a physician, cannot, cannot kill someone actively. It would be like to inject poison into him." O, a resident in a large oncology department, ex-

pressed a similar view, implicitly referring to the emotional difficulty in disconnecting the patient: "It is an active deed. It is difficult for the physician, it is difficult for the family, it is difficult for the patient. It is as if you have a situation where you say we are now killing, really. There is something that keeps him alive, and the moment we disconnect, it is dramatic, like in a TV series."

P, a young specialist in internal medicine, addressed the intention behind the physician's conduct and the causal link between withdrawal of treatment and the patient's death: ". . .if I know that. . .it is not a natural process of weaning [from the ventilator], that I don't really want to wean the patient, and the weaning is used simply to disconnect him, because I know that there is no prognosis, it is problematic in my eyes, it is not simple. It is not simple for me. The feeling is that I actually caused it." P elaborated and highlighted the causative aspect, saying: "I think there is a difference. I think, I agree that it is easier for us not to connect the patient [than to disconnect]. Not to connect is letting the natural process of dying take its course, because death is a natural process. Ultimately, we are all going to die." This view was shared by I, an ICU specialist, who said that if he does not connect a dying patient to a ventilator, then death "is a natural process."

VI. Discussion

This study provides interesting findings that shed light on the application of the legal rules regarding withholding or withdrawing ventilation to dying patients. The discussion in this part will concentrate on the relationship between practice and law in this area. It corresponds with the main themes found in the study.

1. Attitudes towards withholding or withdrawing ventilation

First, the study's participants, like physicians in other Western jurisdictions,²²⁴ distinguish between withholding ventilation and its

224. See generally Nili Karako-Eyal & Roy Gilbar, *The Dying Patient Act 2005: Practice, Ethics and Law in Israel*, BIOETHICS IN ISRAEL: SOCIO-LEGAL, POLITICAL AND EMPIRICAL ANALYSIS (Shai Lavi et al. eds., forthcoming 2017) [hereinafter Karako-Eyal].

withdrawal. This, as one can see, accords with the legal position of the Israeli Act, which also distinguishes between the two.²²⁵

The reasons the study's participants provided for this distinction are related to the factors discussed in the bioethical debate about acts and omissions.²²⁶ The physicians raise the issue of human agency, which is required when withdrawal takes place (but is absent when withholding ventilation).²²⁷ They highlight the close causative link between withdrawal of ventilation and the patient's death and their moral responsibility for the patient's death. Interestingly, there were physicians who used the same terminology employed in the scholarly debate, highlighting that in withholding ventilation, they allow nature to take its course and let the patient die, whereas in its withdrawal, they actually perform an act of killing. Lastly, some participants mention the emotional difficulty they feel when asked to withdraw ventilation. Notably, these findings are similar to those found in previous empirical studies reviewed in Part III.

Our conclusion, therefore, is that the duty not to cause harm, or the ethical principle of nonmaleficence, is dominant in the physician's attitudes in end-of-life decision-making. This conclusion is not surprising, considering that the principle of nonmaleficence is central in bioethics and is rooted in the practice of medicine.

Second, despite the conservative view about withholding and withdrawing life-prolonging treatment, the study's participants were critical of the legal prohibition on withdrawal of ventilation. This is interesting because it reflects professional ambivalence towards a legal rule. On the one hand, the physicians, like the legislator, distinguish between withholding ventilation and its withdrawal, but on the other hand, they are critical of the legal prohibition. The physicians prefer to conduct their practice within a legal framework that allows them the flexibility of stopping ventilation, which prolongs the life of a dying patient for a short while. Although, as some participants admitted, they would not perform an act of withdrawal, they would like to have this option available to them, especially in cases where it is discovered that a patient who was connected to a ventilator has already expressed a wish not to be connected to it.

225. See generally *The Dying Patient Act*, *supra* note 161.

226. See Karako-Eyal, *supra* note 224.

227. *Id.*

The findings also suggest that the physician's preference for having the legal option of withdrawing ventilation stems from a liberal approach they hold. Quantitative findings that were not reported here, but are part of the large study we conducted, suggest that physicians believe that the patient has a right to autonomy and, specifically, a right to refuse treatment at the end of life.²²⁸ This is also indicated indirectly in the findings reported here, namely, that physicians want to have the option of withdrawing ventilation in the following situations: (1) when the physician discovers after connecting the patient to the ventilator that he or she expressed a wish not to receive life-prolonging treatments, and (2) when a patient who was connected to a ventilator later on changes his or her mind when the health condition deteriorates (e.g., in ALS patients). These findings show that in these situations, the physicians want to have the option of respecting the patient's wishes to stop ventilation. It also indicates that, similar to their Western colleagues, the physicians in this study ascribe importance to patient autonomy, at least theoretically.

Summing up, the findings discussed indicate that the legal prohibition on withdrawal of ventilation accords with the views of the physicians. However, unlike the legal position, the physician's view is more nuanced. Despite the explicit admission of some that they have not performed an act of withdrawal of ventilation, they prefer to have this option and would like to see this legal obstacle abolished.

2. Dealing with the Prohibition on Withdrawal of Ventilation in Practice

Moving on to the physician's actual conduct, it is clear from the findings that the distinction set by the Act between withholding and withdrawing treatment is followed. The participants knew they could refrain from connecting the dying patient to a ventilator, and they made decisions to this effect. However, the physicians also knew that they are not allowed to switch off a ventilator or disconnect the dying patient from it, and they followed this rule. Furthermore, the findings described above indicate that the legal prohibition on withdrawal of ventilation is not the only reason for the adoption of this practice. The perception of withdrawal of ventilation as an act led at least few phy-

228. These findings are reported elsewhere. *See id.*

sicians to state that they do not actively switch off ventilation. It follows that this conduct is also connected to the moral attitudes held by some of the study's participants.

However, the physician's accounts on how they deal with the legal prohibition on withdrawal of ventilation also suggest that the approach they hold towards the issue of withdrawal is much more complex than the legal position.

Although the participants felt bound by the legal prohibition to withdraw ventilation, they nevertheless listed several methods of conduct that indicate respect for the wishes of the patient and/or the patient's relatives to stop ventilation (and the pain and suffering that come with it). The modes of conduct the physicians listed reflect different levels of acceptance of the patient's wish not to receive ventilation. Some physicians adopted a passive mode of conduct, e.g., stopping the provision of antibiotics and blood transfusions or not increasing the amount of oxygen the ventilator produces. Others were more active and disconnected the patient from the ventilator once they appreciated the patient could breathe without mechanical help and refrained from connecting them back minutes or hours later when the patient needed it. Furthermore, there was one physician who described a process of weaning the dying patient from a ventilator, fully aware that the chances the patient would survive without it were practically non-existent.

From a bioethical perspective, the different modes of conduct the physicians adopt when facing a request to stop ventilation reflects their different approaches to the central principles of autonomy, non-maleficence, sanctity of life, and prevention of suffering, which were set as the founding principles of the Act.²²⁹ Thus, a physician who weans the patient from the ventilator knowing that the chances of survival are effectively non-existent expresses a preference for the principles of autonomy and prevention of suffering over the principles of sanctity of life and a strict duty not to cause physical harm. These preferences were indeed echoed in the interviews with the participants. Furthermore, as the theoretical discussion in Part II indicates, the same difference in the approaches to the conflict between autonomy and nonmaleficence exists in bioethics.

229. *Id.*

Moreover, the different modes of conduct the physicians in the study adopt show that—unlike Savulescu and others who argued that physicians' moral views should not be an overriding factor when making end-of-life decisions²³⁰—the physician's personal beliefs have an impact on their decisions and actions. Although not stating this explicitly, it can be argued that the various modes of conduct the physicians in this study adopt when facing the legal prohibition on withdrawal of ventilation reflect their different personal views on the issues at hand. The various modes of conduct they adopt show that the physicians did not strictly follow a single legal rule but acted, to some extent, according to their particular set of values and beliefs.

The practice of adopting a mode of conduct that corresponds to the physician's particular set of values finds support in the legal rules set in the Act.²³¹ Despite the Act's rather restrictive and clear approach, it does allow discretion to physicians when facing the decision of whether to respect the wishes of a patient who no longer wants ventilation.²³² Thus, Article 21 of the Act, which prohibits the withdrawal of ventilation, does not bar physicians from trying to wean the dying patient from the ventilator if they professionally believe this can be done.²³³ Moreover, from a narrow linguistic perspective, the legal prohibition on withdrawal of ventilation does not prevent a gradual reduction in the ventilator's level of oxygen, as was approved by the court in the *John Doe* case, simply because adjusting the level of oxygen is not the same as switching it off.²³⁴ Interestingly, there was no physician in the study who raised this option in the interviews.²³⁵

Summing up, it is clear that despite the fact that the physicians respect the Act's prohibition on withdrawal of ventilation, it raises

230. See Savulescu, *supra* note 85; JACKSON, *supra* note 3; *Relationship Between Medical Law and Good Medical Ethics*, *supra* note 88.

231. The Dying Patient Act, *supra* note 161.

232. *Id.*

233. As discussed in Part IV, the Act reflects the general principle in Israeli medical law that the provision of medical treatment to patients is based on the physician's professional judgment. This can be shown in Articles 55 and 56 of the Act.

234. Although this court decision does not relate to dying patients as they are defined by the Act (because the petitioner's prognosis exceeds six months), it can nevertheless be argued that a physician who employs this mode of conduct in the case of a dying patient does not breach the legal prohibition set in Article 21.

235. However, during an informal conversation one of the authors had with a senior neurologist during the course of the study, the physician admitted that he started using this method long before the court gave its judgment.

practical difficulties that they have to address. The various modes of conduct the physicians employ to help patients materialize their request imply that the physicians are critical of the law. The physicians' various modes of conduct also shed some light on the role of the law and its impact on medical practice. It is clear that despite their principal approach, which distinguishes between the withholding of ventilation and its withdrawal, the physicians perceive the legal rule as an obstacle that prevents them from fully exercising their professional judgment. It is also evident that some of the physicians were reluctant to accept this legal obstacle and, therefore, found creative, though legal, methods to overcome it. This reflects the physicians' complex view on the conflict between the principles of nonmaleficence and autonomy: On the one hand, they do not want to fail in their duty to not cause physical harm to patients, but on the other, they want to respect the patient's wishes and prevent further pain and suffering. In fulfilling the latter, the law is perceived as a hindrance rather than an asset.

3. Working under emergency circumstances

Another problematic area most of the participants raised in the interviews concerns situations when the medical condition of the dying patient in the ward suddenly deteriorates at a late hour or when the patient arrives at the ER in critical condition, and the young physician, who is responsible for the patient's care, faces the decision, which has to be made quickly, of whether to put the patient on a ventilator. In these situations, the physician faces a difficulty due to the prohibition on the withdrawal of ventilation set in Article 21.²³⁶ On the one hand, the physician's duty not to cause harm to the patient and to improve her condition leads the physician to connect the patient to a ventilator quickly. On the other hand, if the medical team discovers later on that the patient has already expressed a wish not to receive ventilation should he or she reach this stage, then the legal prohibition on withdrawal infringes upon the patient's right to make autonomous decisions and prolongs the pain and suffering involved in ventilation.

236. The physician does not face a moral dilemma because in most cases, as was presented in the previous part, she knows what the ethical course of action should be. The physician faces moral distress, which is discussed below.

The findings indicate that in these situations, the physicians tend to connect the patient to the ventilator. Comparing this practice to the legal rules suggests that there is a gap between the Act and the conduct of the young physicians in practice. This requires an explanation.

It should be recalled that Article 18(a) of the Act states that in a situation of emergency, the physician can provide the patient urgent medical treatment without the patient's consent if, due to the circumstances and the patient's physical or mental state, it is not possible to obtain the patient's informed consent.²³⁷ Treatment should not be provided if the physician knows that the patient wishes not to receive treatment in this situation.²³⁸

Undoubtedly, Article 18(a) is highly relevant to the situations discussed here.²³⁹ It indicates that, in an emergency, physicians who know that their patient is dying can provide treatment, such as ventilation, unless they know that the patient does not want it.²⁴⁰ Thus, the young physician who needs to make an urgent decision late at night in the ER of whether to connect the patient to a ventilator, *not knowing whether the patient wants it*, acts within the law.²⁴¹ As some physicians stated in the interviews, when the young physician has two to three minutes to make a decision, he or she has no time to find out whether the patient had expressed a particular view about it. However, as some physicians in this study admitted, there are cases where the patient's close relatives are present and can tell the physician that the patient already expressed a wish not to receive ventilation should she reach this stage. As the study's participants stated in the interviews, young physicians who face such a decision ultimately decide to connect the patient to a ventilator despite the relatives' statement. In our view, the physicians who connect the patient to the ventilator despite the statement of a close relative may not be acting strictly according to the law. This is due to Article 5 of the Act, which states that the physician has the authority to make the final decision, but he or she first has to receive a statement from a close relative regarding the patient's

237. See The Dying Patient Act, *supra* note 161.

238. Article 18(a) of the Act refers to Article 15(3) of the Patient Rights Act 1996, which set this legal rule. Article 15(3) also states that in particular types of medical treatment, such as major surgeries, the provision of treatment under these circumstances requires the approval of three physicians.

239. The Dying Patient Act, *supra* note 161.

240. *Id.*

241. *Id.*

wishes when the patient was legally competent to express his or her views.²⁴² Thus, if a physician disregards the relatives' statement and decides to connect the patient to a ventilator, she might not be acting according to the rules set in the Act.²⁴³

Two other Articles are also relevant to these situations. The first is Article 16 of the Act, which determines that if it is known that an incompetent dying patient who suffers significant pain has already refused a life-prolonging treatment, the patient's wishes should be respected, including the wish not to receive ventilation.²⁴⁴ This Article applies to emergency situations as well.²⁴⁵ The second is Article 18(b), which states that when a dying patient in the *final stage* is in a situation of emergency, the physician can withhold life-saving treatment unless the physician knows that the patient wants to receive treatment in this situation.²⁴⁶ Thus, when the dying patient faces the circumstances described in these two Articles, the only justification for a young physician who decides, in the ER or in the ward, to connect the dying patient to the ventilator is if the physician cannot ascertain that the patient is indeed dying.²⁴⁷ In other words, if the physician does not know and cannot ascertain, due to the emergency circumstances, an accurate diagnosis, lines of treatment, and prognosis (life expectancy of less than six months), then it might be justifiable to provide ventilation, because then the Act might not govern the case.²⁴⁸ In such a case, the Patient Rights Act 1996 becomes relevant, and under Article 15(3) of this Act, the physician can provide treatment to eliminate a risk to

242. *Id.* at art. 5.

243. Notably, while the Act does not state how a relative's statement should be made, the Ministry of Health's regulations require that this statement be made in an affidavit; see The Dying Patient Regulations (Committees, Documents, Database and Report), 6628-2007, SH No. 6628 art. 16 (Isr.) [hereinafter The Dying Patient Regulations]. Moreover, neither the law nor the regulations state whether the requirement for affidavit is a technical requirement or material legal requirement. It is therefore left for interpretation what is the force of a relative's statement that was not made in an affidavit. For reasons that exceed the scope of this paper, we believe that this is a technical requirement. According to this approach, a physician should consider a relative's statement even if not made in affidavit. According to this interpretation, if a physician disregards the relative's statement and connects the patient to a ventilator, he or she is not acting according to the Act. However, a different interpretation that yields a different approach is also possible.

244. See The Dying Patient Act, *supra* note 161.

245. *Id.*

246. *Id.* at art. 18(a).

247. *Id.*

248. *Id.*

the patient's life without his or her informed consent.²⁴⁹ However, if the young physician knows that the dying patient is in the final stage and has not expressed a wish to receive ventilation, he or she may not act strictly according to the rules set by the Act.²⁵⁰ As the interviews in our study indicate, such a situation might occur in hospital wards.

Concentrating on the aim of this article, the legal analysis so far indicates a gap between the Act and the conduct of young physicians who connect a dying patient to a ventilator in a situation of emergency. The gap derives from the fact that the Act assumes that the physician has sufficient time, even in a situation of emergency, to get the full picture of the patient's diagnosis, lines of treatment, and prognosis.²⁵¹ Furthermore, it assumes that physicians have sufficient time to obtain information about the patient's prior wishes.²⁵² However, as the study findings indicate, one of the main reasons for connecting patients to a ventilator is the lack of time needed to obtain information about the patient's medical condition or wishes. Thus, the discrepancy between the legal rules and medical reality in the ER or the ward leads physicians, in some circumstances, to act counter to the law.

Interestingly, despite the discomfort the physicians expressed when legally prohibited from helping the dying patient end the pain and suffering involved at the end-of-life, they justify the conduct of the young physician who needs to make an urgent decision. It was clear that in adopting this approach, the physicians applied a narrow interpretation of the principle of nonmaleficence, namely, that a physician should not cause *physical* harm to the patient. In addition, the physicians expressed a preference for this principle over the principle of autonomy. It thus follows that in this context, the physicians express a moral position that stands in contrast to the moral approach of the Act. Whereas the Act protects the dying patient's right to autonomy and her right to refuse life-prolonging treatments when an emergency situation occurs and certain conditions are met,²⁵³ the physician provides an overriding preference for the principle of nonmaleficence when connecting the dying patient to a ventilator. This is quite understandable in light of the significance the physicians attach to this prin-

249. The Patients Right Act, 5756-1996, SH No. 327 (Isr).

250. *Id.*

251. *Id.*

252. *Id.*

253. *Id.*

principle. For many, it reflects the essence of their work. In fact, it follows from the interviews that acting in a manner contrary to the principle of nonmaleficence is emotionally difficult for physicians, especially when they are young. Therefore, it is not surprising that when having to choose under pressure between the principle of nonmaleficence and the principle of autonomy, precedence is given to the former (which leads them to connect the dying patient to a ventilator).

Another important point that comes up in this context is the physicians' attitudes towards the prohibition on withdrawal of ventilation. The physicians' comments indicate that the legal prohibition on withdrawal of ventilation causes them moral distress but not necessarily a moral dilemma. This claim requires some explanation as to the difference between the two. Whereas a moral dilemma occurs when the physician believes he or she is in conflict about the correct ethical choice due to contrasting moral values, moral distress occurs when the physician feels certain about the ethical course of action but is limited in following their preferred course of action due to external obstacles, such as legal rules.²⁵⁴

In our context, it appears that the physicians in the study express moral distress. They are of the view that the right course of action in an emergency is to resuscitate the dying patient and connect them to a ventilator to save their life from an immediate and imminent risk, but they feel uncomfortable with not having the option of stopping ventilation if it is found out later that the patient has already expressed a wish not to receive ventilation in these circumstances. Notably, the physician's comments do not indicate that they face a moral dilemma over what the right ethical course of action is—they want to resuscitate the patient. However, it is clear that the physicians are in moral distress due to the legal prohibition on withdrawal of ventilation.

Summing up, in this particular context, contrasting the physician's statements with the existing legal rules suggests that, in some

254. Ann B. Hamric & Leslie J. Blackhall, *Nurse-Physician Perspectives on the Care of Dying Patients in Intensive Care Units: Collaboration, Moral Distress, and Ethical Climate*, 35 *CRITICAL CARE MED.* 422, 423 (2007); Lilia Susana Meltzer & Loucine Missak Huckabay, *Critical Care Nurses' Perceptions of Futile Care and its Effect on Burnout*, 13 *AM. J. OF CRITICAL CARE* 202 (2004); Mary C. Corley, *Nurse Moral Distress: A Proposed Theory and Research Agenda*, 9 *NURSING ETHICS* 636 (2002); Sofia Källemark et al., *Living with Conflicts—Ethical Dilemmas and Moral Distress in the Health Care System*, 58 *SOC. SCI. & MED.* 1075 (2004); Walter S. Davis et al., *Moral Distress in Health-Care Providers: What is it and what can we do about it?*, 69 *PHAROS OF ALPHA OMEGA ALPHA HONOR MED. SOC'Y* 16 (2006).

cases, they do not go hand in hand. It appears that physicians in a situation of emergency (especially young physicians, who actually face these situations) adopt a narrow interpretation of the principle of nonmaleficence and try to eliminate an imminent and immediate risk to the patient's life, even when there are clear indications that the patient would not have wanted it. The implications of this gap as well as the gaps we discussed above will be addressed below in the last part of this article.

4. Family involvement

The last issue the study's participants raised was the involvement of the family, particularly when the patient has diminished or no capacity to make decisions. The overwhelming finding is that the family is inherently involved in the decision-making process about ventilation. Moreover, the data analysis suggests that the physicians respect the relatives' request to provide ventilation even when this request stands in contrast to their own personal views. The interviews show that physicians know that respecting the relatives' wishes may lead them to provide futile and painful treatment to a dying patient, but they prefer to go along with the family. Furthermore, the findings indicate that although the physicians know that family members have no legal status, they nevertheless involve them in the decision-making process.

Involving the family in the decision-making process and, more so, accepting their request to provide ventilation to the dying patient despite their personal and professional view that ventilation should not be offered,²⁵⁵ indicates that the physicians give the family a dominant independent role in the decision-making process. The relatives' position is preferred in these circumstances by the physicians over their values, professional discretion, and despite the fact that it may harm the patient by prolonging his or her suffering and may result in negative bioethical implications of infringing on the right to autonomy. This, in our view, shows how strong the family is as an independent party in the end-of-life decision-making process. As the empirical analysis in Part III shows, these findings accord with the

255. The participants' view that ventilation should not be offered merely to extend life is shared by others. See Craig D. Blinder et al., *Time to Revise the Approach to Determining Cardiopulmonary Resuscitation Status*, 307 JAMA 917 (2012).

conduct of physicians in other jurisdictions who involve the family in the process.²⁵⁶

From a bioethical perspective, the physicians express a relational approach to autonomy. As discussed above, different scholars view relational autonomy differently.²⁵⁷ There are those who perceive the family more as a party that nurtures the patient's capacity to fulfill treatment plans,²⁵⁸ whereas others give the family nearly equal weight in the decision-making process.²⁵⁹ Similar to these scholars, the participating physicians also express different views towards relational autonomy. Some physicians in the study believe relatives should be given a substantial role because they know the patient as no one else does. They thus appreciate, as relational autonomists, that the patient is not an isolated individual who is separate from her social circle. On the contrary, they reflect a position that values the contribution of relatives to the patient's interest in making decisions about the way he or she wants to live. Other physicians reflect a different relational approach.²⁶⁰ They do not make an effort to distinguish between the patient's wishes and the personal views of the relatives, although they know there might be differences between them. This practice leads to the conclusion that these physicians perceive the relatives not merely as a means to receive information on the patient but also as part of the patient's identity, or even as an extended part of the patient.

Concentrating on the purpose of this article, the findings suggest there is a gap between practice and law. Legally, as stated in Part IV, the family has no independent formal status in the decision-making process.²⁶¹ First, if the patient is defined as legally competent to make decisions, then despite the diminished capacity, the family, according to the Act, has no role to play in the decision-making process.²⁶² Thus, the physician's statements that they listen to the relatives and involve them in the process when the patient is legally competent to make decisions stand in contrast with the legal framework.²⁶³

256. *Id.*

257. *Id.*

258. See LINDEMANN-NELSON, *supra* note 68.

259. See HARDWIG, *supra* note 71.

260. See O'Donovan, *supra* note 75.

261. *Id.* at 357.

262. See The Dying Patient Act, *supra* note 161.

263. These findings were reported elsewhere. See NILI KARAKO-EYAL & ROY GILBAR, THE DYING PATIENT ACT 2005 TEN YEARS ON: LAW, ETHICS AND MEDICAL PRACTICE (Shai Levi et al. eds., forthcoming 2017).

Second, if the patient is defined as legally incompetent to make decisions and left no advance directives or a relative with a power-of-attorney to make decisions on his or her behalf, then, as discussed above, the physician is authorized to make the decision provided the physician received a statement from a close relative who can shed light on the patient's preferences.²⁶⁴ If there is no close relative in the picture, then the physician should approach the patient's legal guardian, if one was appointed, and ask his or her opinion. Clearly, the Act perceives the family as a means to obtain information about the preferences of the dying patient when mental capacity has been lost; it does not give the relatives an independent status and certainly does not establish that their position is the crucial consideration when making decisions about treatment.²⁶⁵

Analyzing the physician's conduct from a legal perspective, it is clear that this does not fully accord with the Act, which, as we saw, does not provide such a significant role to the relatives when the patient has no or diminished capacity.²⁶⁶ However, more importantly, if physicians go along with the relatives' request without eliciting from them what the patient's personal wishes were before losing mental capacity, they once again do not follow the legal rules set by the Act.²⁶⁷ They infringe upon the patient's fundamental right set by the Act that wishes not to receive treatment, and especially not be connected to a ventilator, should be respected even when the patient no longer has the mental capacity to ensure they are fulfilled.²⁶⁸

When raising this aspect in the interviews, the participants who addressed this issue were quite dismissive about it. They prefer to respect the relatives' preferences at the expense of prolonging the life of the dying patient by a few days. They expressed feelings of empathy towards the patient's relatives and a desire to allow them a proper farewell from their loved ones. It was also clear that they were aware that the decision to go along with the relatives' request has implications for the relatives' welfare, and they believe that this is an important factor. However, it was not just altruistic motives that led the physicians to adopt this practice—personal interests were also im-

264. *Id.* (noting the most common scenario in Israel).

265. *See* The Dying Patient Act, *supra* note 161.

266. *Id.*

267. *Id.*

268. *Id.*

portant. Thus, the desire not to face a conflict with the relatives and to avoid a lawsuit led the physicians to collaborate with the relatives and respect their request. It thus appears that the physician's principal objection to provide dying patients a futile treatment was not as important to them as other altruistic and self-interested considerations. The result was to adopt conduct that reflects the negative aspect of relational autonomy and the concerns expressed by the proponents of a more individualistic approach to autonomy, namely, that family involvement is not always positive.

VII. The Study Implications

The discussion so far shows that there are areas where physicians conduct their practice in a manner that accords with the legal rules set in the Act, primarily regarding the prohibition on withdrawal of ventilation. However, there are also areas where this is not the case. The study reveals that in some cases, physicians adopt practices that directly contradict the law.²⁶⁹ This is the case, for example, regarding family involvement, where physicians often respect the requests of relatives, even though they have no formal legal status. In other cases, physicians adopt practices that formally accord with the Act but reflect efforts to bypass its strict legal rules.²⁷⁰ This is the case, for example, when physicians develop creative ways to respect the wishes of patients or their relatives to stop ventilation despite the prohibition imposed by the Act.

This yields three interconnected conclusions. First, there is a gap between physicians' practice and views on the one hand and the Act on the other. Second, physicians may consider existing legal rules when making decisions (assuming they are aware of them), but their conduct is not guided solely by these rules. Third, in practice, the impact of the law on physicians when making end-of-life decisions is only partial.

As the study findings reveal, the partial influence the Act has on physicians is the result of several factors. First, the legal rules are inconsistent with physicians' moral views, ethical duties, or professional discretion. As the study shows, physicians may feel morally compelled to follow their personal views, ethical duties, or professional

269. *Id.*; see Rydvall, *supra* note 119.

270. See The Dying Patient Act, *supra* note 161; Steinberg, *supra* note 202, at 552.

discretion, knowingly choosing a path that does not strictly follow the law. Second, the physician's emotions may lead them to disregard the legal rules set by the Act. This is reflected, for example, in going along with a family's request to connect a dying patient to a ventilator without any indication that the patient wants it or is benefited by it. Third, the characteristics of the medical setting make it difficult to apply the legal rules. This occurs, for example, when the physicians have only a few minutes to make a decision about ventilation. Fourth, fears of tort lawsuits and the desire to prevent them create difficulties in following the law. Paradoxically, when physicians appreciate that acting according to the law creates a risk for tort litigation, which is more substantial than the risk involved in not complying with the law, they may choose to infringe the legal rule in order to prevent litigation or at least decrease the risk of its occurrence. This was one of the reasons the physicians stated for respecting relatives' requests to connect the patient to a ventilator, even if they do not have any legal status, and despite the possibility that their request does not reflect the patient's wishes.

These findings lead to the conclusion that the Act is only one factor, among several, that influences the physician's decision-making process about ventilation. Other factors, including physicians' emotional difficulties, moral views, ethical duties, professional discretion, and the fear of future lawsuits may also influence their decision about ventilation.

The factors described above are not the only reasons for the partial impact the Act has on physicians. The Act itself provides a few indications that suggest that some of the legal rules it set are not binding.²⁷¹ An important indication is Article 56, which states that the rules set in the Act do not impose a duty on the physician to provide the dying patient a particular treatment or to refrain from giving the patient a particular treatment that stands in contrast with the physician's values, conscience, or medical judgment.²⁷² A physician who refuses to provide or to refrain from providing such a treatment to the patient can transfer the care of the patient to another physician, according to the procedure set by the director of the medical institution.²⁷³ Another

271. The Dying Patient Act, *supra* note 161.

272. *Id.*

273. See Farber, *supra* note 115; Smedira, *supra* note 148; Gillon, *supra* note 13 (Another indication is the substantial authority an institutional ethics committee is

indication is the absence of explicit prohibitions in the Act against using methods that aim to bypass the prohibition on withdrawal of ventilation.²⁷⁴ As the above discussion shows, this indication was reinforced by the court in the *John Doe* case, where despite the Act's prohibition on withdrawal of ventilation, the court approved a gradual reduction in the ventilator's oxygen level, taking into account that the expected result was the death of the patient.²⁷⁵ Finally, the Act allows—by installing timers on ventilators—a continuous treatment, such as artificial ventilation, to be turned into a cyclic treatment, which the physician can legally stop.²⁷⁶ The reliance on timers show how weak the legal prohibition on withdrawal of ventilation is. It follows that the Act itself enables physicians—at least to some extent—to follow their values, professional discretion, or emotions instead of the legal rules set by the Act.²⁷⁷

The conclusion that there are gaps between physicians' practice and views, on the one hand, and the legal rules set by the Act on the other raises two questions: should society strive to close this gap and, if so, how?

Concerning the first question, a gap between the rules set by the Act and the physician's practice may have several negative implications. First, it should be recalled that the Act is a product of a long process of negotiation among various groups in Israeli society.²⁷⁸ To gain the assent of the Israeli Parliament—the Knesset—liberal and conservative groups had to reach an agreement and a compromise.²⁷⁹ Because the Act includes several rules that gained wide agreement throughout the legislative process, a medical practice that contradicts these rules compromises the democratic process of legislation and, consequently, the principle of the rule of law. Second, one should also remember that discrepancies between the physician's practice and the law do not necessarily serve the liberal approach. As the study's findings reveal, the practice adopted by the physicians may result in the

given by the Act to resolve various conflicts among physicians, patients and the relatives.).

274. The Dying Patient Act, *supra* note 161.

275. See *John Doe Case*, *supra* note 206.

276. The Dying Patient Act, *supra* note 161; see Vardit Ravitsky, *Education and Debater: Timers on Ventilators*, 330 *BMJ* 415 (2005) [hereinafter Ravitsky].

277. Ravitsky, *supra* note 276.

278. The Dying Patient Act, *supra* note 161.

279. See *The Dying Patient Regulations*, *supra* note 243.

infringement of patients' right to autonomy. This was discovered in emergency situations or in situations when the physician respected the family's request regardless of the possibility that it may not accord with the patient's wishes.

A third implication is related to the impact of the gap between law and practice on physicians. This gap may cause physicians to experience feelings of frustration, moral distress, and other negative emotions. This, as we saw, was found with regards to the legal prohibition on the withdrawal of treatment, which prevents physicians from disconnecting the dying patient from the machine even after it is discovered that the patient has already expressed a wish not to have it. A fourth negative implication concerns legal sanctions. When physicians choose a practice that infringes upon a legal rule set by the Act, a legal sanction may follow in the form of a tort law claim, disciplinary procedures or criminal charges. It follows that the existence of a gap between the physician's medical practice and the law may incur personal as well as social costs.

This, we believe, leads to the conclusion that the gap between physicians' practice and views, on the one hand, and legal rules on the other should be bridged. This immediately raises the question of what measures should be taken to minimize the gap. Should the gap between the legal position and physicians' medical practice be minimized through a reform in the law, or should we try to change physicians' practice and views in this area to reflect the legal rules? Answering these questions raises a third one: what role should the law play in the context of medical practice?

When considering these questions, several factors must be considered: the causes of the gap between law and medical practice (e.g., physicians' moral views, the characteristics of the medical settings); the possibility of removing these causes, fully or partially; the costs required to do so; and the possibility of changing the legal rules (taking into account the different views and interests of the relevant stakeholders, particularly those who promote a liberal-secular approach and those who adhere to a conservative and religious position).

Concentrating on the third question regarding the role of law, in our view, an application of these factors to end-of-life decisions regarding ventilation leads to the conclusion that the law should play a limited role in regulating the issue of withdrawal of ventilation. As

already noted, in light of the various bioethical and personal views on this subject, the issue of withdrawal of ventilation raises conflicts and disagreements among different groups (including policy-makers and physicians).²⁸⁰ These disagreements are often intensified by the circumstances of the particular case, the characteristics of the medical settings, and the patient's medical condition. As the findings of the study reveal, under these circumstances, insisting on a strict compliance with the legal rules would result in a gap between the law and physicians' practice. This, as discussed above, has negative implications. Therefore, a legal rule that leaves the issue to the discretion of the physician may be preferable.²⁸¹ In other words, we believe that in the context of withdrawal of ventilation, the law should play a limited role. It should only set the legal framework for making decisions regarding withdrawal of ventilation instead of firmly prohibit it.

As the discussion above indicates, this approach is not foreign to the legislature. Several Articles in the Act enable physicians to apply their moral values and professional discretion regarding withdrawal of ventilation to some extent.²⁸² However, the Act still prohibits, explicitly and firmly, switching off a ventilator when the dying patient depends on it.²⁸³

This leads us to the question about the measures that should be used to minimize the gap between law and the physician's conduct. One option is to adjust the law so it would accord with daily medical practice and physicians' views. Considering the findings of the study, we believe that one measure to close the gap between law and medical practice is to abolish the prohibition on withdrawal of ventilation. The study discovered that physicians perceive the prohibition on withdrawal of ventilation as an obstacle in several common situations in daily practice. Thus, physicians prefer having the option of withdrawal in cases where its legal prohibition prolongs the patient's pain and suffering and prevents the physician from respecting the patient's

280. Gilbar, *supra* note 190.

281. Thus, for example, the law can leave the issue to the discretion of the Israeli medical association, which publishes professional ethical guidelines. It can also be determined that breaching these guidelines may result in disciplinary action (rather than legal proceedings when breaching the Act). Another possibility is to leave the issue to the discretion of institutional ethics committees. *See* Ravitsky, *supra* note 276.

282. The Dying Patient Act, *supra* note 161.

283. *Id.*

wish not to receive ventilation. Moreover, physicians generally perceive the provision of ventilation to a dying patient in the final stage as a futile treatment, and some even see it as abuse. It was also indicated that the legal prohibition on withdrawal of ventilation does not prevent physicians from discontinuing it using various creative methods that are not explicitly prohibited by the Act. Thus, abolishing the prohibition would accord with physicians' views.

The alternative measure to close the gap between law and practice is to change physicians' views. However, this might be difficult or costly, considering the physician's position, which is rooted in moral, personal, and professional beliefs and convictions. Moreover, considering that physicians already differentiate between withholding and withdrawing ventilation, it is questionable whether changing their views is the solution. The problem, so it seems, drives from physicians' negative views toward the legal prohibition on ventilation. Finally, as scholars who support the patient's right to autonomy, we hold the position that a request of a dying patient to stop ventilation should be respected. Therefore, we do not believe that changing physicians' views is the appropriate solution.

We therefore argue that Israeli physicians should be allowed to withdraw ventilation when they discover, after connecting the patient to a ventilator, that he or she expressed a wish—when still mentally competent to make decisions—not to receive life-prolonging treatment or when a patient who is connected to a ventilator changes his or her mind and would like to stop this treatment. Not only does this go along with the physician's moral compass, but it also accords with the main principles set in the Act of respecting autonomy and preventing pain and suffering.²⁸⁴ Moreover, the concern expressed by those who hold conservative and religious views that without the legal prohibition on ventilation, physicians would hasten the death of many dying patients²⁸⁵ is proved in this study to be unfounded. As demonstrated above, the physicians expressed reluctance to perform acts of withdrawal. Thus, it seems that the physicians do not need the law to refrain from withdrawing ventilation. They have their moral views and ethical duties.

284. *Id.*

285. *See* Gilbar, *supra* note 190.

Furthermore, abolishing the prohibition on withdrawal of ventilation is not expected to dramatically change the current legal position. As already noted, the Act allows—by installing timers on ventilators—to turn a continuous treatment, such as artificial ventilation, to a cyclic treatment, which the physician can legally stop.²⁸⁶ Moreover, the Act does not explicitly prohibit the use of creative methods to discontinue ventilation.²⁸⁷ It follows that the legal option of withdrawing ventilation from a dying patient is feasible. Therefore, abolishing the prohibition on withdrawal of ventilation is only expected to change the methods physicians can legally use.

Nevertheless, abolishing the legal prohibition on withdrawal of ventilation may be impossible in the current political climate in Israel, in which the conservative and religious approach receives precedence over the liberal and secular approach.²⁸⁸ Being aware of the current difficulty of amending the legal position, we suggest that the legal prohibition on withdrawal of ventilation be softened through interpretation of the Act in courts. An option that was applied by the court in the *John Doe* case is to allow physicians to gradually reduce the level of oxygen the ventilator produces.²⁸⁹ This judicial interpretation can create the required legal changes and enable physicians to discontinue ventilation.

VIII. Conclusions

Through an empirical study, the article examines the relationship between law and medical practice. It investigates how existing legal rules affect the practice of making decisions about withholding or withdrawing ventilation from dying patients. Although the study

286. See Ravitsky, *supra* note 276. Arguably, a day might come when timers would be installed on each and every ventilator in Israel, which would then free the physicians from the moral dilemma and distress they experience today. Installing timers on ventilators would soften the physician's opposition towards withdrawal of ventilation. The study shows that the physician's main concern is that in withdrawing ventilation, they perform an act, whereas in withholding treatment, they do not. Thus, human agency is an overriding factor in their support of the distinction between withholding and withdrawing ventilation. Installing timers on ventilators would resolve this because it would free the physician from the need to physically switch off the ventilator or disconnect the patient from it. It would also make the conservative and religious moral objections irrelevant.

287. The Dying Patient Act, *supra* note 161.

288. See Gilbar, *supra* note 190.

289. See *John Doe Case*, *supra* note 206.

was conducted in Israel, it provides important insights for law-makers in other jurisdictions regarding the impact of the law and its role.

The central conclusion derived from the study's findings is that legal rules are not strictly followed by physicians when making decisions about withholding or withdrawing ventilation. As a result, a gap between law and physicians' practice is revealed. The study also indicates that several factors lead physicians to adopt practices that are inconsistent with the law. These factors include physicians' moral and professional views, their emotional difficulties, the characteristics of the medical system, and the fear of litigation. Thus, another important conclusion of the study is that the law is only one of many factors influencing physicians' conduct in this area.

Furthermore, the study raises a principal question that arises when research is conducted on the relationship between law in books and law in action.²⁹⁰ When a study, like the one we report here, indicates that legal rules are not applied by those who are required to follow them, law- and policy-makers should be aware that the gap between law and practice might have negative implications. In striving to minimize this gap, they have to decide whether to change the law in the books or educate physicians to follow the law. This question, as discussed above, is closely connected to a more general question of the role of the law in end-of-life decision-making.

Looking more widely at the area of end-of-life, there are issues closely related to withdrawal of treatment—such as physician/family-assisted suicide and voluntary euthanasia—that are still under debate in some Western jurisdictions²⁹¹ and are subject to an ongoing discourse among lawyers, bioethicists, and others. The lesson that can be learned from this study is that, in this area of end-of-life decision-making, the law operates in a particular social context and, as a result, has only a limited influence on physicians' practice. Law- and policy-makers have to consider this and take into account the moral views

290. See Roscoe Pound, *Law in Books and Law in Action*, 44 AM. L. REV. 12 (1910); David Nelken, *Law in Action or Living Law? Back to the Beginning in Sociology of Law*, 4 LEGAL STUD. 157 (1984).

291. One example is English law. See *R v. Ministry of Just.* [2014] UKSC 38; *Nicklinson and Lamb v. U.K.* [2015] ECHR 783; see generally Elizabeth Wicks, *The Supreme Court Judgment on Nicklinson: One Step Forward on Assisted Dying; Two Steps Back on Human Rights*, 23 MED. L. REV. 144 (2015); see generally Elizabeth Wicks, *Nicklinson and Lamb v United Kingdom: Strasbourg Fails to Assist on Assisted Dying in the UK*, O MED. L. REV. 1 (2016).

and practices of those who are closely involved in the decision-making process if they want to create an effective and workable legal framework.

APPENDIX A-THE STUDY'S METHODS IN DETAIL

The findings reported in this article are based on a qualitative study that aspires to examine social phenomena as they are perceived by the people who experience them. The phenomenon this study examined was whether the modes of conduct physicians adopt when making decisions about the provision of ventilation to dying patients, accord with the legal rules set by the Dying Patient Act 2005.

To fulfill the study's aims, data were collected at four different hospitals through semi-structured interviews with physicians who treat dying patients. The inclusion criteria required that the participant be a physician who treats dying patients on a daily basis. Physicians from various medical specialties and different professional ranks were included. The physicians came from various specialties, including internal medicine, oncology, cardiology, nephrology and intensive care. An equal number of male and female physicians participated in the study. Twelve participants were specialist physicians, 8 were heads of units or wards, and two were residents. As for specialties, 5 participants came from internal medicine, 5 were oncologists, 3 specialized in nephrology, 3 were cardiologists, 2 worked as neurologists and one was a hematologist. The participants' characteristics are provided in Table 1.

The study adopted purposive sampling, where participants are recruited because they are a source of rich data that can help the researchers answer the research questions and understand the phenomena they examine. The Israeli Act imposes on physicians the responsibility to determine the patient's wishes and to conduct the decision-making process regarding treatment at the end of life generally and regarding ventilation specifically, so it is important to understand their modes of conduct. Choosing a diverse population is an accepted research method. In this study, this approach helped the researchers examine how physicians from different areas of medical practice address the issue of decision-making at the end of life, particularly in the context of provision of ventilation as a means to prolong the dying patient's life. This enabled the researchers to study the ways the legal mechanisms the Act established are applied in practice.

Another reason for choosing a diverse sample is that the law in this particular area does not distinguish among physicians based on medical specialty. The Act applies to all physicians who practice med-

icine in Israel. The decision to conduct the study in four different hospitals was made because the study aims to examine whether the internal policies of hospitals have an impact on the decision-making process the physicians adopt in practice.

To answer the research questions, the research team developed an interview guide that helped the interviewer question the participants. In the interview, the participants were asked if they notify the patient that she is defined as a dying patient, how they determine the patient's wishes and what the decision-making process is when the patient is legally competent to make decisions and when she is not. The participants were asked about familial involvement and influence on the decision-making process. According to the context of this article, the physicians were also asked to address the issue of artificial ventilation. The interview guide is attached as appendix B.

Data were collected once an institutional ethics approval for the study was granted by the authors' institution and following the approval of the research ethics committees in the relevant hospitals. The participants were recruited in the following manner: First, members of the research team with links to the hospitals that took part in the study identified the physicians who met the inclusion criteria. In the second stage, the researcher who conducted the interview asked the interviewees at the end of the interview to identify other suitable candidates for the study.

Regarding consent to participate, the researcher who conducted the interviews approached the candidates by email and telephone and invited them to take part in the study. The researcher sent the candidates study information sheets and a consent form that provided information about the study. The researcher then set a date for an interview with those who agreed to participate. All the interviews were conducted at the participants' offices. Before the beginning of the interview, the researcher provided the participants details about the study and its aims, and once they gave oral consent, they were asked to sign a consent form. The interviews lasted 40 minutes, on average, and apart from one interview, they were audio-recorded. The candidates' sole reason for not taking part in the study was lack of time.

Data analysis included several stages. It was based on a framework approach, which suits a study whose aims are selected in advance, whose research questions are specific and relatively narrow, and whose time frame is limited. First, the researcher who conducted

the interviews listened to the recordings and read the transcripts to gain a general understanding and to identify the main themes. Some of these themes were selected in advance (for example, the role of the family when the patient is legally competent and when she is not), and some were identified during data analysis (for example, the physician's attitudes towards connecting patients to the ventilator and disconnecting them). These themes were used as the grounds for a thematic analysis of the interviews. Then, at the next stage, every interview was read thoroughly by the researcher who coded it. Every paragraph or several paragraphs were marked as a separate segment based on the selected themes. In the next stage, these segments were sorted and grouped together in sub-categories under the main themes. This process was dynamic, and throughout the process, more themes were identified and created (for example, the attitudes towards futile artificial ventilation). This process helped the researchers understand the various meanings that came up in the interviews. In the last stage, when the analysis of the themes was summed up in writing, the research team discussed the findings and their implications. Disagreements among the three researchers were discussed and most of them resolved. Finally, theoretical, bioethical and legal interpretations were given to the findings.

TABLE 1- THE PARTICIPANTS' CHARACTERISTICS

Participants	Specialty	Gender	Rank
A	Internal medicine	Female	Department head
B	Internal medicine	Male	Resident
C	Nephrology	Male	Unit head
D	Cardiology	Female	Unit head
E	Nephrology	Male	Department head
F	Oncology	Female	Specialist physician
G	Internal medicine	Female	Specialist physician
H	Neurology	Male	Department head
I	Intensive care	Male	Specialist physician
J	Intensive care	Male	Department head
K	Hematology	Female	Department head
L	Oncology	Male	Specialist physician
M	Internal medicine	Female	Specialist physician
N	Neurology	Female	Specialist physician
O	Oncology	Female	Resident
P	Internal medicine	Female	Specialist physician
Q	Oncology	Male	Specialist physician
R	Intensive care	Male	Department head
S	Nephrology	Male	Department head
T	Oncology	Female	Specialist physician
U	Cardiology	Male	Unit head
V	Cardiology	Male	Department head

APPENDIX B- THE INTERVIEW GUIDE

General

-What kind of decisions do you have to make when you treat dying patients?

-How do you make these decisions?

-Do you have discussions with the patient and/or the relatives about life-prolonging treatments? And particularly about ventilation?

-What do you think about withholding and withdrawing ventilation?

The legally competent patient

-What do you do when you have a dying patient and you need to find out her wishes regarding life-prolonging treatments (for example, about ventilation)?

-What you do when the patient's state makes it difficult to find out what she wants?

-Can you share with me a case where you had to find out what the patient wants?

-Do you talk to dying patients about their overall condition and prognosis? Why?

-How do you make decisions about life-prolonging treatment (e.g., ventilation) when the patient is legally competent? Can you share with me one case?

-How do you perceive the role of the family when you need to know what the patient wants?

-Have you encountered disagreements between you and the family, between you and the patient, or among the relatives about life-prolonging treatment? What did you do?

-Ultimately, who has the final word (the physician, the patient or the family)?

The incompetent patient

-What do you do when you have a dying patient who has lost her mental capacity and you need to find out her wishes regarding life-prolonging treatment?

-How do you make decisions about life-prolonging treatment, such as ventilation, when the patient is legally incompetent?

-How do you perceive the role of the family when the patient is legally incompetent?

-Who has the final word in these situations (you or the family)?

-Do you have disagreements with relatives? If yes, how do you resolve them? Can you share one case with me?

-Have you encountered advance directives, or met relatives with a power-of-attorney? What did you do?