

Advance Directives in Israel

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1.1 Introduction

This chapter explores advance directives in Israel, arguing that, paradoxically, the Israeli state's formal legislative instruments to protect the autonomy of terminally ill individuals by empowering them to make decisions about the scope, nature and extent of medical treatment they wish to accept (or to reject) as they approach the end of life, and affirmed their right to die with dignity, have in fact led to the under-regulation of the use of advance directives. The chapter first discusses the legal and political-religious context that led to the enactment of legislation – the Dying Patient (DP) Act¹ – which constitutes the main legal framework for the use of advance directives in Israel.² The main attributes setting the legal framework in which advance directives are incorporated into this law are next explained, followed by a discussion of the state's guidelines for the formulation of advance directives. Finally, the chapter demonstrates how the restrictive nature and the supposed strict regulation of Israeli advance directives have actually led to their under-regulation. Some reasons for this include the practical difficulties posed by the actual implementation of advance directives, the many “shades of grey” faced by healthcare providers when interpreting the law, and legal critiques of, and precedents questioning the DP Act.

¹ Dying Patient Law 2005, *Sefer Hukim* [Book of Laws] 330.

² It is interesting to note that, while the “Dying Patient” Act is the literal translation of the law's Hebrew title, some academic English language articles refer to this law by other forms of translation, such as “Terminally Ill Patient” and “Near Death Patient” Act/Law. See O. Asman and Y. M. Barilan, ‘End-of-Life Medical Decisions in Israeli Law – How Jewish Law Represents a Balance between Principlist and Situationist Approaches to Medical Law’, in N. Emmerich et al. (eds.), *Contemporary European Perspectives on the Ethics of End of Life Care* (Cham: Springer, 2020), pp. 105–15; A. B. Jotkowitz and S. Glick, ‘The Israeli Terminally Ill Patient Law of 2005’ (2009) 25 *Journal of Palliative Care* 284–8.

1.2 Legal, Religious and Political Background Leading to Legislation

Prior to the introduction of the Patient's Rights Law (1996),³ Israel had refrained from addressing the issue of end-of-life care, as evident by its ambivalence towards the introduction and enactment of specific legislation to address the matter. In fact, Israeli penal law perceives euthanasia – even for the sake of preventing suffering – to be an act of killing. Similarly, until the 2005 passing of the DP Act, under penal law, even passive euthanasia – namely, the act of refraining from carrying out actions designed to prolong the life of a DP – which was carried out without the explicit permission of the court constituted an act of manslaughter.

The draft of the Patient's Rights legislation originally included a clause entitled “The Right to Die with Dignity”. That section (originally, section/clause 10 in the preliminary law proposal) reads as follows:

A terminal patient is entitled to [can be understood as ‘having a right to’] die in dignity and in accordance to their viewpoint and belief, and as much as possible, in the presence of a person that the patient requests. The physician and the medical institution will assist in fulfilling this patient's right, and will refrain from [doing] anything that might infringe this right.⁴

However, this section was subsequently removed, supposedly due to opposition from some ultra-orthodox Jewish parties; notably, the final law that was passed did not include any specific reference to end-of-life care.⁵ Indeed, until the enactment of the DP Law – particularly with respect to the matter of prolonging the lives of terminally ill patients – since the mid-1980s and even more so in the 1990s, the main progress made to address this issue was achieved through the courts.⁶ Some

³ Patient's Rights Law 1996, *Sefer Hukim* [Book of Laws] 729.

⁴ Quoted in M. Halperin, “The Dying Patient Law – Past, Present and Future from a Systematic Standpoint” (2019) 51 *Refua Umishpat* [Medicine and Law] 124 [in Hebrew].

⁵ Patient's Rights Bill 1992, *Hatza'ot Hok* [Legislative Bills] 359; C. Shalev, “Reclaiming the Patient's Voice and Spirit in Dying: An Insight from Israel” (2010) 24 *Bioethics* 134. It should be noted that, according to a later article by Rabbi Professor Mordechai Halperin, the author explicitly denies the objection of these religious parties, though he does admit that he was not present in the specific discussions in which it was decided not to include the “right to die in dignity” clause/section. See note 4, p. 125.

⁶ The pivotal influence of the courts during this period is also acknowledged in a document issued by the director-general of the MOH. See Israel MOH, *Treatment of the Dying Patient*, Director-General Circular No. 2/96 (1996).

pivotal cases, such as those of *Tzadok*, *Binyamin*, *Tzadi*, *Gilad*, *Bivas*, *Ploni* (“John Doe”), pushed towards greater acknowledgement of patients’ right to personal autonomy in the context of end-of-life care.⁷

The courts’ decisions regarding these cases should be understood against the backdrop of the “constitutional revolution”, a term often associated with Aharon Barak, the Deputy Chief Justice and later Chief Justice of the Israeli Supreme Court. Chief Justice Barak’s employment of this term suggests his preference for a court activism approach.⁸ This approach gained favour after 1992 when the “Basic Law: Human Dignity and Liberty” was enacted to express and confirm the judiciary’s commitment to upholding the state’s main human rights principles. Thus, the governing premise of Justice Barak and many other Supreme Court justices was that the enactment of this Basic Law had opened the way to the court for further interpretations and applications of this law, in specific realms beyond the original written letter of that law. Indeed, during the years 1992–5, various verdicts in the regional courts and in the Supreme Court had expressed a heightened activism approach, which laid stress on strengthening aspects of dignity and liberty in cases addressed by the courts. In fact, the “constitutional revolution” and its emphasis on the court activism approach were explicitly mentioned in the pivotal verdict of the *Hamizrahi Bank* case of November 1995, a few days after prime minister Yitzhak Rabin was assassinated. Rabin’s murder sent shockwaves across the world, for it held potentially major global political implications; its media reporting was so extensive that it overshadowed the court’s verdict on the *Hamizrahi Bank* case, which attracted scant media coverage at the time.

At any rate, the case of *Miriam Tzadok v. Beit Hae’la* in 1992 is considered fundamental to the end-of-life care issue for a number of

⁷ Motion 759/92 *Miriam Tzadok v. Beit Hae’la and others* (10 June 1992); C.A. Motion 1141/90 *Binyamin v. Dr Vilenski* (1990) 51(3) 187; C.A. Motion 498/93 *Tzadi v. Kupat Holim Clalit* (1993) (unpublished); C.A. Motion 1030/95 *Gilad v. Soroka* (1996) 56(1) 441; C.A. Motion (Tel Aviv) 528/96 *Bivas v. Tel-Aviv Municipality (Ichilov Medical Center)* (1996); C.A. Motion (Tel Aviv) 1513/01 *Ploni [John Doe] v. The Attorney General* (1996); I. Doron and C. Shalev, ‘Between the Patient’s Rights Law and the Dying Patient Law: Advancing Forward or Going Backwards’ (2011) 43 *Refua Umishpat* [Medicine and Law] 25 [in Hebrew].

⁸ Judicial activism may imply different things and indeed has varied definitions. In what follows, I employ the term “judicial activism” to indicate a stance advocating “judicial review” that allows courts an equal say with the other branches of the state – legislature and government – so that the court (and specifically the supreme court) is not merely following the letter of the law.

reasons.⁹ It was the first case regarding end-of-life care that concerned an older person with dementia. The case revolved around the withholding of a feeding tube and raised questions about the authority of healthcare professionals to refrain from offering life-prolonging treatment. Some former cases had focused mainly on the issue of withdrawing ventilator support as death approached. In this case, however, and while still cognitively competent, the patient Ms Tzadok had left clearly written instructions (effectively, directives) requesting that medical staff should refrain from feeding and keeping her hydrated by artificial means, when her dementia had progressed to an advanced stage. The court ruled that although Ms Tzadok was no longer capable of expressing her wishes by the time her case reached the court, her directives – written while she was still cognisant – represented her true desires. It was therefore decided that Ms Tzadok's desires be respected, and that the right to personal autonomy be recognised, in the interests of preventing her further suffering. In accepting Ms Tzadok's written directives, the court not only upheld the principle of personal autonomy as a critical value, but by extension, confirmed the patients' right to refuse life-prolonging interventions. Indeed, the court went even further in applying this value in the context of a non-terminal disease.

Other rulings similarly applied the value of personal autonomy when justifying the withdrawal of ventilator life support for patients with amyotrophic lateral sclerosis (ALS). A landmark case in this respect was the 1996 ruling on the request made by Itay Arad, an ALS patient. Arad had sought the court's permission that he be allowed to be disconnected from a ventilator, once he reached the stage where he was unable to live without requiring the constant support and care of others.¹⁰ The court granted his request, thus upholding his autonomy and dignity, and two years later, his disease having progressed to the stage where he was dependent on medical support to maintain his life, Mr Arad was disconnected from the ventilator, as he had explicitly requested.

Another noteworthy case was that of *Yael Shefer* (1993);¹¹ the verdict in that case was interpreted as permitting the withdrawal of life support, and was subsequently cited in nine different cases, including that of *Arad*.

⁹ Motion 759/92 *Miriam Tzadok v. Beit Hae'la and others* (10 June 1992); See Doron and Shalev, note 7, p. 25.

¹⁰ C.A. Motion (Tel Aviv) 2242/95 *Itay Arad v. Kupat Cholim Clalit* (1996); R. Gilbar, 'Until Breath Ends' (2015) 42 *Hamishpat Bareshet* [Law in the Internet] [in Hebrew].

¹¹ CA 506/88 *Yael Shefer v. State of Israel* [1993] IsrSC 48(1) 78.

Shefer's case concerned a toddler with Tay-Sachs disease, who had, in fact, passed away before the court could publish its verdict. The court had been asked to decide on the issue of withholding various life-sustaining treatments for the toddler. The written deliberation by Justice Elon of the Supreme Court in this case became of importance because of the decision laid down by him. Judge Elon's deliberation was based on both modern Israeli law and the Jewish religious (*Halakhic*) perspective, derived from biblical commandments, and subsequent Talmudic and rabbinic teachings.¹² Indeed, when referring to the possibility of withdrawing ventilators, Judge Elon offered an in principle interpretation of the Jewish religious law that supported this action be taken, if the patient was suffering. Of interest also is that Judge Elon's written deliberation explicitly addressed both types of euthanasia – active and passive. The latter he referred to as legitimate *in principle, including* from the Jewish religious perspective. As we shall see in the following, Elon's religious perspective in the *Shefer* case departs some distance from the religious viewpoint practically fostered in the letter of the law that was enacted more than a decade later.

The aforementioned courts' rulings and deliberations that fostered the principle of personal autonomy in order to allow passive euthanasia to end suffering were mainly written from a secular perspective. Some representatives of the ultra-orthodox parties within the Israeli parliament regarded these rulings as a "step too far"; their understanding of end-of-life care was primarily grounded in values that stressed the sanctity of life, a philosophical and religious standpoint which emphasised a commitment to preserving and saving human life, regardless of the individual's desires. This perspective offers, at the most, quite limited scope and space for recognising human suffering as a legitimate justification for overriding the commitment to the sanctity of life. Due to the complexity of the *Halakhic* law and its interpretations through varied rulings by rabbis with expertise in this law, it is well beyond the scope of the current chapter and its author's expertise to delve into the specifics and nuances of these interpretations.¹³ However, there is no dispute that the *Halakhic*

¹² M. Raz et al., "Dying of 'Old Age' in Israel" (2011) 16 *The European Legacy* 363; Shalev, note 5.

¹³ For a more elaborate discussion about the orthodox (and certainly ultra-orthodox) Jewish perspective and/or the embedded tension in the Israeli legal system between this perception and a liberal-secular viewpoint, see Asman and Barilan, note 2; Doron and Shalev, note 7, p. 25; N. Karako-Eyal et al., "The Dying Patient Law 2005: Law, Ethics and Medical Practice" (2018) 41 *Iyunei Mishpat* [Tel Aviv University Law Review] 185 (in Hebrew); C. Shalev, 'End-of-Life Care in Israel – The Dying Patient Law, 2005' (2009) 42 *Israel Law*

law – certainly from an ultra-orthodox religious perspective – is framed less in terms of regard for autonomy and individual rights, but rather, privileges the principle of the sanctity of life as a fundamental value that (in many of the cases) took precedence over other values. It is also not disputed that for the majority of Israeli Jewish citizens (and the 20 per cent of Arabs residing within Israel), the *Halakhic* law does not play an important role in their perceptions and lifestyle values.

Against this backdrop, in 2000, Rabbi Shlomo Benizri, the Health Minister of the ultra-orthodox Shas political party, convened a committee to establish guidelines for a new law to regulate end-of-life care. This regulation can be interpreted as a backlash against what was considered a “liberal-secular” stance, for its support of most court decisions that acknowledged the rights of individuals to refuse life-prolonging treatment, and for that right to be respected and lawful. Rather than appoint a secular bioethicist, physician, or legal expert, Benizri settled on Avraham Steinberg, a rabbi and physician, as committee chairperson. In a demonstration of his political power, Benizri used his position as Health Minister to appoint an individual with a self-declared ultra-orthodox rabbinical viewpoint as chairperson to a committee that set the legal framework of the DP Act. Steinberg’s committee held discussions for two years before submitting its main recommendations for the suggested law’s framework, eventually leading in 2005 to the enactment of the DP Act. Scholars such as Carmel Shalev have commented on the final version of the legislated DP Act, noting in particular that in substance, this law is conceptualised within a *Halakhic* framework rather than a secular-liberal perspective.¹⁴

1.3 DP Act: Main Attributes

Israel’s DP Act constitutes the main legal framework for advance directives, a legal instrument for a terminally ill patient to explicitly request the extent and nature of medical treatment and interventions at

Review 279; Shalev, note 5; A. Shapira, “The Dying Patient Law – Does It Reflect a Right Bioethical Balance?” (2013) 59 *Refua Umishpat* [Medicine and Law] [in Hebrew]; J.D. Bleich, *Bioethical Dilemmas: A Jewish Perspective* (Brooklyn, NY: Ktav Publishing House, Inc., 1998), p. 1; A. Shaulov et al., “Death Is Inevitable – A Bad Death Is Not”. Report from an International Workshop” (2019) 8 *Israel Journal of Health Policy Research* 79.

¹⁴ Shalev, note 13, p. 279; Shalev, note 5; Shapira, note 13; A. Tichu, “The Dying Patient Law 2005 – The Influence of the Jewish Religion on Euthanasia in Israel” (2008) 1 *Mishpat Refuee Ve-Bioetika* [Medical Law and Bioethics] 107 [in Hebrew].

the end-of-life stage. Patients with a terminal illness are enabled to leave written instructions as to whether they would wish their life to be prolonged (or otherwise) at the point when their suffering becomes unbearable. However, before delving into the details of these directives under this law, it is important to highlight some main attributes and definitions that inform the framework in which advance directives are employed.

A good point to begin with is the definition of the law's goal, as set out in section 1(a) which pertains to "the regulation of medical treatment given to the DP, while striking the right balance between the value of the sanctity of life and the value of a person's autonomy and the importance of the quality of life". Still within the "Goal" section of the law, section 1(b) states that it is "based on the values of Israel as a Jewish and democratic state, as well as on core values in morality, ethics and religion". Thus, in two respects, the DP Act resonates quite well with its legal and political background, as previously described. First, the DP Act acknowledges the tension between the so-called liberal secular viewpoint, which emphasises individual autonomy and quality of life (i.e. where suffering is unbearable to the point that the patient cannot be said to enjoy any quality of life), against the more "religious" perspective which cherishes and privileges the principle of the sanctity of life. Second, the legislature explicitly states that religion (in particular, Judaism) constitutes an important foundation of the law, in line with the reason for which the Steinberg's committee was appointed in the first place.

Following on from the aforementioned tension is the matter of the very definition of a DP according to this law, which distinguishes between two types of DP: a DP and a DP in the "final stage". Section 8 of the law defines a DP as originating from "a patient suffering from an incurable medical problem with a life expectancy of *no more than six months*, even with the provision of medical treatment" [emphasis added]. In contrast, a DP in the "final stage" refers to "a patient with acute systems failure [of his/her body] who, even with the provision of medical treatment, has a life expectancy of *no more than two weeks*" [emphasis added]. Furthermore, the law distinguishes between a "competent" DP and an "incompetent" DP, the determination of which both fall under the jurisdiction of this law. Competent DPs possess adequate mental and cognitive capacity¹⁵ to autonomously reach an informed decision, as well

¹⁵ Under the DP Act, a person is considered competent if s/he (1) has reached the age of seventeen, (2) is able to express his/her will, (3) has not been declared incompetent, and

as having the ability to communicate that decision to medical staff. By contrast, the incompetent DP is without the mental or cognitive capacity to reach an informed decision, or may be unable to communicate their decision to medical professionals. While both a DP and a DP in the “final stage” may choose not to prolong their life, the law is clear that accompanying treatment and nourishment can be withheld only from a DP who is in the “final stage” of life, as will be discussed later. Given that a DP in the “final stage” refers to a patient with acute systems failure of his/her body (also known as “acute multi-organ dysfunction”), for all intents and purposes “final-stage” DPs lack the capacity to express their “choice”, since they are usually sedated, a state which implies that they cannot, and therefore do not conform with the definition of “competency”, as defined by the DP Act (see note 15).

Sections 9–10 of the law require that a senior attending physician explain to the patient their terminal condition, and to ask the patient how they wish to proceed, should the physician decide that the patient’s condition conforms with the DP status as previously defined. In the event that the patient is already incompetent, whether as a DP or if they are DPs in the “final stage”, the physician will contact the patient’s family and explain the situation to them.

Israel’s legal definition of a DP is quite limited, as it does not extend to the inclusion of patients with chronic illnesses yet without a clear prognosis, such as dementia or ALS. Such a narrow definition seems to be in conformity with more orthodox religious standpoints that regard the sanctity of human life to be a fundamental religious and philosophical principle – a key foundation on which the DP Act rests. The narrowness of this definition prompts the question of autonomy for patients who fall outside the jurisdiction of this law: what rights can they exercise in terms of their ability to fulfil their desire not to have their lives prolonged? This is especially pertinent in instances where patients lack the ability to express their choice (due to incapacitation arising from their disease) since their advance directives cannot be followed, as they do not fit the letter of the law as DPs.¹⁶

(4) is not excluded from the assumption of legal capacity (section 3). There is a statutory presumption that one is competent (section 6), unless otherwise determined by the responsible physician based on a reasoned and documented medical decision (section 7).

¹⁶ Non-DPs who are adults (i.e. age eighteen and above) and who do have the capacity to express their choice and are not deemed incompetent for mental or cognitive reasons may refuse to receive treatment, and their choice will be ultimately respected since the Patient’s Rights Law recognises the right of a competent and fully capacitated adult

Yet another important attribute of this law concerns the forbidden and allowed actions that may or may not be taken in weighing the decision whether to prolong (or otherwise) the life of a person deemed to be either a DP or a DP in the “final stage”. For both categories of patients, section 19 of the law explicitly forbids euthanasia, which is understood as “an action aimed to kill or that its probable result will lead to death”. Section 20 also explicitly forbids physician-assisted suicide. In defining euthanasia as actions taken in the knowledge that the *probable* result will lead to death, Israeli law extends the scope of activities defined as euthanasia. For example, administering morphine in such dosages that will likely kill the patient might be interpreted as an act of euthanasia, even if the intention is to provide comfort and to ease the patient’s pain.

The DP Act not only forbids these extended forms of “euthanasia”, but also strongly mandates the conditions and manner in which “passive euthanasia” may take place. The legislature has placed significant limits on non-life-prolonging actions, even if they do not involve performing actions intended to bring about the death of the patient (e.g. lethal injection, orally administered poisonous pills). A major restriction, in this respect, is that in some medical contexts, the law does not permit certain actions of withdrawing or withholding treatment. Withholding and/or withdrawing treatment are the main actions in which “passive euthanasia” takes place, and the Israeli legislature has forbidden the withdrawal of a “continuous” treatment (e.g. ventilators). In fact, the distinction between “continuous” and “cyclical” treatments in the DP Act arises from the fact that withdrawal of continuous life-sustaining treatment is prohibited. The rationale here is that a cyclical treatment (e.g. dialysis, chemotherapy) can/could be not renewed; thus, stopping such treatment is not regarded as the withdrawal of an existing treatment, but rather as withholding the next or new cycle of treatment.¹⁷

That being said, the Israeli DP Act does allow for the withdrawal and withholding of nourishment (feeding and, in case of severe suffering, or

patient to refuse treatment. Depending on the particular circumstances, such refusal may be delegated by the attending physician to the ethics committee (established as part of the Patient’s Rights Law).

¹⁷ Originally, when drafting the DP Act, the intention was to employ the use of ventilators with timers, so that this sort of treatment could be withheld, once the cycle set on the timer finishes. However, in reality, timers were not employed on ventilators, rendering this type of medical treatment as “continuous” or “ongoing” rather than “cyclical”. For an interesting discussion about timers and ventilators in the context of the DP Act, see V. Ravitsky, ‘Timers on Ventilators’ (2005) 330 *BMJ* 415.

harm hydration), palliative care, and secondary/accompanying treatment from incompetent DPs in their “final stage”. In an article published about the *Halakhic* law basis for the DP Act, Rabbi Steinberg outlined the justification for allowing such exceptions in cases where patients have reached the “final stage”.¹⁸ Rabbi Steinberg draws on key *Halakhic* rulings to argue that refraining from giving the aforementioned treatments is allowed, in situations where three or more systems in the human body have failed, and it is clear from a medical perspective that death is inevitable sooner than later. As it stands, the DP Act defines DP patients in the “final stage” as patients with “acute systems failure [of his/her body]”, and it is clear that this definition finds resonance with *Halakhic* stipulations that there must be failure of three or more systems in the human body. Rabbi Steinberg’s distinction between “final stage” DPs and DPs not in the “final stage” allows for the withdrawal of particular treatment in the DP Act, in accordance with pivotal *Halakhic* rulings.

Interestingly, the DP Act departs from general definitions of the age of consent in a manner distinct from the general legal system. The DP Act allows people from the age of seventeen to autonomously decide whether they wish to accept or reject life-prolonging interventions, as opposed to the general age of consent (and adulthood) in the Israeli law which is legally understood to be when the individual reaches eighteen years of age. This stipulation is relevant for both competent and incompetent DPs (see sections 5 and 14).¹⁹

Another interesting facet of the DP Act that has ramifications for the employment of advance directives is section 56 of the law that permits individual doctors to declare themselves conscientious objectors. This status permits doctors to withdraw from any involvement in the enactment of an advance directive (which will be discussed in further detail in the next section). Under these circumstances, the physician is obliged

¹⁸ A. Steinberg, “The Halakhic Basis for the Proposal of the Dying Patient Law” (2003) 18 ASSIA [Jewish Medical Ethics] 3–4, www.daat.ac.il/daat/kitveyet/assia/habasis-2.htm [in Hebrew].

¹⁹ It is interesting to note that, as part of the preparations process of the DP Act, in a joint meeting of two Knesset (Israeli Parliament) committees – the Welfare and Health Committee and the Law and Justice Committee – it was stated that there were no disputes regarding the lowering of the age of adulthood for this particular law to the age of seventeen. Some participants did raise questions as to the minimal age of mandating that the choice of adolescents under the age of seventeen should be respected and in what circumstances. See Joint Session of Knesset Committee on Welfare and Health and Knesset Committee on Law and Justice – Protocol No. 12 (22 November 2005), http://fs.knesset.gov.il/16/Committees/16_ptv_131323.doc [in Hebrew].

to refer the patient to another physician who is able to respect the patient's choice.

Finally, the law stipulates that the default assumed decision concerning whether a DP wishes to accept or reject life-prolonging treatment is that they would wish to prolong their life. However, according to the law, a DP's wish should be equally respected, as much as possible, regardless of whether they choose to prolong their life or not.

1.4 DP Act: Advance Directives

Advance directives are one mechanism for informing medical staff of the wishes of an incompetent DP regarding the manner in which they should be treated, within the legal framework set by the DP Act (sections 5, 14). The law also stipulates other alternative mechanisms for achieving this end, including assigned durable power of attorney by the patient (when still competent) to a close relative, an institutional or national committee defined as within the law. The latter is particularly relevant in cases where there are disputes, such as between parents of a minor or between two close family members in instances where the patient did not leave an advance directive. In the absence of these mechanisms, a final mechanism is a decision by a senior attending physician, based on a close relative's explicit declaration of the patient's expressed wish to prolong or end their life.²⁰ This latter option was intended as a last resort when all other options were either unavailable or inapplicable. However, as we shall see, this mechanism was actually applied more frequently than originally expected, at least according to the letter of the law.

Before delving into the manner in which advance directives are completed, it should be noted that, under sections 34(a) and 39(a) of the law, both advance directives and an assigned durable power of attorney by the patient to a close relative are limited for a period of five years, and must be renewed every five years by the patient in order to maintain validity. For certain patients (e.g. patients with dementia), the renewal of advance directives is practically impossible, once the patients' cognitive and/or

²⁰ To a certain extent this alternative mechanism for deriving the patient's choice in the absence of a clear statement by the patient (whether orally or as an advance directive) resonates with the idea of "consent by next of kin proxy". However, in the DP Act, the close relative does not have a formal legal standing for consenting or not as a proxy for the patient. Rather, it is the attending physician's decision based on the close relative's declaration, if the physician does not deem the relative to be in a potential conflict of interest with the incompetent or incapacitated DP.

mental condition renders them unfit to make an informed decision. Advance directives completed five years previously cannot be renewed, and will become invalid once more than five years have passed since they were originally completed or renewed.

Advance directives are required to be written on a specific designated form which, once completed, must be signed by the patient and two witnesses, and then mailed to the MOH (sections 32, 44), where it is then placed in a national registry, which is designed to record all submitted advance directives in Israel. The form may be completed by a person defined as a DP (while still competent), but it could also be filled out by a healthy person before becoming a patient, let alone a DP (section 31). This form includes thirteen specific actions pertaining to not prolonging the life of an incompetent DP, and eighteen such particular actions for a DP in the “final stage” (of which the first thirteen actions are similar to those available for DP not in the “final stage”). In other words, the scope of legally recognised and applied advance directives is limited to these particular possible actions for not prolonging the DP’s life. As noted earlier, the default assumption of the law is that people wish to prolong their life as long as possible (although a DP’s decision in this regard should be equally respected whether they want to prolong their life or otherwise). Accordingly, the advance directives mechanism used under the DP Act is formulated in such a way that healthy people or patients (while still competent) must specify for each available action whether they wish to refrain from having that action taken.

Furthermore, the specified actions are quite particular. For example, the person filling out the advance directives form cannot simply state that they wish to refrain from having any form of resuscitation. There are five different actions pertaining to resuscitation, only one of which is defined as “performing resuscitation in any possible way”. Other specified actions of resuscitation include, for instance, providing resuscitative medicine, performing defibrillation, and inserting a tracheal tube. Other actions that do not pertain to resuscitation include the following:

1. Being hooked to a ventilator
2. Starting a dialysis treatment and determining whether to continue treatment if it is futile
3. Performing large surgical operations (e.g. amputation of a leg or arm, removing an internal organ)
4. Performing small surgical procedures (e.g. amputation of a finger)
5. Performing radiations for a malignant disease

6. Inducing chemotherapy for a malignant disease
7. Administering antibiotics in a situation of severe sepsis that cannot be treated by usual antibiotic treatment
8. Conducting diagnostic tests (e.g. blood, X-ray)

Treatments that individuals may choose to refrain from (or not) *only* in the case of becoming a DP in the “final stage” include the following:

1. Regular (accompanying) treatment such as antibiotics or transfusion of blood and its products
2. Treatment for a secondary disease, such as the provision of insulin for a diabetic patient
3. Use of a feeding tube (nutrition)
4. Pushing of fluids (hydration)
5. Palliative care

Finally, it is interesting to note that, as part of the advance directives form, future incompetent DPs will have an opportunity to define the physical and/or cognitive conditions that for them would amount to “unbearable suffering”, and which would cause them to wish to refuse further life-prolonging treatment. In this section of the form, built-in options include conditions that are not necessarily terminal, and certainly do not comply with the legal definition of a DP, such as severe dementia or quadriplegia. Given that these particular options do not comply with the lawful definition of the DP, they cannot then legally be directly applied by the medical staff, merely on the basis of their stipulation on the form. Rather, these built-in options in the official advance directives forms are at worst, simply moot, or at best, might be used as a basis for appealing to the court; notably, the court, in turn, is obliged to act within the boundaries set by the DP Law. It is therefore unclear to what extent (if any) such personal definitions of what constitutes “unbearable suffering” may be applied in practice, given the narrow definition of a DP, as stipulated under the law.

1.5 Discussion: Over-regulation Leading to Under-regulation in Practice

A key feature emerging from the description of the Israeli DP Act is its extensive regulation in general, and specifically with respect to advance directives. Such extensive regulation also expresses the quite narrow boundaries of practically allowed passive euthanasia in Israel and their

corresponding advance directives. This narrowness can be attributed to both the definition of the DP and the limited actions allowed to be taken in order to comply with the patients' stated desire that their life should not be prolonged.

In fact, this extensive regulation – with its emphasis on the limited scope of allowed actions that will not prolong a DP's life, including in the advance directives form – is in stark contrast to the manner with which end-of-life care was handled by the courts before the passing of the DP Act. As previously noted, in the absence of a general official regulation prior to the enactment of the DP Act, the courts simply ruled on a case-by-case basis. No less importantly, these rulings generally covered a wider diversity of patients, including those who did not suffer from terminal illnesses (e.g. dementia, as in the case of Miriam Tzadok), or alternatively, did suffer from a terminal disease but did not have the precise "date of expiry", that is, that the patient was expected to pass away within six months of receiving the prognosis, as required by the DP Act.

Similarly, these courts' verdicts allowed a wider scope of actions for not prolonging the life of patients than the DP Act permits. For instance, this law explicitly forbids any individual from disconnecting a DP from a ventilator, or the withholding of tubal feeding or liquid pushing, except for DPs languishing in their "final stage". In contrast, as already discussed, prior to the DP Act, the courts allowed the disconnection of dying persons from ventilators upon the patient's request (including any written instructions in advance), as well as confirming requests for artificially administered nourishment and liquids to be withheld from patients without a clear life expectancy of two weeks, at most.

Moreover, a gap also exists between the law's presumption to represent a so-called Jewish religious perspective, and the particular interpretation of this perspective by Justice Elon, prior to the enactment of the law. As it may be recalled, Justice Elon's interpretation – also based on *Halakhic* law and rulings, as was the DP Act – nevertheless did not reach the same conclusion, that the *Halakhic*-inspired definition of a DP should be contingent upon a specific time frame (i.e. the up-to six months' life expectancy prognosis). In addition, and again in stark contrast to the DP Act's underlying interpretation of the *Halakhic* law, Justice Elon acknowledged the possibility (in principle) that in the case of severe suffering, DPs could be disconnected from ventilators. This gap is an indication of the complexity and multifaceted nature of the *Halakhic* law, and undermines its somewhat monolithic representation, when it was driven and advocated by the political power of the ultra-orthodox political parties.

Against the backdrop of this observed contrast between the DP Act and many former courts' rulings, some legal experts have argued that precisely because of the law's limited inclusion of patients that it covers, it is entirely possible for different individual interpretations of the law. Instead of the assumption that patients who are not covered by the law are not allowed to request that their lives should not be prolonged (including through advance directives), the suggested interpretation seems to run in the opposite direction. According to some legal experts, this suggested interpretation could allow the courts to revert to the case-by-case rulings that were the norm prior to the passing of the DP Act, since this law (presumably) does not apply to patients who are not covered under its jurisdiction. Such an interpretation also emphasises the right to autonomy, which had been upheld in the Patient's Rights Law, as well as the general spirit that celebrated patients' autonomy (and which characterised most of the courts' rulings), before the DP Act was enacted.²¹

Fundamentally, this interpretation serves to illuminate the unbalanced manner in which the law addresses the tensions between a liberal-secular perspective and a more religious standpoint in favour of the latter, as already noted in this section, and at the end of the "Legal, Religious and Political Background Leading to Legislation" section.²² Admittedly, in practice, it appears that this interpretation has not secured the support of the courts.²³ Hence, the law's framework regarding the definition of a DP, as well as the allowed and forbidden actions in order to refrain from prolonging life was upheld by the courts, regardless of whether or not the patient was a DP, as stipulated by the DP Law.

Nevertheless, this interpretation reveals the paradoxical possibility that the extensive regulation employed by the law could effectively lead to limiting its application (i.e. under-regulation). On the one hand, there is extremely restrictive regulation regarding the definition of a DP, and the limited permissible actions that may be taken to prolong their life (as demonstrated in previous sections), all of which originate from and are influenced by a particular and strict religious standpoint. On the other

²¹ Karako-Eyal et al., note 13, pp. 185–252; Shalev, note 5, pp. 134–44; A. Tichu, "The Dying Patient Law 2005 – The 'Right Balance' Formula between the Sanctity of Life and Autonomy as well as Quality of Life" (2006) 35 *Refua Umishpat* [Medicine and Law] 32 [in Hebrew].

²² Doron and Shalev, note 7, p. 25; Shapira, note 13; Tichu, note 14, p. 107.

²³ Gilbar, note 10; Shalev, note 5, pp. 134–44; Tichu, note 14, p. 107.

hand, there is the more liberal and secular legal perspective, which undermines the restrictive nature of the DP Act, as evident in its suggestion that precisely because of the narrow definition of DPs, the law holds little relevance for many patients. These legal experts suggest therefore that for patients who do not meet the narrow definition of DP, decisions regarding end-of-life matters should be delegated back to the courts, while not binding them to the letter of the DP Act.

In fact, although this particular legal interpretation remains underutilised by the courts, other aspects concerning the application of the DP Act already reveal its under-regulation in practice. While these aspects are supposedly varied, I argue that – at least to a certain extent – they echo the same tensions between a law that is substantively grounded in religious philosophy, and in its praxis, which is influenced by medical professionals and more secular perspectives of patients and their families. At the very least, the latter side of the tension leads to the under-utilisation of different aspects in the restrictive regulation embedded within the DP Act, and could ultimately lead to the very undermining of this regulation. In other words, such under-utilisations of the DP Act can be interpreted as an under-regulation of it in practice.

Specifically, the discussion here briefly addresses three such aspects: (1) practical difficulties in implementing advance directives; (2) “shades of grey” in healthcare providers’ interpretation of the law; and (3) other legal decisions and interpretations undermining the regulation set by the law.

As evidenced by the conclusions of two studies conducted approximately ten years after the enactment of the DP Act, advance directives have rarely been submitted by the potentially relevant population. One study, based on official records of the Ministry of Health, found that as few as 3 per cent of older people had completed advance directives forms.²⁴ Another study, based on a random sample of 720 people over fifty years of age, found that only 4 per cent of the respondents indicated they had written advance directives, and only 5 per cent had appointed a durable power of attorney.²⁵ Recall if you will that completion of the advance directives form and the appointment of a durable power of attorney were

²⁴ P. Shvartzman et al., “Advance Directives – The Israeli Experience” (2015) 49 *Journal of Pain and Symptom Management* 1097.

²⁵ N. Bentour et al., *Knowledge and Attitudes of GPs and the General Public towards End-of-Life and Palliative Care* (Jerusalem: Myers, JDC & Brookdale Institute, 2016), <https://din-online.info/pdf/mb28.pdf> [in Hebrew].

supposed to be the main mechanisms through which future incompetent DPs could ensure that their wishes would be respected within the boundaries of the law. Yet, if the low proportion of research respondents who employed these mechanisms in the two aforementioned studies reflect the overall reality, then the main regulative vehicles employed by the law for achieving this end appear to be considerably under-utilised. Furthermore, it would seem that the “last resort”, that is, the most under-regulated mechanism, might be the most favoured, possibly against the spirit of the highly regulated law. In the absence of any written documentation, the option for a senior attending physician to act on the best considered decision – on the basis of a declaration made by a close relative that the patient did not want to receive life-prolonging treatment – becomes the most potent mechanism.

In seeking to explain the under-utilisation of advance directives, the studies concluded that low public awareness about DP directives and cultural-religious values represented possible factors underlying their reasoning. Both studies emphasised the need to increase the general public’s awareness of the purposes and benefits of advance directives. In fact, the second study (with a random sample of 720 people from the general public), found that only seven respondents (1 per cent) had been contacted by a healthcare provider to discuss their preferences for end-of-life care, and almost half of the respondents (43 per cent) thought that the mass media did not offer sufficient information regarding end-of-life care choices.²⁶

In terms of the influence of cultural-religious values, the majority of respondents (73 per cent) in the second study offered the view that from a Jewish-religious perspective (not necessarily reflecting their own viewpoint and certainly not based on expertise in *Halakhic* law) every effort should be made to preserve a life. A small minority of respondents who identified as religious or ultra-orthodox were more likely to deny the need for advance directives,²⁷ thereby echoing yet again the unresolved tension leading to the under-regulation of the DP Act: in this case, a stricter religious proclivity that is embedded in the law, but in actuality, a viewpoint not shared by the majority of Israelis. Furthermore, it has been suggested that at the very least, the lengthy advance directives form contains too much legalese and medical terminology, and that the

²⁶ Ibid.

²⁷ Ibid.

complexity of the form makes it difficult for laypersons to comprehend.²⁸ This factor may help to explain its low utilisation.

Another practical difficulty appears to stem from the absence of discussion and communication about end-of-life preferences. Some studies carried out among staff of nursing homes in Israel found that staff members were generally unaware of residents' preferences for their end-of-life care.²⁹ These studies also revealed an overall lack of communication and support resources to facilitate discussions around such care, and which would include conversations with patients about their wishes for end-of-life care. The conclusions of another more recent study, focused on hospital staff, echoes these findings, certainly insofar as lack of sufficient communication with patients regarding their end-of-life care. Therefore, these studies highlight additional barriers to the implementation of advance directives, while stressing the under-regulation of the law – particularly its advance directives mechanism – in practice.³⁰

With respect to the shades of grey in healthcare providers' interpretation of the law, at least some elements of the DP Act that are supposedly strictly regulated are not necessarily so, despite being very thoroughly detailed. For instance, the very definition of a DP includes the requirement that the patient has a prognosis of six or fewer months to live. But this raises the question of what happens if – according to the medical literature – the patient receives a prognosis of six- to eight-months life expectancy; how should the physician interpret this range when deciding whether this patient should be deemed a DP? Similarly, let us take for instance, an individual with early-stage dementia, who, while still competent, and wishing to avoid the poor quality of life that is projected with the progression of this disease, completed an advance directive requesting that physicians refrain from all possible actions denoted on the form, including being administered antibiotics when in the “final stage”. If this person is hospitalised due to acute pneumonia, where it is uncertain whether the pneumonia can be successfully treated by currently available

²⁸ Shalev, note 13, p. 279.

²⁹ R. Nissanholtz-Gannot et al., *The Dying Patient Act – The Letter of the Law and Implementation of the Law* (Jerusalem: The Smokler Center for Health Policy Research, Myers-JDC-Brookdale, 2017); A. Shaulov, *Preparation for End of Life in Nursing Homes at Jerusalem District* (Jerusalem: Hadassah Medical Center, 2012) [in Hebrew]; A. Zigdon and R. Nissanholtz-Gannot, “Barriers in Implementing the Dying Patient Law: The Israeli Experience – A Qualitative Study” (2020) 21 *BMC Medical Ethics* 126.

³⁰ Karako-Eyal et al., note 13, pp. 185–252.

antibiotics, but without which the pneumonia will possibly cause their death within seven to ten days, how should the medical staff interpret their condition? Should they view the patient's condition as a DP in the "final stage", based on the possibility of pneumonia being acutely terminal, or just as a person with dementia, who is not considered as a DP, let alone a DP in the "final stage"? In the former scenario, the law allows physicians to withhold different medical treatments, including antibiotics. Such a case is hardly clear cut as high dosages of antibiotics may resolve the acute pneumonia, thereby returning the patient to their previous state, as persons with dementia who are not considered to be DPs. The physician is placed in the difficult position whereby s/he is required to make a clear-cut decision on whether the pneumonia is terminal, despite the inherent uncertainty as to whether it is treatable. Thus, these two examples again illustrate how the very specificity of a law that is mainly grounded within a particular and quite restrictive religious cosmology contradicts the uncertainty of some diseases, and might actually lead to problems in interpretation. That the law allows room for clinical discretion in these matters potentially undermines the regulative framework set by the law.

Although the Israeli MOH has issued guidelines for Implementing the Dying Patient Law in 2008, which summarise key provisions of the law and provide instructions to healthcare practitioners on the implementation of advance directives, a study conducted in 2014 found that many physicians remained unaware of the specifics of the law.³¹ The majority of physicians surveyed could not provide the correct definition of a DP or the age of competency under the law. This suggests that the complexity and specificity of the law may cause difficulties in its implementation; in other words, stricter regulation (and possibly over-regulation) is, paradoxically, leading to under-regulation.

Finally, a third aspect of this paradox is from a judicial perspective: namely that other legal decisions and interpretations may undermine the regulations set out in the law. In 2014, the court addressed the matter of the legality of a "workaround" suggested by the attorney general to circumvent the restrictive scope of the law. The case concerned a patient with ALS who requested that they be allowed to be disconnected from a ventilator.³² The employed workaround was that, instead of physically

³¹ D. Doron et al., "Israeli Dying Patient Act: Physician Knowledge and Attitudes" (2014) 37 *American Journal of Clinical Oncology* 597.

³² C.A. Motion (Tel Aviv) 16813-11-14 *Ploni [John Doe] v. The Attorney General* (2014).

disconnecting the patient from the ventilator, the percentage of oxygen in the ventilator was gradually decreased until it reached the normal rate in the air (21 per cent), which would not sustain the life of the DP in this case. Here, the court simply confirmed the attorney general's suggested workaround to be lawful. Still, in granting the patient's request, the ruling is essentially at odds with the DP Act in at least two respects.³³ First, this ruling effectively (even if not literally) recognised an ALS patient as being a DP, even though the patient clearly did not have a prognosis of a life expectancy of less than six months. Second, the verdict essentially undermined the legally established principle that non-cyclical treatments should not be stopped or withdrawn. To be sure, this court's ruling is not considered an official legal precedent, as it was issued by a lower court and, therefore, has no binding force for future court verdicts. However, this case cogently demonstrates how the strict regulation embedded within the law has led even the Attorney General of Israel to support the undermining or under-regulating of the law in practice, even if this pertained only to a single case. I would also suggest that this case echoes the same tension between a law that is grounded in strict religious faith, and its actual praxis, that was influenced by the less religious perspectives of patients and their families. In this case, there was an attempt to resolve this tension, but had the tension not existed, the attorney general would not then have needed to resort to an action that undermined the letter of the law.

1.6 CONCLUSION

Israel represents a particularly interesting case study with respect to the legal framework and its implementation insofar as advance directives are concerned. The Israeli case highlights how the interplay of politics and religion may be highly influential in the formulation of the legal framework for advance directives. Such formulation is manifested in relatively restrictive and highly regulated advance directives, certainly when compared to the courts' rulings prior to the enactment of the DP Act. As this chapter has demonstrated, in practice, this restrictive and highly regulated form of advance directives paradoxically leads to an

³³ Roy Gilbar discusses this case thoroughly and offers a robust critique about the verdict in this case, which goes well beyond my critique here. See Gilbar, note 10.

under-regulation of those very same directives. Unfortunately, as long as Israeli politics are plagued by a disproportionate power for religious political parties (as demonstrated in the case of Steinberg's committee appointment and its influence on the phrasing of the DP Act), it would seem that the core reason underlying and leading to this paradox is largely unresolvable.