

RESEARCH REPORT

The Dying Patient Act – The Letter of the Law and Implementation of the Law

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The study was initiated with the assistance of a grant from
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Related Myers-JDC-Brookdale Institute Publications

Bentur, N.; Laron, M.; Azoulay, D. and Oberman, A. 2015. *Palliative Services in General Hospitals and Geriatric Medical Centers in Israel*. RR-704-15 (Hebrew).

Bentur, N and Resnizky, S. 2009. *Spiritual Care in Israel: An Evaluation of the Programs Funded by the UJA-Federation of New York*. RR-526-09.

Bentur, N.; Sternberg, S.; and Shuldiner, J. 2015. *Assessing the Quality of End-of-Life Care for Older Persons with Advanced Dementia Living in the Community*. RR-652-15 (Hebrew).

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Executive Summary

1. Background

Technological advances in recent decades have increased the treatment options for many patients who otherwise would not have survived. Nevertheless, ethical issues often arise regarding the use of technology and its less desirable outcomes. On the one hand, technology can provide life-extending treatment for seriously ill patients, while, on the other, delaying death can cause suffering, pain and very poor quality of life. The treatment of patients at the end of life is an issue that the entire developed world is grappling with. The accepted approach in the Western world is that individuals have the right to die with dignity, without losing their autonomy and their right to make life-and-death decisions. However, treatment at the end of life raises serious ethical dilemmas and countries vary in how they balance the patient's autonomy with other values, such as the sanctity of life and quality of life.

There are also practical differences in the way that individuals exercise their right to express their preferences about end-of-life care. Many studies have shown that frequently during end-of-life care, there is inadequate or no information at all about the patient's wishes.

One of the tools that is being increasingly utilized to improve the ability of the health system to take account of the wishes of terminal patients is the advance directive (AD), also known as a living will or advance care planning. This document sets out the patient's wishes so that they are available to the family and care providers when the time comes to make end-of-life decisions, if the patient is no longer competent to make decisions. The document can also be used to help patients cope with their condition and think about the end of life, and it can promote good communication between the patients and their care providers and between them and their family. This can help family members and care providers to make decisions that are in keeping with the patient's wishes when the time comes.

In recent years, many countries have passed legislation that prescribes rules for end-of life care. The Netherlands, Belgium and Luxembourg, for example, permit active euthanasia, while Switzerland allows assisted dying. Germany and France are among the countries that allow reduced medical intervention if the patient wishes to end his life.

In the United States, federal law does not provide for euthanasia or assisted suicide and the conventions are in the hands of the individual states. In 1997, Oregon was the first state to allow physician-assisted suicide in law. At present, assisted suicide for the gravely ill is legal in specific circumstances in Washington State and Montana.

In Israel, the Dying Patient Act was passed in 2005 and it came into effect in 2006. It is based on the values of the State of Israel, which is a Jewish and democratic state, and takes into account a range of religious and traditional beliefs and ethical values, such as the sanctity of life, the quality of life, the prevention of pain and suffering, and the principal of autonomy.

One of the most significant changes that the law has introduced is that it enables individuals to prescribe the care to be provided at the end of life while they are still healthy, fully competent and capable of understanding their condition and make decisions, and does not take this possibility away from them at the end of their lives. In addition to setting the framework for respecting the patient's preference at the end of life, the law also stresses the obligation of the health system to offer the dying patient palliative care and provide support to family members.

The Ministry of Health (MOH) has determined several procedures for implementing the law and these were published in 2008 and 2015.

Since the law was passed, rather than witnessing its widespread implementation, we are seeing difficulties and barriers to its implementation. Some of the challenges in implementing the law in Israel are not unique to this country. The literature both here and abroad presents various challenges in addressing and providing end-of life care and raises ethical, moral, religious and ideological differences. Among those that appear in the literature:

- ◆ The objective difficulty of dealing with someone's death, particularly in cases and communities where the subject of death is taboo
- ◆ The tension between the need to allow an individual to make the decision and the pressure sometimes applied by the family
- ◆ The lack of knowledge, preconceptions, and lack of awareness among the public and patients
- ◆ The lack of tools and resources to encourage people to address the issue.

The consensus among those engaged in this field is that the law is scarcely implemented. It is important to examine the problems that are impeding implementation of the legislation.

2. Study Goals

The study goal was to examine the challenges facing implementation of the Dying Patient Act, focusing on the community setting. The study was intended to identify the reasons for the difficulties in implementation and assimilation of the law. The study was also intended to indicate ways of coping with these challenges so that the rights prescribed in the law are better exercised.

Specifically the study goals were:

- ◆ To review efforts to implement the law in the community, hospitals and nursing homes
- ◆ To identify the barriers to assimilation of the legislation from the perspective of senior figures in the health system, care providers in the field and activists outside of the health system (e.g., heads of NGOs working in this area)
- ◆ To learn how the above individuals perceive ways to improve application of the law, particularly with regard to end-of-life care in institutions.

3. Study Design

The study was conducted in two stages, each utilizing a different study instrument.

Stage 1: Study Instrument: In-depth Interviews

The respondents were selected using the snowball method and included professionals and decision-makers of varying rank (from those working in the field through mid-level managers and top-level policymakers) and of various professions (physicians, nurses and social workers) from different organizations (health plans, hospitals, hospices and old-age homes). Since the study focused on implementation of the law in the community, we made sure that all four health plans (HPs) were represented. Altogether, 37 people were interviewed.

The interviews were conducted by one or two of the researchers in 2014-2015.¹ All of the interviews, with one exception, were conducted in face-to-face meetings and lasted 45-75 minutes. In two cases, we were obliged to conduct a joint interview with two professionals from the same organization. Most of the respondents agreed to have their interviews recorded, and those interviews were recorded, transcribed and summarized.

The interviews were conducted according to an interview guide written by the primary researcher. The interview guide helped the interviewers to remain open towards the respondents and the particular issues that they raise, while at the same time, not to forget to ask about essential issues relating to the subject of the study. The interview guide varied somewhat from one interview to another, in the way that the emphasis is placed on issues that are relevant to the role of the respondents or the organization where they work.

The interviews were analyzed using the Naralyzer program, distinguishing the different groups of respondents. The interviewers drew up a list of categories at the beginning of the coding, and during the coding process, additional categories and sub-categories were added.

Stage 2 Study Instrument: Focus Groups

We set up two focus groups, one with nurses, the other with social workers. We chose focus groups for these professions because they spend time talking with their patients and engage in psychosocial aspects more than members of other professions do. They have greater exposure to patients and the patients feel more comfortable talking to them. The focus groups met in the center of the country and included representatives of old-age homes and homecare units of all the HPs. Ten nurses or social workers and two researchers participated in each group.

The focus groups were conducted as brainstorming sessions, with the goal of obtaining information and gaining insights about the subject, creating interaction among the members of the group and

¹ Note that during this period, action was taken following changes in policy. Most notably, the MOH conducted an inspection to ascertain implementation of the law in general hospitals. These changes affected implementation of the law and were reflected in the study findings.

encouraging discussion, thereby acquiring a lot of information in a relatively limited time. The questions were open and the researchers made sure that every one of the participants had an opportunity to respond.

The discussions in the focus groups were summarized by one of the researchers during the discussion and the summary was then amplified while listening to a recording of the discussion. The discussion was analyzed in a similar way to the interviews and was based on the same categories. Since we did not find a substantial difference between the findings from the focus groups and from the interviews, the final analysis of the findings was based on both sources together.

Documentation and Observation

In addition to the above instruments, the analysis included documents provided by the respondents about relevant activities in their organizations. We also conducted an observation of a workshop for residents and nurses in hospitals on the subject of communication and care at the end of life.

4. Findings

4.1 Implementation in the Community

Availability of Palliative Care through the Health Plans

The Dying Patient Act demands the provision of palliative care, which includes painkillers, palliative sedation, and spiritual guidance to help cope with the patient's illness and death. Palliative care is provided in the community in several settings:

Home hospice: In three of the four HPs, home hospice services (i.e., care in the patient's home towards the end of life) are usually purchased from external suppliers. However, there is some variance even within each HP, depending on the geographical location and the illness, so that the services are sometimes provided directly by the HP through the homecare unit. The fourth plan is exceptional in that it aspires to provide hospice services through its own staff wherever possible. In this case, too, the services are provided by the homecare unit. In an interview, a physician from this HP reported that the hospice staff is specially recruited for each case and the members of the team fulfill their role in addition to their work at the clinics. In contrast, the teams provided by external suppliers are mostly full-time hospice workers and in the opinions of the respondents, they are highly professional in this field.

According to critics of the provision of services through external suppliers, this system creates an incorrect distinction between palliative care, which is provided during the final weeks of life, and care of severely ill patients who have not yet reached this stage. Professionally, the respondents believe it would be right for treatment before the final weeks to be provided with a palliative approach with a level of intensity appropriate for each patient.

As a rule, the interviews reveal that home hospice treatment is not commonplace and in general, approval is given for home hospice care only when the patient has just a few days left. Many patients die a matter of days after they have been included in the hospice program.

Homecare units: Most severely ill patients in the community are treated at home by the homecare units of their HPs. The interviews indicate that it is unclear to what extent the homecare teams in these units are prepared and trained to give palliative care. For example, the training and guidance provided by the HPs on the subject of end-of-life care and the Dying Patient Act focus on these units, but they are limited. Furthermore, there is evidently much variance among the HPs, and within the HPs, as to the training given to members of the units. We were told that in one of the HPs the teams in the unit were given training on the subject more than 5 years ago and had not had any refresher course since. In another, we heard that there is no consistent method regarding the training: it is not stipulated who will participate in the training programs; rather each district decides which social workers and which nurses will be sent for training initiated by the HP or locally. Managers at the third plan explained that the palliative care system is in the process of development, and this is happening at different rates in different districts, which is why there is variance in the availability of care.

The care provided by the homecare units is much less intensive than the home hospice service because it is not available outside of working hours. According to some of the physicians, the intensity of the care required at home does not necessarily depend on the fact that the patient has reached his final days. In the opinion of one physician, it is possible to reconstruct the service provided in homecare units to include appropriate care for palliative patients without the need for additional personnel. The point of departure proposed is that patients need highly intensive care and a 24-hour service both when they join the program and when they start to show signs of reaching the end-of-life. In the period between these two stages, which may last several months, it is possible to provide care during working hours only and the physician can be in daily contact with the patient to identify when he approaches the stage of requiring more intensive care.

Palliative clinics: One of the HPs is currently conducting a pilot in which two palliative clinics have been set up for ambulatory patients allowing them to receive palliative services in the community. The clinics are for oncology patients and those with heart failure. The goal of the clinics is to provide a basis for palliative services in the community that will include additional types of illness. Essentially, the service is intended to provide service in the clinic, but it also has a 24-hour telephone answering service staffed by the palliative team. The program is also intended to reduce the number of referrals of end-of-life patients whose families take them to the hospitals. These referrals are sometimes due to the families' difficulty in coping with the patients' pain.

Care provided by the family physician: Some family physicians have the professional view and personal preference to care for their severely ill patients in hospitals through to their death and to provide palliative care themselves instead of referring them to homecare or hospice. The advantage is that it preserves the continuity of care and the patients receive treatment from physicians who know them, which rarely happens in home hospice care. This approach is in line with the professional leadership approach of family medicine, which is built on the idea that the family physicians should stay with their patients throughout their lives. However, the HPs do not provide support for this. In most cases, family physicians do not have time to remain with all their patients in this way and they do not receive specific remuneration for so doing. Another disadvantage is that the patients have no

one other than their family physician in an emergency and there is no support from nurses and social workers, as there is in the case of homecare units and home hospice.

Discussions about End of Life in the Community: Seriously Ill Patients (whether or not Defined as "Dying")

Discussions about the end of life and clarification of the patient's preferences for treatment or non-treatment are considered the cornerstone of palliative care. According to the law, when a patient is dying, it is obligatory for the "physician responsible" for the patient to initiate a discussion and inform the patient about the opportunity to complete an AD form and/or power of attorney (POA) form. The "physician responsible" is the one appointed by the Dying Patient Act to be the professional authority who determines whether the patient is "dying." The current study found that the legal mechanism for allowing the "physician responsible" to define the patient as dying is hardly used in the community.

We were told of an attempt by one HP to incorporate the procedure in its work by building and disseminating a flowchart. However, here too they admitted that they had not succeeded in integrating the procedure and that transferring cases to a "physician responsible" in order to define the patient's status is perceived as unnatural and inappropriate for clinical purposes. We shall therefore address the general clarification of preferences conducted with seriously ill patients:

Discussions in the framework of homecare: The HPs have no clear procedure for conducting a discussion of this kind at a specified stage of the illness. Nevertheless, we discerned an expectation at the management of three of the plans that the process of admitting patients into homecare units, and particularly into home hospice, would include a discussion to clarify preferences. However, it is unclear to what extent this discussion actually takes place. In the home hospice of one of the hospice companies, the care includes discussion of end of life, but not the completion of the formal MOH directives, unless the patient asks to do so.

Discussions during routine treatment by the family physician: We were told by one HP of an auxiliary tool that has been distributed to the physicians. The tool was designed to help them talk about the available medical and legal options with patients diagnosed with serious illnesses. The tool is a computerized program that includes mention of legal guardianship and ADs.

Documentation of the discussions: We were informed in the interviews that medical records in the community do not currently have a section for discussion of end of life. Respondents noted the importance of having a menu tab specifically for documenting discussions in the patient's records. If a patient has already given an AD, a tab of this kind would make it easy to find it, making it available to the care provider when the time came and would not get buried under a pile of treatment documents, as happens when they are filed in the same way as any other routine care document.

Implementation of the Law at the Acute Stage: How are Decisions Made at the End of Life in the Community?

A number of respondents, both those working in the community and those in hospitals, are of the opinion that it is not up to the family physician to consider the patient's wishes when planning treatment, and in any case, at the end of life, a patient goes to the hospital and not to the family physician. Nevertheless, conversations with some physicians in the field reveal a different picture: respecting patients' wishes is essentially to refrain from sending them to the hospital to start with. The family physician and caregivers in the homecare units have the power to help patients realize their wish of dying at home without unnecessary interventions.

Discussions about End of Life in the Community: Healthy Patients and those with Background Conditions who are not Seriously Ill

Many of the participants in the study noted the advantage of enabling patients to complete advance directives when they are still healthy. Furthermore, according to the law, it is the basic right of individuals to give instructions as to what should be done if their condition renders them incapable of expressing their wishes in the final stages of their lives. However, there was no consensus among the respondents if and what the system should do to promote discussion of this kind with healthy patients. For this reason, in this case, implementation of the law has been measured by the extent of the response given in care frameworks to patients who wish to complete the forms.

In the framework of primary care: The study found that none of the HPs have directives stipulating that physicians or nurses in primary care clinics have to take the initiative and propose to patients that they complete an AD or power of attorney, or in general to initiate a discussion about the end of life. One of the HPs has a structured discussion that is distributed to physicians for assistance. It is evidently very rare for a family physician to initiate a discussion with patients who do not currently have a life-threatening illness.

In old-age homes and assisted living facilities: The picture here is mixed. Discussions with two directors of old-age homes revealed that it is very rare for AD or POA forms to be completed according to the law. Staff members do not bring up the subject at their own initiative for fear of the patients' response and for fear of encouraging them to want to die. In contrast, a physician working at a nursing home on a kibbutz reported that a social worker always raises the subject when patients are admitted and talks to them about it when the opportunity arises. She also tries to involve family members and convince patients who are competent to sign a POA or AD form.

Note that in addition to the initiatives in institutions, we also heard about independent initiatives to raise awareness of the subject and get healthy people to sign an AD by organizations working in this area and by individuals. The Lilach organization, for example, provides members with forms expressing the wish not to receive treatment at the end of life. Other organizations hold conferences and seminars, etc.

4.2 Implementation in Hospitals

The description of implementation of the Dying Patient Act in hospitals in this report emphasizes local initiatives, because the recent MOH inspection in hospitals and the study of palliative care in hospitals by Bentur et al.² have already provided comprehensive information. According to this information, demonstrable efforts are made to implement the law, and they need to continue in order to be yet more successful. Along with the provision of a small number of clinical specialists and a small number of palliative beds in the hospitals, action taken includes drafting procedures on the subject, staff training and the appointment of in-house palliative staff.

Documentation of the patient's preferences and clinical directives: The most prominent evidence we saw of work done in hospitals to clarify the patient's preferences was the development of ways to document discussions to clarify preferences and the ensuing clinical instructions. This is not taking place across the board in hospitals, but compared to the situation in the past, there is less apprehension about documenting decisions to refrain from life-extending interventions. We saw some interesting initiatives for addressing the subject in some hospitals, such as introducing a tab for palliative care in the patients' computerized medical records and placing a DNR wristband on patients.

Appointing committees and officials as defined by the law: We did not hear extensive evidence of the appointment of institutional committees regarding the Dying Patient Act or of initiatives taken to define "physician responsible" or to place responsibility for identifying dying patients as defined by the law. In one large hospital where they do have an institutional committee, it was found that most of the committee's work is educational and training-related and does not necessarily focus on ethical questions on the wards.

Availability of palliative care in hospital: One of the topics that arose regarding the availability of palliative care was that the inpatient hospice service is very limited and there are very few hospice beds in Israel. It was also noted that a considerable number of patients defined as "palliative" or who should be defined as "patients with a palliative emphasis" are hospitalized in complex nursing wards, where there are almost no palliative specialists and the level of expertise of the existing staff does not meet requirements. However, it was found that there has been some improvement in recent years and that staff in complex nursing wards have begun to talk more with the families about the possibility of transferring the patient to hospice or of withholding proactive treatment at the end of life.

4.3 Barriers

The study participants reported the following barriers to implementation of the law.

Lack of clarity about how to implement the law: The lack of clear standards makes it difficult to implement the law. Note that some of these difficulties can be attributed to the fact that the protocol stipulated in the law and the Ministry's procedure for identifying dying patients, as well as the demands to ascertain their preferences, are seen as unrealistic and inappropriate for the clinical situation.

² Bentur, N.; Laron, M.; Azoulay, D. and Oberman, A. 2015. *Palliative Services in General Hospitals and Geriatric Medical Centers in Israel*. RR-704.15 (Hebrew).

Lack of clarity about the division of responsibility among care providers: This has to do mainly with the question of clarifying the care preferences of complex patients who may be dying. In most cases, these patients receive treatment from many providers – the HPs, the hospitals and the nursing homes – but it has not been determined who should be responsible for conducting discussions towards the end of life. Managers whom we interviewed at one of the HPs believed that since decisions to extend lives are usually made in hospitals, the responsibility for executing the decision and conducting explanatory discussions should be there. On the other hand, at a workshop we observed at the Israel Center for Medical Simulation (MSR) and in some interviews, we found that ward staff believe that the hospital is not the right place due to the urgency and the pressure under which decisions are made and because the patient is less well known than in the community.

Absence of a clear protocol for implementation: There are no clear directives, mainly with regard to homecare units. Some participants in the focus groups believe that the fact that the matter of clarifying preferences and completing AD forms is not stipulated in the protocol for home visits is a hindrance to implementation of the law.

Absence of standards for palliative care: Several palliative specialists noted the difficulty caused by the fact that the MOH has not set clear standards for palliative care. For example, it has been determined that the HPs have to provide palliative care, including home hospice, but the eligibility criteria for palliative care, and a designation of what it should include are not clearly specified.

Lack of public responsiveness – lack of awareness and opposition: Patients are not aware of what they are eligible for under the law. This was felt by many respondents. They believe that the fact that the number of ADs completed is relatively small and that almost no forms requesting continued treatment in cases where there is no hope are completed, testify that patients are unaware of their entitlements under the law.

Cultural barriers: For some patients, the subject of death is taboo. Caregivers noted that when they brought up the subject, they encountered serious opposition from the patients or their families. There were many cultural barriers in certain populations, particularly among the ultra-Orthodox, and Arabs and immigrants from the former Soviet Union. Among these communities, it is generally unacceptable to contemplate death and the non-prolongation of life. More than once, study participants noted junctures when it would have been possible to raise the subject, but every time they rejected the discussion as "inappropriate." For example, the directors of assisted living facilities reported reluctance to discuss the subject when an elderly patient enters their facility ("because we are starting a new chapter"); family physicians do not want to talk about it with patients who have been discharged from hospital following an event that is likely to recur (because the emphasis is on rehabilitation).

Lack of emotional and psychological support for the care staff: The difficult moral dilemmas, the existential questions that arise, and the sadness due to the frequent loss of patients were noted in most of the interviews. The difficulty was brought up particularly by the physicians and social workers, who expressed a sense of isolation. They noted the great importance of close teamwork, interdisciplinary

cooperation, and emotional and professional support. In addition, they proposed regular shared forums enabling staff members to ventilate the feelings and talk about the dilemmas and having to cope.

Lack of discussion skills: Holding frank and sensitive discussions with terminal patients and their families is a very difficult task. Many professionals avoid doing so because they do not know how and because their medical training does not prepare them adequately. Even if they are aware of the need to conduct such discussions, the results are not always satisfactory.

Similarly, but from the other side, when staff speak about the possibility of end-of-life care, they sometimes encounter opposition from the patients or their families because they fail to clarify the meaning of recognizing the end of the life and to explain that withholding aggressive treatment does not mean abandoning the patient.

Efforts are being made to address this matter in some of the HPs, but not in an official way. For example, one HP has held workshops on end-of-life preferences, at the MSR, which were attended by over 100 participants. Another HP held a conference and devised work processes and tools to assist staff members. A large proportion of the relevant tools are currently being worked on and will be incorporated into the work plans for the coming years.

Cultural barriers among the caregivers: The sentence "In medicine, death is considered a professional failure" was repeated in the interviews and focus groups. Many physicians have difficulty not only actively proposing to terminal patients the possibility of stopping aggressive treatments, but also in hearing the patients propose it themselves. This causes them to oppose the development of palliative care and cooperation with tests regarding the quality of care at the end of life. Respondents also noted that the barrier is also reflected in the fact that it is only in recent years that palliative medicine has been recognized as a specialty.

Physicians lack knowledge about the possibility of offering palliative care: Inadequate familiarity with the field of palliative medicine has led many physicians to perform life-prolonging treatment as the default even when they do not believe that it will do any good – the reason being that they have no knowledge of alternative care. Note that in recent years, there has been improvement in this area, but there are still large gaps among the different units (both homecare units and hospitals). Awareness of the subject is higher with regard to oncology patients than those who have dementia or heart failure.

Lack of awareness among old age home staff about the patients' wishes: This lack of awareness stems from fear of allowing patients to die in the home if that is their wish. Often they are taken to hospital against their wishes. This, despite the fact that some participants in the study believe that nursing homes and assisted living facilities are ideal settings for palliative care outside of hospitals because they have nursing and support arrangements that are generally unavailable to elderly individuals and patients living in private homes.

Lack of practical knowledge: There is not enough awareness in the system that high doses of morphine may be administered to patients who do not have cancer. Many physicians avoid prescribing the drug for fear of the legal implications of accelerating death, even though there is a specific clause in the law that permits relief treatment even if it is liable to shorten the patient's life. Similarly, relatively few physicians know how to administer palliative sedation.

Lack of awareness of patients' rights: Some of the respondents noted that many physicians still take the paternalistic approach that the decision – whether to withhold treatment that will not do any good or whether to prolong life – is a professional matter for the physician alone. It was, however, noted that there has been some change here and today there is greater awareness, particularly among younger physicians both of the need to consult with the patient how he would like to be treated at the end of life and of the specific directives in the Dying Patient Act.

Shortage of earmarked funds: The law and MOH procedures do not allocate additional earmarked resources for those responsible for implementing the law. Since discussions with patients are time consuming and frequently entail follow-up meetings, and since they require the caregiver to free up time during a hectic working day, many professionals simply do not have time. Furthermore, with the exception of one HP, no organization provides remuneration for meetings to complete AD forms. Even there, the physician is remunerated but is not required to initiate this type of discussion unless in response to the patient's request.

There is no budget to expand the service: No additional budget has been earmarked to increase palliative services, particularly positions for specialists and personnel responsible for sustainability and budgets to train and mentor staff. The feeling among the respondents was that this is not a high priority for the MOH.

Difficulty advising the care staff about the patient's wishes in an emergency: In an emergency, the staff do not have time to clarify the patient's preferences and, even if the patient has completed an AD form, the staff cannot check if it is valid and relevant in the specific circumstances. In many cases, the staff will tend towards over-treatment. It is therefore important to make provision for the directives given by the patient to be made known to the staff. It is also important to find a solution so that in cases where patients have given directives for palliative care only, they are not even brought to the hospital in an emergency.

Agencies outside of the health system: There are agencies outside of the immediate care system that are not aware of the law and do not act in accordance with it. Magen David Adom (MDA), for example, instructs its staff to perform resuscitation without consideration of the patient's wishes.

Lack of agreement and coordination between caregivers: Not all care frameworks are equally committed to palliative care. This sometimes creates difficulties vis-à-vis the patient and his family. For example, a physician in ICU may propose considering hospice care while the ward physician suggests another round of aggressive treatment.

Insufficient regulation: Many study participants noted the MOH regulation in a positive light, as an incentive to the system to take steps to implement the law, particularly in the hospitals, and also in the HPs. However, it was argued, particularly by professionals in the community, that the regulation is insufficient, and in particular, that there is no meaningful regulation for clarifying preferences and completing ADs.

Insufficient backing from management: The study found that enlisting the support of management, with an emphasis on hospital and ward directors, is critical to the successful incorporation of the law and palliative care by the staff. On the other hand, it was noted that management is liable to be a barrier, because they often want to adhere to the forms and bureaucracy demanded by the law.

Fear of litigation: This barrier is felt mainly by the professionals when one or more family members insist on aggressive treatment even when this is against professional judgment or the patient's wishes. In contrast, it emerged that the law could be the cause of fears in the opposite direction – in other words, fear of lawsuits for over-treatment given against the patient's wishes. This fear has led one of the HPs to oppose documentation of discussions to clarify preferences beyond the MOH ADs, for legal reasons.

4.4 Participants' Opinions on Various Aspects

The physician's place in discussion with patients at the end of life: An absolute majority of the professionals with whom we spoke believe that it is the job of physicians to lead discussions with patients about decisions to be made at the end of life. This is the approach taken by the law: responsibility for clarifying the preferences of a dying patient lies with the "physician responsible." However, at present, the nurses constitute the majority of staff members who have undergone training about the law and supportive care and the MOH recognizes the clinical specialization of nurses in the field of palliative care according to criteria fixed in the procedures. The training enables these nurses to perform acts that not all nurses are permitted to do. As a rule, the respondents consider there is greater awareness of the matter among nurses than among physicians.

However, in practice, responsibility for setting up a care plan lies with the physician. So, even if the nurse is aware and informed about the matter, there is little she can do, without calling in the physician, to inform the patient of the option of transferring to palliative care. This is because many of the required steps need the authorization of the physicians or because the nurses are afraid of saying something that conflicts with the message given to the patient and his family by the physicians. This sometimes leads to conflicts among the staff and frustration among nurses who have been trained, but cannot put their skills into practice.

Place of the family: Our study found that the patient's family plays a significant part in the end-of-life care process. Note that an important aspect of the law is that it accords status to the family for the first time. Firstly, the law requires the medical staff to support the family. Secondly, the law gives legal authority to the testimony someone "close to the patient" as to his wishes. This does not have to be a member of the family, but it is reasonable to assume that many relatives are considered "close to the

patient." However, participants in the study recognized that it is not possible to encourage communication in every family and in any case, it is necessary to contend with conflict between the patients' wishes and those of their families.

Contribution of the law: Although there is criticism of the details of the law, most of the study participants believe that it has played an important part in raising awareness of the matter and spurring the medical agencies into action.

According to some of the participants, the law has given legitimacy to practices that were already in place in some of the wards. Another advantage is that it can be used to support physicians wishing to open discourse, which makes it easier to deal with aversion to the subject. Participants also responded positively to the obligation in the law to provide palliative care and to the place that the law accords to family members. Many participants noted that in recent years, the atmosphere in hospital wards has started to change – today there is greater sensitivity to patients' rights and more awareness of the fact that it is not necessary to treat patients at any price.

Proactive initiatives with patients who are not seriously ill: Many respondents noted that the advantage of writing an AD when patients are healthy is that at that stage they can consider the matter without pressure and without the emotional burden of the illness. This makes it easier for patients' caregivers and family when the time comes. The fact that there has already been a discussion with the patient also makes it easier for the physician to re-open the discussion when the patient is ill, since there is already a starting point. It is possible to remind the patient of the previous discussion or to mention the AD that he signed and asks what he currently thinks about it.

Some of the respondents noted that in their opinion the family physician should take the initiative in raising the subject. Others felt that the right time for this is when the patient has other encounters with health system, such as prior to undergoing routine surgery.

4.5 Programmatic Directions

The following are some of the concrete proposals and ideas raised by participants to improve the handling of end-of-life care.

1. Involve social services, even those outside of the health system, with the care of patients at the end of life
2. Create a directive form that is acceptable to MDA, in order to avoid life-prolonging treatment without consideration of the patient's wishes
3. Increase public awareness through an advertising campaign
4. Examine the possibility of abolishing the distinction between home hospice and homecare or refine the authority of the caregivers in homecare treatment so that they can provide the care that home hospice staff are permitted to perform
5. Develop a model of home hospice that allows family physicians to treat their patients at the end of life, and includes the tools and support of the HPs that come with home hospice.

5. Discussion

The study shows that there has been considerable progress in all aspects of the perception of a dying patient, of allowing patients to express their wishes, and of respecting these wishes. However, almost a decade after the law came into effect, there are still barriers and difficulties with its implementation.

5.1 Measures to Increase Awareness of Patients' Rights and the Ability to Exercise them

One of the most prominent subjects that came up in the study is the gap between the rights accorded to residents of Israel in the law and awareness of these rights. Evidently, the lack of awareness of the law and what it covers demands proactive initiative to increase awareness about planning for the end of life in general and, specifically, the completion of AD forms before serious illness endangers their life. This could perhaps come from sources outside of the health system.

Following the above, it is important that the system make it possible to document discussions with patients or members of their family about their preferences for end of life. It is important that the AD completed by the patient be kept in a prominent place and in the patient's records (in the hospital or community). Some hospitals have already created systems that allow this and it should be encouraged in other hospitals and in the community. Furthermore, with the ongoing effort to establish an effective digital interface between medical records in the community and in hospitals and as it becomes easier to see the information from the hospitals in the community and vice versa, this could help the staff to know patients' wishes in an emergency.

One of the obstacles to holding discussions is the lack of training for medical staff in general and in particular for physicians. Training physicians and in particularly recruiting senior physicians to integrate end-of-life care, could promote awareness and action.

Next, it is also important that physicians in units caring for end-of-life patients be more aware of palliative medicine so that they can provide basic palliative care without referring patients to specialists and become aware of the options for care at the end of life. During specialization, residents should be encouraged to choose palliative medicine for their rotations. This has only recently been recognized as a specialization, and although there are departments recognized for this specialty, there are not many.

5.2 Aspect Relating to Legislation

In almost every interview, problems with the law itself were noted. One indisputable fact is that the AD forms in their current format are convoluted and hard to understand. The forms should be simplified and reconstructed. Many of the forms received by the MOH have been returned to the patients to be corrected. However, in the past year, after the POA in the Patients' Rights Act was merged with the POA in the Dying Patient Act, most of the forms have been completed correctly. Further steps can be taken to simplify the forms and make them more user-friendly, and at the same time, it is possible to promote a change in the law that would recognize ADs given in other forums, such as that provided by the Lilach organization.

Another problem with the legislation is that there is no correlation between the definitions in the law and professional definitions and clinical situations, particularly with regard to the definition of a dying patient as a person with 6 months left to live. This presents many patients with an obstacle preventing them from falling within the law (e.g., patients with ALS and dementia). The current definition emphasizes palliative care for oncology patients. There is no doubt that these patients deserve palliative care, but at the same time, suitable services should be developed for patients with other illnesses. It would therefore be appropriate to make the definition of a dying patient more flexible and allow the physicians to include other considerations in their decision to classifying their patients as "dying" and abolish the timeframe set in the current legislation.

Further, it is important to define stages during the last six months of life – the amount of time that a patient is determined to be dying. Currently, only when medical opinion deems the patient has two weeks to live, is he defined as "terminal." Additional definitions of the gravity of the illness could allow patients to receive both basic and supportive treatment.

5.3 Addressing the Community

The community is the basis for all patients. Most of us live in the community, receive treatment there, and are well acquainted with the physicians treating us. Many patients prefer to end their days at home. So the care in the community at the end of life should be strengthened, to avoid unnecessary hospitalization, which causes suffering, difficulty and needless expense.

For this reason, it is worth examining the homecare units and the service they provide – and expand them or think of new models such as specialist clinics for palliative medicine, which provide palliative care in the patients' homes or, where relevant, at the clinic itself though a multidisciplinary specialist team.

It is also fitting to strengthen the role of the family physician at the end of life, as the person who has been a key player in the lives of the patients and their families and to encourage regulation and supervision by the MOH, which has become involved in the area, particularly in old age homes and assisted living facilities. It is expected that regulation will lead to action.

From the foregoing, one can see that much is being done in the field of palliative care and implementation of the Dying Patient Act, but much remains to be done. In our world, dying for most people is a slow, and sometimes painful, process. Knowing that a person has the basic right to express his wishes as to the way he wishes to reach the end is a basic given in the modern, progressive world. This report has illuminated a certain angle of a vast issue and provides the legislator and professionals with food for thought that could lead to the advancement of the rights of all residents of Israel.

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