



---

## RESPECTING THE AUTONOMY OF THE PATIENT IN GENERAL PRACTICE – THE OPPORTUNITIES OF THE ADVANCE DIRECTIVES

Sv. Dimitrova<sup>1\*</sup>, B. Parashkevova<sup>1</sup>, J. Marinova<sup>1</sup>, Kr. Benkova<sup>2</sup>,  
G. Petrova<sup>1</sup>, G. Chamova<sup>1</sup>

<sup>1</sup>Department of Social Medicine and Health Care Management, Medical Faculty  
Trakia University, Stara Zagora

<sup>2</sup>Department of Social Activities, Medical Faculty, Trakia University, Stara Zagora

### ABSTRACT

Respecting patients' autonomy is a basic moral requirement in the contemporary general practice. An AD is a way of recognizing the right of autonomy prospectively by providing instructions in advance on what the patient would want after being no longer able to communicate his or her decision. **PURPOSE:** The aim of this study is to describe the current foreign practice concerning respecting patients' rights in general practice by the means of advance directives. **METHODS:** A review of the literature in the field of the investigated topic has been done. **RESULTS AND DISCUSSION:** In The USA, the use of ADs has been studied extensively. Several studies have attempted to identify factors associated with the formulation of ADs and to find opportunities to increase their use. In Europe, The Netherlands is a country where the AD concept is widely accepted. The reasons and obstacles for having an AD and some approaches to increase compliance with ADs are discussed in this article. **CONCLUSIONS:** AD are a relatively new phenomenon in medical care. Changes in medical practices, the public's awareness, and the documents themselves have been proposed in order to encourage their use. The primary health care physician is the key figure and the initiator of this change.

**Key words:** advance directives, general practice, general practitioner

*'Yes, we in the medical fields can do a lot to bring people back from the brink of death. That doesn't mean we should. Death is not the enemy.'*

*Carmen M. Balfour, Hospice Intake Coord/RN,  
St. Elizabeth Hospice*

### INTRODUCTION

Autonomy is a basic right of every human being including patients. Respecting patients' autonomy is the first bioethical principle and the core of the new models of doctor-patient relationship. The contemporary patient is much more informed and autonomous than the one from the past. She or he knows a lot,

sometimes even more than a GP about their illness and what they really expect is to be treated as a partner in their own medical care.

The patient's autonomy has to be respected not only from bioethical point of view but as a law requirement as well. It is a central issue in the informed consent doctrine that is widely accepted in all over the modern world including Bulgaria.

Respecting patients' autonomy is a basic moral requirement in the contemporary general practice. From one hand, the ambulatory patient is more autonomous than the hospitalized one. From the other hand the trust that is the main characteristic of the doctor-patient relationship in primary health care can not be maintained without recognizing the patient's right of autonomy.

What is an advance directive (AD)? It is a statement that declares what kind of lifesaving medical treatment a patient wants after he or

---

\*Correspondence to: Assoc. Prof. Svetlana  
Metodieva Dimitrova, 11 Armeiska Street,  
Department of Social Medicine and Public Health,  
Medical Faculty, Trakia University, 6000 Stara  
Zagora, e-mail: [svdimitr@mf.uni-sz.bg](mailto:svdimitr@mf.uni-sz.bg), tel: +359  
42 664 457

she has become incompetent or unable to communicate to medical personnel. Advance directives (ADs) are a response to the increasing ability of physicians since the 1950s to delay death through an array of medical technology, such as respirators, feeding tubes, and artificial hydration. This ability to prolong life has led to the need for doctors, patients, and patients' families to make decisions as to whether such technology should be used, especially in those situations when the patient is either near death, comatose, or severely and chronically ill.[2]

ADs are an outgrowth of the doctrine of "informed consent." An AD is a way of recognizing the right of autonomy prospectively by providing instructions in advance on what the patient would want after he or she is no longer able to communicate his or her decision.

There are two forms of ADs: living wills and health care powers of attorney. A living will, so named because it takes effect while the person is still alive, is a written statement expressing whether or not a person wants to accept life-sustaining medical treatment and under what conditions. A health care power of attorney, also known as a durable power of attorney or a proxy, provides for someone else, usually a family member or close friend, to make decisions for the patient when he or she is unable. It is broader than a living will because it includes all medical decisions, not just those pertaining to life-sustaining medical treatment. It does not require that the person be terminally ill or in a vegetative state before it is triggered. However, unlike a living will, a proxy may not contain specific instructions on a patient's willingness to accept certain life-sustaining treatment. Instead it is left up to the appointed family member or close friend to determine what the patient would want, based on what the patient has said in the past or the patient's overall life philosophy. For this reason, it is helpful to combine living wills and a power of attorney in one document. (1)

Working the document out is the final stage of a process named 'Advance care planning' (ACP). ACP is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. (2) It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and

communicated to key persons involved in their care. An ACP discussion might include: the individual's concerns and wishes, their important values or personal goals for care, their understanding about their illness and prognosis, their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

With the individual's agreement, discussions should be documented, regularly reviewed and communicated to key persons involved in their care. If the individual wishes, their family and friends may be included.

## PURPOSE

The aim of this study is to describe the current foreign practice concerning respecting patients' rights in general practice by the means of advance directives.

## METHODS

A review of the literature in the field of the investigated topic has been done. The key words that are used for the search in Google are: advance directives, general practice, general practitioner. All the popular materials are excluded; only the scientific publications in English in the last decade have been reviewed.

## RESULTS AND DISCUSSION

There are some important prerequisites for the real respect of patients' autonomy in general practice: the long lasting relationship with the patient, the trust, the patients' preferences and some other factors associated with formulation of the ADs.

In USA, the use of ADs has been studied extensively, in order to identify opportunities to increase their use. Several studies have attempted to identify factors associated with the formulation of ADs, in order to achieve better understanding of the people who have ADs and those who do not, and to find opportunities to increase their use. (3,4,5,6,7,8,9) Predisposing factors are demographic factors (e.g. age, gender) and factors concerning beliefs (e.g. religion, attitudes). Enabling factors could facilitate access to health care, or in this case more specifically the formulation of ADs (e.g. education, social support). Need factors are healthrelated factors, either evaluated or self-perceived, that could motivate someone to access health care or formulate an AD. Many predisposing factors were found to be

associated with the formulation of ADs in one or more studies, such as: being older, being female, being white, coming from a rural area, being more religious, and not being married. Enabling factors that were found to be associated with having formulated an AD were: higher education, higher socio-economic status, higher income, and higher social support. Need factors that were found to be associated with having formulated an AD were: worse (self-perceived) health status, and residing in a nursing home or hospice. Furthermore, several negative experiences were associated with having formulated an AD: death or illness of a loved one, and negative life events in general. Predisposing factors played an important role in the formulation of an AD. Women, older people, nonreligious people, especially those who lived in an urbanized area, and people with less confidence that the physician would respect their end-of-life wishes were more likely to have formulated an AD. Female gender and higher age were also reported to be factors in studies in the USA.(3,6,8,9)

In Europe, The Netherlands is a country where the AD concept is widely accepted. Although both in the USA and in The Netherlands adherence to an AD often has a life-shortening effect, ADs in the USA usually concern the limitation of treatment, which can be consistent with religious beliefs, whereas ADs in The Netherlands mainly express a wish for euthanasia, which is less reconcilable with most religious beliefs. According to Mette and all., the interaction between urbanization and religious beliefs might be a consequence of people living in rural areas having more strict religious beliefs than people living in urbanized areas.(7)

In The Netherlands, living wills had been formulated by 3% of younger people, 10% of older people, and 23% of the relatives of a person who died after euthanasia or assisted suicide. Most living wills concerned a request for euthanasia. In all age groups, 26–29% had authorized someone to make decisions if they were no longer able to do so themselves. Talking to a physician about medical end-of-life treatment occurred less frequently, only 2% of the younger people and 7% of the older people had done so. Most people were quite confident that the physician would respect their end-of-life wishes, but older people more so than younger people. In a multivariate analysis,

many predisposing factors were associated with the formulation of an AD: women, older people, non-religious people, especially those who lived in an urbanized area, and people with less confidence that the physician would respect their end-of-life wishes were more likely to have formulated an AD. Furthermore, the enabling factor of a higher level of education, the need factor of contact with a medical specialist in the past 6 months, and the death of a marital partner were associated with the formulation of an AD.(3)

Although the American law encourages people to complete ADs, most do not. It is estimated that only between 10 to 20 percent of the population have ADs. (1) There are several reasons for this. Young people think that they do not need one, even though the most well-known cases involving the right to die—Karen Ann Quinlan and Nancy Cruzan—involved young women in their twenties in persistent vegetative states. For old and young alike, bringing up the issue with potential surrogates, such as family and friends, can be uncomfortable and upsetting. Some individuals, especially those from traditionally disenfranchised populations such as the poor and minority groups, may fear that an AD would be used to limit other types of medical care. (1,9)

Another primary reason why ADs are not completed is that oftentimes patients wait for their physicians to broach the subject, rather than initiating it themselves. In a 1991 Harvard study four hundred outpatients of thirty primary care physicians and 102 members of the general public were interviewed to determine the perceived barriers to executing an advance directive. The most frequently cited reason for not completing an advance directive was the failure of physicians to ask about it. There are several reasons why physicians often do not initiate such discussions, including a belief that such directives are unnecessary (especially for younger patients) and lack of specific knowledge on how to draft one. Also, insurance companies do not reimburse physicians for their time spent discussing advance directives. (1,6,7)

Even when ADs are completed, they may not be complied with. One reason is that they may not be available when needed. In a self-administered questionnaire distributed to 200

outpatients in 1993, half of the patients who had executed an advance directive kept the only copy locked in a safe-deposit box.(1) Hospitals may also fail to include a copy of the patient's advance directive in his or her chart. Physicians may be unaware of a patient's advance directive even when the document is placed in the patient's chart.

Another obstacle to the implementation of ADs is that the documents themselves may contain ambiguities or terms open to interpretation, making it difficult to apply. For example, some living wills may simply state that the patient does not want heroic medical measures to be undertaken if the condition is terminal. But the term "heroic measures" can mean different things to different people. Artificial nutrition and hydration may be considered heroic to some, but not to others. Other living wills (and some state laws) require that a patient be terminally ill before it is activated. But physicians may disagree over the definition of terminally ill; for some it means imminent death and for others it means an irreversible condition that will ultimately result in death. And even a clearly written advance directive may no longer represent a patient's wishes as death becomes imminent.

Health care proxies also have limitations. They often contain no guidance for the appointed person on the patient's views toward life-sustaining medical interventions. Decisions may therefore be based on what the proxy wants and not the patient. Because the proxy is usually a relative or close friend, this person's strong connections to the patient, and own feelings and beliefs, may influence the decisions made. This is especially true when it comes to withholding certain controversial treatments, such as a feeding tube. Figuring out what the patient would want can also be difficult. Past statements may not be indicative of present desires because a grave illness can alter views held when healthy. (1,4,5,6,7,9)

Even when a patient's preference is clear, as expressed by the surrogate or within the document itself, physicians may not always comply with the patient's wishes. One of the largest studies of clinical practices at the end of life, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (the Support study) involved 4,805 patients in advanced stages of serious illnesses in five teaching hospitals located throughout

the United States. The study found that physicians often ignore advance directives. This was true even where, as in the Support study, efforts were made to improve physician-patient communication on end-of-life decisions. The reasons are several, including unclear advance directives and pressure exerted by family members to ignore directives. Physicians may also fear that they may be sued for withholding life supports, although no such lawsuits have ever been successful.

ADs also pose a direct challenge to a physician's medical judgment. While the paternalistic model of the physician-patient relationship has been supplanted by one based on shared decision making and informed consent, remnants of the old model still remain. Physicians who see their primary goal as saving lives may also be less willing to yield to the patient's judgment, especially when it is difficult to predict with certainty whether life supports will enhance the patient's life or render dying more painful.

Attempts to address some of the deficiencies in ADs have taken several tracks. One approach is to make them more practical and easier to interpret and apply. One suggestion is to include specific medical scenarios and more detailed treatments (although too much specificity can leave out the present scenario). Partnership for Caring, an advocacy group located in Washington D.C., suggests including whether or not artificial nutrition and hydration should be provided being that these types of treatment often create disagreements. Another suggestion is to include a values history, a detailed rendition of the patient's religious, spiritual, and moral beliefs, which can provide guidance and clarification of the reasons for not choosing life supports. Still another approach recommended by the American Medical Association is the inclusion of general treatment goals, for example "restoring the ability to communicate" that can be used to assess the appropriateness of a given intervention. (8)

Other approaches to increase compliance with ADs have focused on the behavior of physicians. The medical profession has been criticized for not adequately preparing physicians for dealing with death. Professional medical groups, such as the American Medical Association, have become more involved in

preparing physicians by issuing guidelines and reports. A more extreme approach is advocated by some who have proposed imposing sanctions, either professional disciplinary action or penalties and fines, for ignoring an advance directive. Other approaches include making the public and medical providers more aware of ADs, and making them more accessible. (3,4,5,7,8,9) An important public education component of the law requires health care providers to educate their staff and the public about advance directives.

### CONCLUSIONS

Advance directives are a relatively new phenomenon in medical care, with the first laws providing for them passed in the latter part of the twentieth century. They are a way of recognizing the patient's right of autonomy. Although there is widespread public support, especially in the USA, Canada, The UK, Ireland, The Netherlands, that support is often more theoretical than practical. Changes in medical practices, the public's awareness, and the documents themselves have been proposed in order to encourage their use.

The primary health care physician is the key figure and the initiator of this change.

*'We must then have the courage to comply with their decisions even when those would not be our own decisions for ourselves. That -- and only that -- is truly "doing it all" for our patients.'*

*Steven K. Rothchild, Associate Professor, Departments of Family Medicine and Preventive Medicine, Rush University Medical Center, Chicago IL.*

### REFERENCES

1. Advance Directives. [http://www.deathreference.com /A-Bi/Advance-Directives.html](http://www.deathreference.com/A-Bi/Advance-Directives.html)
2. Advance Care Planning: A Guide for Health and Social Care Staff. The University of Nottingham, [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)
3. Gerrit van der Wala, Dorly J.H. Deeg, Frequency and determinants of advance directives concerning end-of-life care in The Netherlands. *Social Science & Medicine* 62 (2006) 1552–1563.
4. Koch, Tom. "Life Quality vs. the Quality of Life: Assumptions Underlying Prospective Quality of Life Instruments in Health Care Planning." *Social Sciences and Medicine* 51 (2000):419–427.
5. Lens, Vicki, and Daniel Pollack. "Advance Directives: Legal Remedies and Psychosocial Interventions." *Death Studies* 24 (2000):377–399.
6. LoBuono, Charlotte. "A Detailed Examination of Advance Directives." *Patient Care* 34 (2000):92–108.
7. Mette L. Rurup, Bregje D. Onwuteaka-Philipsena, Agnes van der Heide, The Ethical Framework, <http://www.hospicefriendlyhospitals.net/ethical-framework>
8. Monagle John, David C. Thomas, Health Care Ethics, Critical Issues for the 21-st century. Jones and Bartlett Publishers Inc., 2005, pp 594.
9. Silveira, Maria J., Albert DiPiero, Martha S. Gerrity, and Chris Feudtner. "Patients' Knowledge of Options at the End of Life: Ignorance in the Face of Death." *Journal of the American Medical Association* 284 (2000):2483–2488.