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Directing citizens to create advance directives

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Summary

This article describes the Swiss law on advance directives that was passed at the beginning of 2013 and led to more certainty about the legally binding character of such directives. However, for various reasons the drafting of advance directives is not yet widespread in Switzerland, and many resources might be put to better use if this became a common practice. A recent proposal by members of a political party to make the discussion, although not the actual drafting, of advance directives mandatory was rejected by the Swiss Federal Parliament, and the proposal was written off after having been pending for 2 years. We consider that the rejection of this proposal was not justified and that discussion of advance directives should become mandatory, so that individuals can fully assume their role as responsible citizens taking proactive decisions. The decision not to draft advance directives should be a deliberate one, marking a shift from the current "opt-in" approach to an "opt-out" scenario.

Keywords: *advance directives, Switzerland, decision making, mandatory discussion, opt-out approach*

Introduction

The topic of advance directives is becoming more and more prominent in public discussion about the end of life. In Switzerland, a revision of the Swiss Civil Code has made it mandatory for medical staff to act according to patients' advance directives. This law was passed at the beginning of 2013. Unfortunately, even though many people know about the existence of advance directives, only a small minority actually draft them – Breitschmid and Wittwer (2011) estimated 5% of the population – and leave instructions about where to find the documents [1].

Although in theory overtreatment or "medically futile treatment" should not occur if well-informed patients state clearly which treatments they do and do not wish to receive, there are various determinants of overtreatment. Not all of them can be addressed by increased use of advance directives and, of course, when drafting directives, the patient can still choose to have as much treatment as possible, which can be challenging in the context of scarce resources [2]. However, the fact that medical care for patients in hospitals is most intensive during their last year of life might indicate unrealistic wishes and maybe overblown expectations of treatment. Conti et al. (2012) stated that "It is not clear how much should be invested in the last years of life whereas the costs are known to increase in parallel. Since intensive care units (ICU) are costly with highly specialized personnel, it seems of paramount importance that they would be used efficiently" and emphasised the importance of "the need of examining not solely the hospital survival but the quality of life of the patients when they return to their real life" to achieve "a better allocation of resources", judge "the appropriateness of care" (in this case for ICU caregivers, but this can be extended to many other fields of medicine) and initiate "a social and political reflection" [3].

Switzerland is a member state of the Council of Europe and has signed the "Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine" (1997), usually called the "Oviedo Convention". This Convention states in article 9 that the "previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account", underlining the importance of advance directives [4]. The binding character of advance directives is reflected in Swiss legislation, but has not yet led to a notable increase in their use. According to a survey from 2017, 76% of participants in the German-speaking part of Switzerland, 48% in the Italian-speaking part and 38% in the French-speaking part had heard about advanced directives. However, only 27% of persons in the German-speaking, 10% in the French-speaking and 5% in the Italian-speaking part of Switzerland had completed advance directives [5].

Advance directives have been discussed regularly in Swiss medical journals, mostly by physicians. Authors describe various obstacles to addressing them. Lenherr et al. (2012) cite as the two foremost reasons "lack of time and/or privacy" and "personal reasons, such as feeling confronted with one's own mortality" [6]. Organisational problems such as lack of time or privacy might be easily remedied, but more deep-seated problems such as denial of death may represent the main reasons for the general avoidance, as is the case for the topic of organ donation [7]. This is possibly not only on the patients' part but also from that of the physicians, for whom "resistance or denial in their patients" may be one reason to avoid the topic [7]. Lenherr et al. stated that "biomedical rhetoric of death as a 'medical failure'

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now competes with the emerging public rhetoric of 'death as a part of life'" but that "communication about a patient's end of life is not yet a routine part of care", making it too easy to keep this on a general level and avoid it with one's own patients. They also point out that the communication skills of physicians were criticised by family members of dying patients and wondered if participating physicians overstated their willingness to address this topic because of social desirability [6]. Other possible obstacles may be lack of awareness of advance directives, the false assumption that advance directives are mainly used to refuse treatment and consequently shorten life, perceived stress and fear of formalities and technical language, unwillingness of healthcare professionals in general to address the subject, or perceived irrelevance of advance directives [8–10]. Another hypothesis is that the massive extension of out-patient care in the US led to a significant decrease of advance directives there [2].

A well-informed patient cannot make choices without considering questions regarding the end of life, which is not a possibility but a certainty. Lenherr et al. (2012) discussed the "ethical obligation on the side of the healthcare professionals to support openness, respect for autonomy and dignity by addressing issues of dying and death with the patient in order to assist in advance care planning." Too often, however, the notion of "advance care planning" even in palliative hospital wards is not much more than a simple routine question about reanimation wishes and a note "do not attempt resuscitation" [6]. Otte et al. (2014) underlined the necessity of an extensive, specific and concrete record of the patient's preferences [11].

Unlike the case of organ donation, where young people are actively encouraged to think about the issue (in spite of the associated idea of mortality and death) and ideally fill out a donor card, public discussion of the need for clear directives is low-key. For organ donation, certain countries have changed from an opt-in to an opt-out model, making the decision in favour of organ donation the default, unless a clear statement of opting out can be produced. For advance directives, this might be difficult or even impossible from a logistical point of view, and the benefit is not as straightforward and easy to see. However, a possible option could be to make drafting advance directives mandatory unless a specific opt-out document stating that for specific reasons the individual did not want to do so is signed. This document would then be stored in the same place as advance directives (discussed below). In the absence of advance directives, the decision-making process as defined by the law involves the treating healthcare professional and a therapeutic representative designated by the patient. If no therapeutic representative has been named, the healthcare professional must obtain the consent of the patient's legal representative before any intervention. In the absence of a legal representative, relatives can give consent on the patient's behalf. If no relatives are known, or if they do not want to take medical decisions, the competent authority appoints an independent counsel.

In 2014, members of a political party proposed to the Swiss National Council a law to making discussion of advance directives mandatory for everybody aged 50 years or older (Postulate 14.3258 submitted by Alec von Graffenried and taken over by Christine Häsler, see https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20143258). The reasoning behind this initiative was that although in theory advance directives are approved of by a large part of the population, only a minority have drafted one and communicated its contents to family members or healthcare proxies. The Federal Council voted to reject this proposal on the grounds that more experience with optional advance directives was needed and that this topic had been discussed in Parliament, although it also stated that ways in which optional advance directives could become more widespread should be examined. The proposal was finally written off in 2016 because the topic had been pending for more than 2 years.

We wonder if the arguments presented by the Federal Council are sufficient reason for the rejection and would like to develop practical measures to increase public discussion of, and adherence to, advance directives.

Ethical arguments

In bioethics, from a principlist point of view, there are several arguments in favour of a more straightforward approach to advance directives. We will first consider the principles of biomedical ethics as formulated by Beauchamp and Childress in accordance with their principlist approach [12].

Autonomy

Patients should make the decisions that are documented in advance directives after considering all potential consequences for their health and wellbeing, and these decisions must be respected by the other parties involved in the process. Family wishes must not supersede the patient's own wishes; this point must be respected by caregivers and medical staff. A person who, after careful deliberation, does not want to draft advance directives should not be obliged to do so, although the fact of it being a sensitive or personal matter does not in itself constitute enough reason to avoid the discussion (see Shaw 2015 [7]). Advance directives should be seen as a means to maintain autonomy by making personal preferences clear. It might be argued that making discussion of directives mandatory is itself a violation of autonomy, but the aim is to increase patients' autonomy when they are incapacitated, which enhances autonomy overall; in addition, we suggest allowing an opt-out for those who do not wish to create a directive.

Justice

Scarce and finite healthcare resources must be allocated across the whole population. If they are spent on unnecessary interventions, they cannot be spent on treatments that may be beneficial. In the context of dementia patients in nursing homes, Hersch Nicholas (2014) showed that having advance directives was associated with significantly less aggressive care at the end of life and consequently also with less healthcare spending [13], maybe because of fewer interventions such as tracheostomy, intubation, feeding tube placement, haemodialysis or enteral/parenteral nutrition. Resource allocation relates to not only financial but also human resources. Conti et al. (2012) suggested that ICU (and probably other) caregivers might suffer from decreasing motivation and even from burnout when they see the medical situation and that wishes of patients at the end of life are not respected and that the care they provide for

these persons is not appropriate [3]. Physicians need to forgo treatments that are unreasonable or will not achieve the results expected by the patient, not only in line with this principle, but also because futile interventions are against their professional ethics. In addition, Breitschmid and Wittwer (2011) mentioned that significant resources might be needed in order to determine the probable wishes of an individual who has not made an advance directive and to determine the legally binding representation of a person who has neither drafted an advance directive nor appointed a legal representative [1]. Although introducing systematic advance directives could be costly in the beginning, this could be seen as an initial, one-off cost intended to lead to a more just system.

Beneficence

Avoiding discussion about the end of life might increase the number of days lived, but this is not equivalent to quality of life. Predictions of caregivers are incorrect in many cases, and benefit of treatments can be increased by relying on advance directives [3].

The beneficence principle usually revolves around what would be good for the patient. Views of what defines "good for the patient" might differ depending on moral or religious convictions, and problems arise when there is not much information about the patient's convictions. The possibility described by Roscam Abbing in 2012 (relatives of vulnerable persons are influenced by healthcare professionals to agree to the course of action that is considered "best" by the healthcare professional) presents a risk that must not be neglected, even if there usually is no malign intent on the part of the healthcare professional. Advance directives can help to avoid this problem as the individual has the possibility not only to choose specific treatment options for certain situations, but also to convey more general information on preferences, world view and moral or religious values that need to be respected in a situation that was not specifically described in the advance directives. If we assume that a formerly competent patient generally knows best what is good for him or her, this principle is in line with the principle of respect for autonomy [14].

Advance directives can also help in situations where families would otherwise project their own values onto the patient, rather than providing information about his or her values, which might be different. Ideally, treatment options are discussed by the patient and his/her family, and in addition to drafting advance directives, the patient designates a healthcare proxy who is aware of this role and willing to accept it. The choice of a healthcare proxy should not rely on medical or clinical knowledge alone, but must also take into account family dynamics so that the proxy receives as much support as possible when defending the patient's choices. Written advance directives would support the healthcare proxy when discussing treatment options with healthcare professionals. Such a balanced and sufficiently early approach to advance directives would avoid incomplete directives that are hastily drafted as a requirement before moving to a nursing home, as described by Wiesing et al. (2010) in the German context and Otte et al. (2014) for Switzerland [11, 15,]. This practice is still widespread although the 2017 guidelines of the Swiss Academy of Medical Sciences explicitly prohibit it [16].

Non-maleficence

As formulated by Beauchamp and Childress (2001), non-maleficence means that "one ought not to inflict evil or harm." Overtreatment or "futile treatment" can cause actual harm to the patient [12]. As Conti et al. (2012) stated, the care given should be appropriate, and benefit of care and burden of care need to be carefully balanced [3]. Wiesing et al. stated that physicians may sometimes overtreat because they focus on the technically feasible instead of the medically appropriate treatment (which may consist of doing nothing) [15]. Application of treatments mentioned as unwanted in advance directives may represent physical assault, which can result in criminal charges [11]. Possible liability has been described by Castillo et al. (2011) and Burkle et al. (2012); Pope (2017) emphasised that many clinicians seem to think, mistakenly, that there are no legal consequences of "doing too much" and to "err on the side of saving or prolonging life" in spite of the patient's documented wishes [17–19]. The question of whether this might be a reason for physicians to circumvent the topic of advance directives is not within the scope of this article, but merits more thought. More information for physicians on the legal framework might be necessary to show that correctly written advance directives help to clarify the limits of their responsibility.

Other ethical approaches

Apart from the principlist approach, sometimes criticised as being ambiguous or incomplete (see [20]), other bioethical arguments merit examination, for example the deliberative and value-based approach.

A human rights-based approach, as described by Andorno (2016), could be applied to the topic of advance directives because of their high value, as expressed in an international convention, although these directives are not legally binding in all member states of the Council of Europe [21]. Switzerland incorporated the binding character of advance directives into its civil law, so a more proactive approach towards drafting them would show that individuals are seen less as patients or "consumers of health care" (Malpas 2011) and more as informed and empowered citizens that are not only able but supposed to make informed choices [22]. This outlook would correspond to the subsidiary principle that is found in Switzerland on many levels – that decision-making powers should always be at the lowest possible level, and that Swiss citizens are supposed to make many decisions themselves, for example through popular votes and referendums, instead of delegating them to experts.

Zambrano (2016) recommended concentrating on action instead of principles, and establishing a correspondence between the two [23]. For example, on the basis of a wider view of the relations between individuals, drafting advance directives would be useful as the persons involved would know the individual's wishes and could act accordingly, even if they did not agree with all of them. Instead of the individual declaring preferences in isolation, these preferences could be discussed and explained. If goals are genuinely divergent, the will of the individual would prevail, but in many cases where conflict is feared, it can be minimised or eliminated through discussion, explanation or mediation. In this way, our proposal would enhance rather

than violate autonomy through increased discussion and exchange.

Practical steps towards a possible solution

Accepting and facing one's own mortality is not easy, but needs to be addressed not only in order to gain optimal control over one's living conditions, goals and aims in a broad sense, but also to dispel unrealistic ideas concerning healthcare and treatment wishes. If family members or close friends are designated as healthcare proxies, advance directives can help to reduce the burden of decision-making, as the wishes of the patient are documented. According to Hickman et al. (2015) and Lord et al. (2015), healthcare proxies of seriously ill patients who had drafted advance directives reported less emotional and decisional burden than those who were less aware of the patient's healthcare preferences [24, 25]. If a person agrees to face these possibly uncomfortable topics and think about future questions related to health and illness, there are a number of models for advance directives, as many health institutions and nongovernmental associations offer their own versions. Having to choose between these and the additional possibility of drafting a free text directive may be overwhelming and lead to discouragement when trying to find the "best" model. Once the advance directives are completed in a correct and legally binding way, it is important for them to be easily accessible. This means that (1) the existence of advance directives must be known in case of hospitalisation and (2) the advance directives must be easy to find, in either a paper or an electronic version. However, the drafting of advance directives should not be an isolated act, but integrated into a broader framework of advance care planning. As Rietjens et al. (2017) and Bobbert (2016) explained, this involves patients, families and healthcare professionals working together in an interdisciplinary manner, and may even require changes to the healthcare system and society in general to encourage discussions around illness and the end of life [2, 26]. Advance directives should be revised periodically as an individual's circumstances may change, for example, after diagnosis of a disease or its progression.

In line with the proposed law, we suggest that certain timepoints in life could be suitable for discussing advance directives with knowledgeable persons (advance directives experts) employed by some public and neutral body. This could be seen as a modern rite of passage, in order to prepare for older age. We could imagine triggers such as reaching the age for early retirement, or turning 50 and thus entering the second half of life, as the number of centenarians continues to steadily increase: according to the UN (2011), the number of centenarians in 2050 is estimated at 3.2 million, 68% of whom will be living in the more developed regions [27].

An alternative age would be 40 years, the advent of middle age. Although this age (or 50) might seem too young, there is no harm in recording one's wishes with a directive that can be revised whenever one wishes. It would also prevent presumed "ageism" and the erroneous perception that advance directives usually concern end-of-life situations after a long, chronic illness, as discussed by Malpas (2011) [22]. During this conversation, advice could be given on different models of advance directives, their respective advantages and disadvantages, and possible problems when completing them. It would also be stressed that there is no obligation to complete advance directives, only to be aware of their importance. If the person is open to completing advance directives, a follow-up meeting could be offered to go over the completed version and make sure that the contents are in line with legal requirements and are informed, understood and voluntary (see [2]). The discussion could also cover nomination of a proxy for decision-making in the event of loss of capacity.

For this conversation to be nonthreatening and useful, we think that advance directives experts need to be trained in interpersonal communications and negotiation skills, in addition to having a knowledge of psychology. It is also important that the body that employs these experts does not depend directly on an institution connected to health or social benefits, as this could be perceived as a conflict of interest.

Ideally, if complete advance directives are part of a broader model of advance care planning (see [2]), they should include not only treatment wishes and preferences, but also cover related topics, most of all organ donation. If organ donation were included in these discussions as a matter of course, making directives mandatory would also make it mandatory to at least consider recording one's wishes regarding donation – which would probably improve donation rates. Making discussion about directives mandatory would also benefit organ donation in another way in the Swiss context: if (as we suggest below) health insurance cards routinely recorded whether a person has a directive, and most such directives contain a record of donation intentions, a *de facto* organ registry would be created in a country where one does not currently exist, and confidentiality of the information would be guaranteed. Although people can create organ donor cards in Switzerland, many of those who do so do not remember to carry them – this is less likely with a health insurance card. (Electronic directives would be more appropriate in relation to donation as they can be accessed more quickly.) When discussing organ donation in the context of a discussion around advance directives, the advance directives experts must be careful not to express their own preferences or values, or irrational forms of influence, as described by MacKay and Robinson (2016) [28]. Neither should the expert propose treatment options or limitations that have an impact on a possible organ donation. One possibility might be to have a standardised conversation guide.

As stated above, general principles and values can sometimes help to indicate what the person would have preferred in a specific situation that has not been explicitly covered. The course of many illnesses and treatments cannot be predicted, so deducing the patient's wishes from this information can be crucial. The drafting of useful and appropriate advance directives is in itself a complex matter, as many patient organisations and other nongovernmental organisations offer forms that vary in content. Furthermore, it is possible to draft advance directives in a free text format, without any legal requirements other than that their content must not contravene any law that is in place and that the directives must be dated and signed by the person who drafted them.

The completed and signed advance directives could then be stored centrally (for example in a registry on a secured

website) to facilitate accessibility in case of need. Again, this site should be independent from healthcare providers or health insurance companies to avoid any conflict of interest. However, health insurance companies could be notified of the existence of advance directives so that they can make a corresponding entry on the health insurance card and make sure that the data can be read with the software used by nursing homes, hospitals, physicians' practices and other health institutions. Another, less formal, possibility is to add a sticker on the health insurance card indicating the existence of advance directives and giving access information. Even today, article 371 II of the Swiss Civil Code states that a person who has drafted advance directives can enter this fact, as well as the place where the advance directives are stored, on their health insurance card. However, this is only a proposal that is not likely to prevent cases where written advance directives are in the person's home with nobody else knowing about them, as according to article 372 I of the Swiss Civil Code the treating physician must only ascertain the existence of advance directives according to the health insurance card. The change from an optional to a mandatory entry on the health card or a similar document would thus seem reasonable in order to guarantee execution of the patient's wishes.

The electronic patient file that was approved in April 2017 and will be introduced from mid-2018 would be an ideal place, but here as well the opening of an electronic patient file is not mandatory. Persons with an electronic patient file who already have drafted advance directives will probably tend to store their advance directives there for reasons of traceability, but the existence of an electronic patient file *per se* does not address the question of how to reach people who have neither drafted them nor thought about drafting them.

Conclusion

In a modern, secular society, the finite character of life should not be a taboo subject, and topics that once were considered marginal, such as planning one's own funeral or holding death cafés to talk openly about matters around personal mortality, seem to be becoming more popular. Unfortunately, many resources are spent in a suboptimal way because this topic is still avoided and because patients are not always clear about their preferences for the end of life. This, in turn, is partly because of insufficient information about treatment options and their chances for success. Clear and open communication between physicians and patients could partly remedy this. Proactive explanations from doctors and other health professionals of why initiating advance care planning, and as a part of this drafting advance directives, is a constructive and responsible action might encourage patients to think about this matter and follow it up. Some nudging from public authorities might be another step towards having more people taking conscious decisions on how to approach possible and realistic options at the end of life. This should be facilitated by ensuring that the drafted decisions will be easily traceable when necessary.

We are of the opinion that the arguments presented by the Federal Council were not sufficient reason for the rejection, but rather served to avoid the discussion of mortality and illness-related costs in society. In a time of scarce resources, accentuated by an ever-higher life expectancy, this strategy is questionable and does not serve the interests of the general population. Instead, steps should be taken to encourage proactive discussion of advance directives so that their drafting becomes common practice.

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References

1 Breitschmid P, Wittwer C. Die Stellung der Medizinalberufe im neuen Erwachsenenschutzrecht. Jusletter 31 January 2011.
2 Bobbert M. Patientenverfügungen zwischen Antizipation, Selbstbestimmung und Selbstdiskriminierung. Jusletter 25 January 2016.
3 Conti M, Merlani P, Ricou B. Prognosis and quality of life of elderly patients after intensive care. Swiss Med Wkly. 2012;142:w13671. doi: http://dx.doi.org/10.4414/smw.2012.13671. PubMed.
4 Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. European Treaty Series No. 164. 1997. Available at: https://rm.coe.int/168007cf98.
5 Pro Senectute Schweiz. Selbstbestimmen bei Urteilsunfähigkeit – Zahlen und Fakten. 1 October 2017. Available at: https://www.prosenectute.ch/de/medien/newsroom.html. Accessed 11 April 2018
6 Lenherr G, Meyer-Zehnder B, Kressig RW, Reiter-Theil S. To speak, or not to speak -- do clinicians speak about dying and death with geriatric patients at the end of life? Swiss Med Wkly. 2012;142:w13563. doi: http://dx.doi.org/10.4414/smw.2012.13563. PubMed.
7 Shaw D. Organ donation is the right decision: a delicate truth. Intensive Care Med. 2015;41(8):1487–8. doi: http://dx.doi.org/10.1007/s00134-015-3891-1. PubMed.
8 Perkins HS. Controlling death: the false promise of advance directives. Ann Intern Med. 2007;147(1):51–7. doi: http://dx.doi.org/10.7326/0003-4819-147-1-200707030-00008. PubMed.
9 Fagerlin A, Schneider CE. Enough. The failure of the living will. Hastings Cent Rep. 2004;34(2):30–42. doi: http://dx.doi.org/10.2307/3527683. PubMed.
10 Sahm S, Will R, Hommel G. Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff. J Med Ethics. 2005;31(8):437–40. doi: http://dx.doi.org/10.1136/jme.2004.009605. PubMed.
11 Otte IC, Jung C, Elger BS, Bally K. Advance directives and the impact of timing. A qualitative study with Swiss general practitioners. Swiss Med Wkly. 2014;144:w14035. doi: http://dx.doi.org/10.4414/smw.2014.14035. PubMed.
12 Beauchamp TL, Childress JF. Principles of Biomedical Ethics. Fifth Edition. New York: Oxford University Press; 2001
13 Nicholas LH, Bynum JPW, Iwashyna TJ, Weir DR, Langa KM. Advance Directives And Nursing Home Stays Associated With Less Aggressive End-Of-Life Care For Patients With Severe Dementia. Health Aff. 2014;33(4):667–74. doi: http://dx.doi.org/10.1377/hlthaff.2013.1258. PubMed.
14 Roscam Abbing HDC. Health and Human Rights in the European Context. In: Rynning E, Hartlev M (2012). Nordic Health Law in a European Context. Welfare State Perspectives on patients' Rights and Biomedicine. Malmö: Liber; 2012.
15 Wiesing U, Jox RJ, Hessler HJ, Borasio GD. A new law on advance directives in Germany. J Med Ethics. 2010;36(12):779–83. doi: http://dx.doi.org/10.1136/jme.2010.036376. PubMed.
16 Schweizerische Akademie der Medizinischen Wissenschafte. Medizinethische Richtlinien und Empfehlungen. Patientenverfügungen. Bern: SAMW; 2017. Available at: https://www.rwi.uzh.ch/dam/jcr:f7c5b696-6fab-4e8a-9004-18800a87c0e7/SAMW-RL%20Patientenverf%C3%BCgung.pdf.
17 Castillo LS, Williams BA, Hooper SM, Sabatino CP, Weithorn LA, Sudore RL. Lost in translation: the unintended consequences of advance directive law on clinical care. Ann Intern Med. 2011;154(2):121–8. doi: http://dx.doi.org/10.7326/0003-4819-154-2-201101180-00012. PubMed.
18 Burkle CM, Mueller PS, Swetz KM, Hook CC, Keegan MT. Physician perspectives and compliance with patient advance directives: the role external factors play on physician decision making. BMC Med Ethics. 2012;13(1):31. Published online 21 November 2012. doi: http://dx.doi.org/10.1186/1472-6939-13-31. PubMed.

19 Pope TM. Legal Briefing: New Penalties for Ignoring Advance Directives and Do-Not-Resuscitate Orders. J Clin Ethics. 2017;28(1):74–81. PubMed.

20 Serna P, Seoane JA, Eds. Bioethical Decision Making and Argumentation. International Library of Ethics, Law, and the New Medicine, vol 70. Cham: Springer International Publishing; 2016. doi:10.1007/978-3-319-43419-3.

21 Andorno R. A Human Rights Approach to Bioethics. In: Serna P, Seoane JA (Eds.). Bioethical Decision Making and Argumentation. International Library of Ethics, Law, and the New Medicine, vol 70. Cham: Springer; 2016. doi: http://dx.doi.org/10.1007/978-3-319-43419-3. .

22 Malpas PJ. Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand. J Med Ethics. 2011;37(5):285–9. doi: http://dx.doi.org/10.1136/jme.2010.039701. PubMed.

23 Zambrano P. Types of Action and Criteria for Individualizing Them: The Case of Omission of Life-Saving Care. In: Serna P, Seoane JA (Eds.). Bioethical Decision Making and Argumentation. International Library of Ethics, Law, and the New Medicine, vol 70. Cham: Springer; 2016. Doi: http://dx.doi.org/10.1007/978-3-319-43419-3. .

24 Hickman RL, Jr, Daly BJ, Clochesy JM, O'Brien J, Leuchtag M. Leveraging the lived experience of surrogate decision makers of the seriously ill to develop a decision support intervention. Appl Nurs Res. 2016;30:67–9. doi: http://dx.doi.org/10.1016/j.apnr.2015.10.012. PubMed.

25 Lord K, Livingston G, Cooper C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. Int Psychogeriatr. 2015;27(8):1301–12. Published online 14 April 2015. doi: http://dx.doi.org/10.1017/S1041610215000411. PubMed.

26 Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al.; European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol. 2017;18(9):e543–51. doi: http://dx.doi.org/10.1016/S1470-2045(17)30582-X. PubMed.

27 United Nations, Department of Economic and Social Affairs, Population Division. World Population Ageing: 1950-2050. New York: United Nations; 2001.

28 MacKay D, Robinson A. The Ethics of Organ Donor Registration Policies: Nudges and Respect for Autonomy. Am J Bioeth. 2016;16(11):3–12. doi: http://dx.doi.org/10.1080/15265161.2016.1222007. PubMed.