

GUEST EDITORIAL

The misleading simplicity of advance directives

The question of what constitutes a dignified old age has always been a topic of philosophical enquiry. Already in the writings of the stoic philosophers we can find relevant contributions to an ethic of “successful” aging. Seneca, for instance, reflects upon the pleasures of old age in several of his famous “Letters to Lucilius” (Seneca, 1967). However, he also writes about the bad years that may lie ahead and confides to his pupil: “Do not hear me with reluctance as if my statement applied directly to you, but weigh what I have to say. It is this. I shall not abandon old age, if old age preserves me intact for myself, and intact as regards to the better part of myself; but if old age begins to shatter my mind, and pull its various faculties to pieces, if it leaves me, not life, but only the breath of life, I shall rush out of a house that is crumbling and tottering . . .”

Much has changed since Seneca wrote these words. Today, more and more people age successfully, enjoying increased physical and mental fitness and a high level of emotional and personal well-being. However, for those entering the fourth age, growing old still takes its toll, because of impending losses in learning potential and mental functioning and a strongly rising prevalence of dementia. In view of this grim perspective, Seneca’s position appears to be far from anachronistic. For what dignity is there in being left with “only the breath of life”?

The instrument of the “advance directive” – or “living will” as this document was originally named when it was first introduced in 1969 – can be seen as a contemporary, originally American alternative, to the more drastic solution to this challenging question proposed by Seneca in his day. In his book *Life’s Dominion*, legal philosopher Ronald Dworkin – a strong advocate of advance directives – presents the case of Margo, a once intellectually vibrant and independent woman who, as a consequence of dementia, has become but a shadow of her former self and is now totally dependent on the care of strangers. Although there are no signs of suffering, Margo lives a life she would never have chosen if she still had a voice to speak. Yet, as Dworkin hypothesizes, if she had executed an advance directive, refusing any and all treatment, then pneumonia could offer her a dignified way out of her deteriorated state (Dworkin, 1993).

Over the years, the “Dworkinian” point of view has received much support. But do advance directives really offer a realistic solution to the complex problem that called them into existence? What can we learn in this respect from more than 30 years of experience, at least in the USA, with advance directives? This is a relevant question in view of the fact that more and more countries are issuing legislation regarding advance directives. In addition, international organizations such as Alzheimer Europe (2005) promote the use of advance directives for decisions covering a wide range of health-related issues, including treatment and care.

Definition and roles

A widely accepted definition describes advance directives as “written instructions executed by decisionally capable adults that pertain to future medical treatment preferences of the party executing the document. These directives take effect only if the patient is decisionally incapacitated at the time that specific decisions need to be made” (Kapp, 1995).

Advance directives can be classified into two categories: treatment directives and proxy directives. A treatment directive refers to a document specifying what kind of treatment the author desires under specific conditions in the event of incapacity, while a proxy directive empowers another person (e.g. health care proxy or durable power of attorney) to make decisions on behalf of the author. Both types of directives can also be combined (de Boer *et al.*, 2010). Morally, advance directives are rooted in the doctrine of informed consent. With expanding technology they became a key issue of the autonomy based bio-ethics movement of the 1970s. Central to this ethic is the judgment that autonomy is the core value to guide medical decision-making. Respecting autonomy allows individuals to shape their lives according to their personal values and preferences. In case of incompetence, when contemporaneous autonomy is no longer possible, so called “precedent” or “prospective autonomy” in the form of previous statements and expressed beliefs relevant to the treatment issues at stake should govern the outcome (Dworkin, 1986). This is especially true for advance

statements that refuse treatment, since the informed consent doctrine holds that medical interventions are only allowed in the case of free and uncoerced consent – and consent can be withheld, even years ahead (Vezzoni, 2005).

Of course, advance directives were not designed with an exclusive focus on dementia and patients' fear of having to live through all its stages. In fact, their promotion was highly influenced by much-debated court cases on end-of-life decision-making in patients in a persistent vegetative state (PVS), such as the Karen Ann Quinlan case (Brown, 2003; Kirschner, 2005). Such cases enforced patients' feelings of powerlessness with regard to receiving care consistent with their preferences in case of incapacity. Hence, the anticipated role of advance directives was first and foremost to allow people to refuse "death-delaying" interventions in the event of incompetency and terminal illness or PVS.

Initially, the enthusiasm for advance directives was largely ideological, inspired as it was by the "new kid on the block" in medical ethics: the emphasis on patient autonomy (Faden and Beauchamp, 1986). Empirical knowledge on the subject was largely unavailable at the time and it was more or less taken for granted that advance directives would have a positive effect on medical culture and decision-making. However, these supposed positive effects were based on the assumption that the author of the advance directive is in a better position now than others will be in the future to decide how treatment decisions are to be made in the event of incompetency. Further, the author practices "auto-paternalism" by denying herself the right to a change of mind at a later moment and subordinates the interests of the future incompetent person to her prospective autonomy, just as Dworkin did in Margo's case. Moreover, Dworkin contended that prior choices should be implemented even if the patient with dementia explicitly expresses different wishes (Dworkin, 1986). Critical reflection on these premises and their consequences was scarce at the time and Rebecca Dresser (1992; 1995; 2003) was one of the few scholars who drew attention to the potential conflict between prior values of the still competent person and the welfare interests of the later incompetent person.

From theory to practice

With experience, however, came awareness of the problems, and empirical research gradually revealed that the reality was far from what proponents of advance directives had expected it to be. Since the disappointing findings of the first empirical

study into the practice of advance directives, the SUPPORT study (SUPPORT, 1995), a plethora of research articles and critical reviews have been published and multiple interventions were designed to stimulate the uptake of advance directives, including several attempts to redesign them in order to increase their practicability and relevance to decision-making. Of the problems that all this research has revealed, some are more practical, while others are more fundamental in nature. First of all, with the exception of one recent study suggesting a prevalence of 67.6% in a cohort of Americans aged 60 years and older (Silveira *et al.*, 2010), the overall frequency of advance directives continues to be low, notwithstanding the existence of legal rules encouraging their completion, such as the Patient Self-Determination Act (PDSA) in the USA that came into force in 1990 and obliges hospitals and nursing homes to provide written information to all adults concerning their right to formulate an advance directive. Secondly, when they are completed, advance directives are often not complied with because they contain vague or ambiguous instructions, thus raising the question whether the author really understood what he conveyed to paper (Teno *et al.*, 1997). One way of dealing with this problem is to standardize advance statements on treatment preferences and/or stimulate consultation with health professionals when one considers drafting an advance directive (e.g. Emanuel and Emanuel, 1989). In practice however, physicians are seldom involved in this stage and the presentation of the directive is customarily the end of the inquiry instead of the beginning (Vezzoni, 2005). In addition, when advance directives do contain clear information, it may nevertheless be uncertain whether the author wants his directive to be followed. Research has revealed that authors regularly find that their families and physicians should have "leeway" to override their directives (Sehgal *et al.*, 1992). And to further complicate matters, it has been shown that proxies do a poor job in interpreting advance directives, as they are frequently biased by their own treatment preferences (Fagerlin *et al.*, 2001).

However, the most poignant problems of advance directives pertain to the stability of preferences and the effects of advance directives on the quality of care-giving in the final stage of life.

Stability of preferences over time

Studies on the stability of treatment preferences have produced varying results and many of them are based on hypothetical not real-life decisions (Kirschner, 2005). We know, however, that our

anticipatory beliefs often fail to recognize our ability to adapt and that it is notoriously difficult to imagine how one's current preferences will hold in a given situation (such as dementia) that one has never experienced before (Hertogh *et al.*, 2007). In general, preferences for life sustaining treatments are probably most stable in people with a stable health condition. Hence, advance directives are most applicable in case of acute (traumatic) disorders, such as severe brain injury resulting in PVS (Kirschner, 2005). Unstable health, on the other hand, will lead to changing preferences. This phenomenon is often so impressive that it has been termed "the disability paradox": a life that was once despised before the advent of chronic disease is accepted and even embraced with advancing illness (Albrecht and Devlieger, 1999). Dementia is no exception to this "rule", as is testified by a growing body of research on living with dementia from the patients' perspective (de Boer *et al.*, 2007). People do not become demented overnight; instead the gradual course of the disease allows for adaptation and a shift in response. As a rule of thumb, one may say that vulnerable persons often change their minds, particularly when their minds have changed (Kirschner, 2005). But what if they forget to change their advance directive, or are no longer able to do so? Here we touch upon a key obstacle for complying with advance directives.

Effect on care-giving in the final stage of life

In several jurisdictions the condition of applicability of advance directives is restricted to terminal illness or imminent death situations; in others (e.g. the Netherlands) such restrictions do not exist and advance directives take effect from the outset of decisional incapacity. In dementia and associated neurodegenerative disorders, however, mental incapacity precedes the end of life and related medical decisions for an extended period. During this period patients may enjoy relatively good physical health, although they may suffer from intercurrent ailments (e.g. respiratory and urinary tract infections), exacerbation of comorbidity (e.g. heart failure), or trauma (hip fracture). Yet, advance directives offer no guidance with regard to routine medical care, and how they affect the many decisions that have to be taken during the final stage of life is largely unknown (Messinger-Rapport *et al.*, 2009; Gillick, 2010). Nonetheless, we do have some data. One qualitative study performed in the Netherlands showed that doctors and families of demented patients with an advance directive tend to base their decisions more often on a best interest standard, rather than on the advance directive:

the directive is discussed repeatedly but seldom complied with (The *et al.*, 2002). The findings of this study suggest that the conflict between precedent autonomy and current welfare interests, envisaged by Dresser, does not arise as such in actual practice and that the way past preferences are weighed is not influenced by the presence of an advance directive. However, research into the practice of advance directives for euthanasia in dementia has yielded some opposite results (Rurup *et al.*, 2005). Although euthanasia was never performed, it can be gathered from this study that advance directives for euthanasia were occasionally respected by adopting a radical non-treatment policy, resulting in undertreatment of burdensome symptoms and insufficient palliative care. Thus, acting in accordance with prior instructions may very well conflict with the duty to protect incompetent persons from harm. In such a situation, strict adherence to an advance directive can result in the opposite of a dignified death and must be considered unethical.

Advance care planning beyond the living will

In view of these dilemmas, what role can be accorded to advance directives in planning for future care? Looking back on more than three decades of prodigious efforts to implement and increase the uptake of advance directives, Muriel Gillick summarizes a growing consensus among experts when she writes that "the directives have been a resounding failure" (Gillick, 2010). They were a naive solution, proposed by an empirically uninformed bio-ethics for a human problem of overwhelming complexity. Yet, notwithstanding this failure, what the practice of advance directives does demonstrate is the relevance for health professionals to invest in helping people to plan ahead, specifically those who are facing a future of uncertainty with a high risk for incapacity, such as patients diagnosed with dementia and their families. The challenge now is to move on from static documents to a more dynamic practice of advance care planning, defined as a dialogical process of supporting patients and their proxies to think ahead and formulate goals of care as they confront the challenge of a progressive illness trajectory (Messinger-Rapport *et al.*, 2009; Gillick, 2010; Hertogh, 2010). Such advance care planning should start early and must be firmly rooted in doctor-patient communication. It involves clarifying the patient's health status, determining his/her needs and values, and subsequently developing treatment plans that will be reassessed regularly and following any significant change in health. Furthermore, this

process should be flexible and sensitive to the patient's views on autonomy. Indeed, the lesson that must be learned from the experience with advance directives is that clearly not everyone desires to manage and control their future (Winzelberg *et al.*, 2005). Some people prefer to live life one day at a time and many wish to share the burden of decision-making with others, or even delegate this responsibility to their families and health professionals. Nonetheless, a timely start in exploring their ideas about how to deal with the challenges that lie ahead will allow others to better represent the interests of persons with dementia as the illness advances and capacity diminishes. It follows that this approach to advance care planning is time consuming and calls for high quality communicative skills, as well as for preparedness of doctors to take on a (pro)active role, using their knowledge of the disease trajectory in a way that is tailored to the patient's needs and preferences (Hertogh, 2010). Although they may feel a little uncomfortable with this responsibility after so many years of autonomy-centered decision-making, this approach is central to an ethic of care for people with dementia and will better serve their interests and those of their families than the mere signing of a form or the ticking of a checklist of interventions to be accepted or denied.

CEES M. P. M. HERTOIGH

Professor in Geriatric Ethics, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, the Netherlands
Email: cmpm.hertogh@vumc.nl

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