

Lost decisional capacity – lost chance of Advance Care Planning?

Ralf J. Jox^a

^a Chair in Geriatric Palliative Care, Centre Hospitalier Universitaire Vaudois (CHUV)

Comprehensive models of Advance Care Planning (ACP) have been discovered as a more meaningful and effective alternative to the classic advance directive (living will) [1, 2]. This continuity of a new model replacing the old one is already suggested by the linguistic anaphora (both terms begin with the word “advance”). In Switzerland as in Germany and other European countries, ACP projects are being implemented that focus on facilitating anticipated care and treatment decisions of persons who are willing and able to engage in such conversations. These are often elderly citizens, persons with chronic organ diseases or cancer, individuals with an elevated educational background, a firm rooting in the majority culture and a well-developed socio-economic situation. Strikingly, this development risks to neglect the vulnerable persons of society, the less educated, the cultural minorities, the poor, the lonely and, most importantly, those that have already lost their decision-making capacity. There seems to be a generally accepted assumption that it is too late for ACP once the person has already progressed into a state of decisional incapacity: lost capacity, lost chance for ACP. Yet, is this true? In this viewpoint, I intend to show that this assumption is wrong and that, in fact, we need to extend ACP to those individuals who have lost decision-making capacity [3]. In a first step, I will show that there is a huge and rising need for this kind of “ACP by proxy”. In a second step, I will sketch the concept of this form of ACP and uncover both the analogies and differences to ACP with fully autonomous persons. As a third step, I will present the multifaceted ethical justification of ACP that applies equally well to persons without decisional capacity. In the fourth and last step, I will outline an agenda of research and policy projects that should be addressed to fully develop ACP.

Is there a need for ACP with incapacitated patients?

In aging Western societies the number of people with age-related neuropsychiatric diseases like dementia, cerebrovascular disease, neurodegenerative disorders and old-age depression is rising. Many of these people will at some point lose their decision-making capacity temporarily or permanently. In the transitional phase before ACP programs become widely implemented in the population, a large percentage of them will not have

issued any advance statements of their treatment preferences. Yet, even after this transitional phase, there will remain individuals who will not have engaged in ACP for several reasons, one of them being the refusal to plan ahead. In addition, there are people who have never possessed decision-making capacity because of mental retardation. For all of them, surrogates and health care professionals will have to make treatment decisions and prepare for future decisions in the case of a deteriorating health status. General practitioners often report that family members express the need to anticipate and plan treatment decisions for their incapacitated loved ones and in fact use “proxy advance directives” to guide future care [4]. This need is resembling the situation in pediatrics where advance directives by parents is a well-known phenomenon [5]. From a purely theoretical and legal point of view, this may be seen as unnecessary as physicians could always consult surrogate decision makers if decisions should be required. Yet, there are emergency situations that simply do not leave enough time to consult them. In addition, family members are often overwhelmed by situations of crisis and feel much safer and less burdened to discuss these treatment decisions in advance. A culture of planning ahead may reduce not only the burden on both surrogates and health care professionals, but it may also increase the likelihood of making responsible, well-reflected decisions.

What is the concept of proxy ACP?

Proxy ACP, as I will call it, closely resembles classic ACP. It is a comprehensive, longitudinal process of communication between the patient (as far as this is possible), the surrogate, the family, and health care professionals, facilitated by professionally trained persons who follow a structured and evidence-based approach. It also encompasses the regional implementation that is crucial for any effective ACP model. There are, however, two particularities to proxy ACP: (1) As the individual is already severely ill and lacks decisional capacity, his or her surrogate decision maker absolutely has to be involved in the conversations, while in classic ACP this is advised but not necessarily required; (2) The ultimate legal responsibility is assumed by the surrogate, not by the individual (due to decisional incapacity). Nonetheless, proxy ACP should involve the patients as

much as possible in the conversations, while being attentive to an adequate style of communication in order to prevent any burden to the patient. Moreover, these conversations should focus on the patient's values and preferences, especially if the patients have enjoyed decisional capacity before becoming seriously ill. As proxy ACP is not an exercise of *direct* autonomy but rather an example of *indirect* autonomy (with the surrogates representing the previously expressed or presumed will of the person), it may benefit from additional tools and procedures. One such tool may be the "patient preference predictor", a large database of correlates between treatment preferences and demographic characteristics (e.g., age, gender, ethnicity, educational status) that permit an individual prediction of treatment preferences which can support the surrogate's decision [6–8].

What is the ethical basis for proxy ACP?

Superficially viewed, the ethical justification for proxy ACP may be significantly different from that of classic ACP as it is not a direct expression of individual autonomy. But as pointed out above, patient autonomy is still central to most of proxy ACP, although this autonomy is indirectly accessed via substituted judgment and an exploration of the patient's previously expressed or presumed will. Moreover, the ethical basis of any ACP does not solely rest upon autonomy: it derives much of its justification from the psychosocial benefits for both the patient and the family along the process of ACP [9–11]. Putting aside the principles of biomedical ethics that support ACP (such as respect for autonomy, beneficence and non-maleficence), ACP can also convincingly be justified by a care ethics approach or a communitarian ethics approach [10]. All of these justifications are equally applicable to proxy ACP as to classic ACP. In fact, restricting ACP to people who possess full decisional capacity may even be seen an unfair discrimination of incapacitated patients, just as the lack of clinical trials in incapacitated patients is regarded an example of discrimination against this population.

What do we need to know about proxy ACP?

While there is a general need for sound research on ACP, it is even higher for proxy ACP. We need evidence about the right timing and process of proxy ACP, as well as on tools like the patient preference predictor that

can support surrogates in making patient-centered anticipatory treatment decisions. The legal status of proxy advance directives has still to be clarified. Finally, the effects of comprehensive proxy ACP programs on relevant outcomes (like treatment according to patient preferences, burden on caregivers and professionals, fair utilization of resources) should be investigated. These are just a few selected suggestions for future research without pretending to be comprehensive. As a first step, however, much would already be achieved if the idea of proxy ACP were known and seriously considered by all stakeholders in health care and research.

Correspondence

Ralf J. Jox, MD, PhD
Chair in Geriatric Palliative Care
Centre Hospitalier Universitaire Vaudois (CHUV)
University of Lausanne
Avenue Pierre-Decker 5
CH-1011 Lausanne
E-mail: ralf.jox[at]chuv.ch

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