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## The Conflict between Advance Directives and Organ Donation: A New Problem in End-of-Life Planning

I am pleased to have this opportunity to celebrate the career of Hans-Martin Sass who has been my colleague at the Kennedy Institute of Ethics at Georgetown University for over 35 years. He has had a remarkable career simultaneously the founder of the important German Center for Medical Ethics at Ruhr University in Bochum, Germany, and Senior Research Fellow at the Kennedy Institute of Ethics, Georgetown University, in Washington, DC. Reflecting a truly remarkable international career he has also been on the faculty of Peking Union Medical College in China and is a former member of the UNESCO International Bioethics Committee—the group having the strongest claim to legitimately articulating the bioethics standards for the world.

Professor Sass's contributions have covered the fields of philosophy and bioethics including Continental philosophy (Hegel, Marx, Heidegger) (Sass, 1967, 1982, and 1983), global bioethics (Sass, 1989b; Sass and Xioamei, 2011; Muzur and Sass, 2012), stem cells (Sass, 2006), genetics (Sass, 2004), brain life and brain death (Sass, 1989a), organ transplantation (Sass, 1998), advance directives (Kielstein and Sass, 1993), and surrogate decision-making (Sass, Veatch, and Kimura, 1998).

It is in the areas of organ transplantation, advance directives, and surrogate decision-making that I have had my closest and most sustained interaction with him and in which I would like to address some additional remarks. During the 1990s Dr. Sass and I along with Japanese lawyer-philosopher, Rihito Kimura, undertook a major

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cross-cultural project on advance directives and surrogate decision-making focusing primarily on Germany, the United States, and Japan. We were interested in the emergence of clinical, legal, and ethical aspects of end-of-life decision-making, the interplay among patients, their surrogates, and their clinicians in making decisions to forgo life-sustaining treatment, and the emergence of varying definitions of death that are influential in organ procurement.

We created nine research teams studying these three aspects in the three different cultures. Meetings were held in all three countries to conduct the research. We saw that the cultural orientations of the three countries led to significantly different tendencies—heavy emphasis on individualism and autonomy-based self-determination in the United States, deep commitment to family involvement in Japan, and an intermediate set of patterns in Germany showing increasing opening to patient self-determination, but retaining some level of traditional physician paternalism in decision-making.

The overall conclusion of this project and of much of the work of the three of us was a support of the role of the patient as the one who has a legitimate claim to control of terminal illness decisions. The mechanisms of advance directives and surrogate judgment have generally been supported by us and, while we acknowledge the possibility of “pro-treatment” advance directives, the typical role for the directives has been to facilitate treatment refusal thus permitting the dying process to progress uninterrupted.

## **The Discovery of a Conflict Between Advance Directives and Organ Donation**

The new development that I want to add in this brief comment is an increasing awareness of the complex and potentially controversial interplay between the patient’s wishes expressed in an advance directive and that patient’s desires regarding pre- and post-mortem organ donation. It is my concern that advance directives, faithfully followed by clinicians in the manner endorsed in our work of the 1990s, can end up thwarting the patient’s organ donation desires.

Typically, patients writing advance directives or otherwise expressing wishes about terminal care that can be acted upon in substituted judgment by surrogates express a desire to refuse life-sustaining treatments in order to let the dying process continue. They fear the tyranny of clinicians who, for whatever reason, feel it is their duty to preserve life as long as possible. Over the period starting in the 1970s and continuing to this day, bioethicists, lawyers, and patients’ rights advocates have won

battle after battle leading to policies that prohibit physicians from treating against patient wishes expressed in advance directives or otherwise communicated to surrogates.

In the United States physicians have increasingly gotten the message that they should follow the patient's wishes and do not have the right to substitute their own judgment about what is appropriate treatment. Often this is expressed as a resistance physicians second-guessing what is written in the patient's directive. The message is that the physician should simply follow the literal expressed wishes of the patient and avoid attempts to second-guess or reinterpret the directive in a way that circumvents the clear, literal position taken by the patient in a written directive.

Here is the newly discovered problem: Most patients who write anti-treatment advance directives or otherwise express anti-treatment desires, are also sympathetic to organ donation. If asked they would, in high percentages, express a preference for having their organs procured following their deaths if there is any chance they can be of any use in transplant, other therapy, research, or even education. Let's consider this a "modal" position of patients today.

The problem with his modal situation is that, although patients (and many health professionals) do not realize it, the chance of the patient's organs being useful can often be increased if certain medical interventions occur when the patient is in the dying process, that is, prior to the death of the patient. Sometimes these interventions can impact the dying trajectory, perhaps increasing the time it takes to die. For example, in order for organs to be preserved with maximum benefit, patients may need to be ventilated to maintain oxygen levels. Sometimes heparin (an anticoagulant) may be given. This can, in rare instances, influence the events in the dying process, sometimes preserving life, sometimes hastening it. Antibiotics or fluids may be given. All of these may extend life temporarily. But if the patient has an anti-treatment advance directive that is to be taken literally, these are forbidden. They would be considered unethical by anyone who has come to believe that the patient's wishes as expressed in an advance directive or in oral communication to surrogates should prevail. These interventions to increase the chance of obtaining usable, high-quality organs may well be illegal in a jurisdiction that has fought many hard-won battles to prohibit physicians from administering life-extending interventions contrary to the patient's expressed advance directive.

Of course, patients who write anti-treatment advance directives did not have this situation in mind when they signed their treatment refusing documents. Overwhelmingly people who have written anti-treatment advance directives will, if asked, acknowledge that, of course, they would desire interventions to increase the

likelihood of obtaining usable organs after they die. At least if the intervention merely briefly prolongs life and imposes little or no burden on the patient, the overwhelming majority of patients who have written anti-treatment advance directives would say they would want these treatments in spite of the fact that they extended life a bit.

As we become more and more successful in convincing health professionals, judges, and the general citizenry that patient advance directives should be followed without attempts to second-guess the meaning of the words in the documents, patients who would like their deaths include a contribution to their fellow humans are in more and more jeopardy of having their desires circumvented.

## **A Potential Resolution of the Conflict**

The solution to this problem is two-pronged, an easy part and a hard part.

### ***An Amendment to an Advance Directive***

First the easy part. For those who have written anti-treatment advance directives that typically demand the forgoing of life-support at a point when death is imminent and inevitable, an amendment is urgently needed to their documents. This amendment should make clear that, although they generally do not want their lives extended for their own benefit, they are open to, in fact insist upon, interventions to improve the chance of obtaining useful organs and preserving the quality of those organs, even though this could change the dying trajectory, potentially extending life briefly.

The amendment needs to consider two potential complications. First, it is possible, at least in theory, that, even though this is not intended, the intervention could actually shorten the dying trajectory. For example, giving heparin could cause a cranial bleed (hemorrhagic stroke) that causes a more immediate death. Although this is unlikely, its possibility needs to be confronted. Most moral philosophers and theologians who have considered this possibility treat this as a “double effect” or “indirect effect” of the therapy. A significant number of people—probably a majority—continue to find it morally unacceptable to intentionally cause the death of a patient by actively intervening. Many, however, distinguish this from cases in which the death is actively caused by an intervention that is not undertaken for the purpose of causing the death even though death may be known to be a potential side effect risk.

The policy that copes with this set of circumstances is often referred to as the “doctrine of double effect.” Traditional Roman Catholic scholars accept the risk of killing as a side effect of administering high-dose narcotic analgesia, removing a cancerous uterus from a woman pregnant with a pre-viable fetus, and many other such examples (Foot, 1967; Sacred Congregation for the Doctrine of the Faith, 1980, Pellegrino, 1995). Secular commentators in some cases also endorse the doctrine (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983; Marquis, 1991).

There is no reason why this doctrine would not apply to cases involving the administration of treatments that, hypothetically, could shorten a dying patient’s life as long as the intention was to preserve organs and not to shorten the life. It seems reasonable that anyone who stands in the long tradition of applying double effect doctrine to cases of intervention regarding dying patients would accept this logic and support organ-preserving efforts even if they pose a risk of shortening life.

The second complication to a proposal to amend anti-treatment advance directives to include a provision that authorizes interventions to preserve organs even if they may change the patient’s dying trajectory is that, in theory, these interventions could cause the patient pain or suffering. They could prolong consciousness and thus extend the psychological trauma for the dying patient, or they could even inflict significant pain. Thus, an amending paragraph to provide an exception to the general refusal of treatment for the purpose of preserving organs should include a mechanism to recognize a reasonable limit on the organ-preserving intervention if it will burden the dying patient significantly.

I have worried about these problems for many years and have drafted an amending paragraph for my personal advance directive to cope with my desire to be an organ donor and to avoid jeopardizing organs by my instruction to forgo life-support. That paragraph reads as follows:

Let it be known that I expressly desire any medical procedures, including those that are life-prolonging, that shall be necessary in order to make organ or tissue procurement more effective unless the person named in the preceding sentence considers these procedures too burdensome for me.

This paragraph is preceded by the naming of a person, who is also designated as my surrogate for interpreting any other provisions in my advance directive.

### *The Use of Surrogates to Override Advance Directives*

The second part of the solution to the conflict between advance directives and the desire to be an organ donor is more complex. The vast majority of people today who have written an advance directive have not had a chance to think about the conflict between these two desires yet would agree with the provision that organ-preserving interventions should be an exception to the anti-treatment advance directive. Those who have not written an advance directive and therefore rely on the substituted judgment of a surrogate for making terminal illness treatment decisions are in a similar situation. They may have expressed orally while competent their desire not to have life support in the event of a terminal illness and rely on their surrogate to execute that decision. Typically, when they have expressed these views they have not thought about whether they would want an exception for temporary intervention to preserve organs even though it might change the dying trajectory. Even though they have not thought about it, it seems likely that most people writing anti-treatment advance directives would, in fact, want the exception clause.

There is evidence that people differ significantly on the extent to which they want their advance directives followed closely (Sehgal, Galbraith, Chesney, Schoenfeld, et al, 1992). Nevertheless, some policy must be adopted. Of course, the best would be if people, when writing their advance directives, also included a provision indicating how closely they wanted them followed and, who should have the authority to interpret and, if it appears necessary, to override.

Some might assume that the physician is the one who should have this discretion. On reflection, however, that seems to be a mistaken approach. It was because of persistent physician error in judging what patients wanted that we developed policies for advance directives in the first place. There is no reason to assume that the one who is an expert on the medical facts of a case is also an expert on the value judgments about what should be the best therapeutic choices. I have argued that physicians cannot be expected to know what is best for patients. Even if they are in the best position to know the medical facts, they typically are not the ones who know the patient's values the best (Veatch, 2009 and 2015).

Good advance directives should include a specification of who the patient would like to function as a surrogate—often, but not always, a spouse, significant other, or adult family member. The default policy that is emerging as the best option is, if there is no surrogate named, it should be the next of kin unless a court has designated someone else. The valid surrogate should be the one who has the authority to interpret the advance directive, make a judgment about how literally the patient would want the directive followed, and when an exception should be

made to the treatment acceptance or refusal choice in the directive. It seems plausible that some surrogates would conclude that the one for whom they are exercising surrogacy would want an exception made to the refusal of interventions that are likely to change the dying trajectory when making the exception would make organ recovery possible with little or no burden on the patient.

The issue regarding exceptions to advance directives is directly analogous to the problem regarding economic wills. If some writes a valid document, we should normally presume that it should be followed. Only in very exceptional circumstances should the will be overturned. I suggest the same approach to the problem of making an exception to advance directive instructions in order to administer treatments for the purpose of preserving the organ donation option and maximizing the quality of those organs.

## **Imminent Death Donation**

While contemplating an amendment to one's advance directive for the purpose of facilitating organ procurement, there is a related issue that one might wish to consider. Most people find the donation of a single kidney while the donor is alive to be a noble and morally praiseworthy decision. We have begun to contemplate a special circumstance of living kidney donation in the case of a terminally ill patient dependent on life-supporting technologies such as a ventilator. If a decision has been made based on an advance directive or surrogate decision-making to forgo life support and let the dying process continue, it is sometimes technically possible to procure a kidney prior to stopping the life-support. This would be a special case of living kidney donation, special in the sense that the patient will be spared the pain and suffering of the procurement and will avoid any residual risk of continuing to live with only one kidney (Morrissey, 2012).

This has come to be called "imminent death donation." In the United States we are close to adopting policies that permit donation of a single kidney prior to stopping of life-support. This would not necessarily be incompatible with a standard anti-treatment advance directive, but, in a manner similar to what we have been discussing, the intervention to procure a kidney prior to forgoing life-support could require treatments (ventilation, etc.) that would change the dying trajectory, thus raising the problem we have been considering. For someone who is sympathetic to imminent death donation, the amendment to an advance directive should also include a provision that one would want organs obtained prior to death, if possible, provided there was not a significant added burden to the patient.

For the current time, most discussion of imminent death donation is restricted to a single kidney (using standard living kidney donation as a model). Some of us have begun to consider that additional organs might justifiably be procured at this time as well. The moral rationale for standard living kidney donation is that it imposes a tolerable burden on the donor and only a minor risk of unintentional loss of life. That same rationale supports donation of a single kidney as a first step in the process of forgoing life-support and it supports it even more strongly since both pain and suffering and mortality risk are essentially eliminated. That being the case, it is provocative to ask why the same rationale would not support procurement of the second kidney. The patient would not die from kidney failure provided a decision has been made to forgoing life-support. In fact, other organs—liver and pancreas—for example could also be procured based on the same rationale. The removal of any of these organs would not be the cause of death (although that cannot be said for procurement of thoracic organs—heart and lungs).

I suggest the following sentence:

Let it also be known that, if this directive is acted upon, I desire at the time to be a living organ donor. I would like a kidney [or all organs that the procurement team is willing to take] procured prior to forgoing life-support and consent to the procurement as well as any medical treatments that will facilitate that procurement provided my surrogate does not consider such treatment too burdensome for me.

## Conclusion

I put forward these suggestions in the belief that Hans-Martin Sass and others who have contributed so much to the development of advance directives would find them compatible with the work done in previous decades that furthers the respect owed to patients who have developed moral positions about their terminal care. It is striking that all those decades of work left us with model advance directives that were oblivious to the possibility that following the literal words of a directive could end up circumventing the writer's desire not only to have a meaningful and dignified death but also to benefit others through organ donation, especially when doing so would come at no burden to the writer. Some people may not wish to facilitate organ donation and that is their right, but the many who do should take care that their written directives do not jeopardize that opportunity.



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