

Although I agree with the authors' call for more public engagement, I think it is unlikely that communicating the details of cDCDD practice to the public will enhance the ethical acceptability of this OD/T practice in a meaningful way. The conceptual and procedural complexity of cDCDD is such that it would be difficult for an average member of the public to sustain sufficient knowledge of the practice over time to constructively inform her or his potential future role as a direct or indirect decision maker. Although, as I have suggested, disclosing accessible information at the time of the signing of an organ donor declaration could be helpful, I think that the important, detailed, informed-choice work of Consent Elements III and IV is optimally situated in real, potential-donation circumstances after the decision to withdraw life-sustaining treatment has been made. Despite my reservation about the utility of enhanced public education about cDCDD, I do believe that core stakeholders, including members of the general public, family members of organ donors, and past critical care receivers, should be directly engaged as collaborative deliberators in the development of policies that guide the practice of cDCDD within health care organizations. ■

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Resolving Some, But not All Informed Consent Issues in DCDD—the Swiss Experiences

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We fully agree with Overby and colleagues (2015) that donation after circulatory determination of death (DCDD) poses special problems that need to be addressed in the consent procedure (Bastami, Krones, and Biller-Andorno 2012). In our comment, we want to refer to the Swiss experiences related to DCDD that are able to overcome

some, but not all, concerns raised by the authors. Those concerns refer to the issues of premortem interventions, the potentially questionable irreversible loss of brain functions, and the challenge of making an adequate prognosis in certain patient (we do not discuss the last point).

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Swiss transplantation centers have a considerable long experience with DCDD starting in the 1980s. When the first national law regarding transplantation came into effect in 2007, DCDD was stopped for 4 years—interestingly, due to informed consent issues, because usually close relatives have been asked to consent to donation before the death of the patient has occurred, which was considered to be potentially incompatible with the new legislation. Further legal refinement was needed until the practice of DCDD was finally considered to be legal. In October 2011 DCDD was restarted—mainly in the University Hospital Zurich and only as controlled DCDD—and now accounts for 10.9% of all donations in Switzerland (data of 2013).

However, there is a unique feature ever since DCDD has been practiced in Switzerland:¹ It requires a neurological determination of death after a 10-minute no-touch period. This brain death diagnosis involves all standard neurological tests except the apnea test (which makes no sense as the patient is no longer ventilated anyway) and testing the vestibulo-ocular reflex where stimulation is based on pouring of cold or warm water into the ear. Performing the tests usually takes an additional 1–3 minutes, meaning that warm ischemic time is in the order of 11–13 minutes after cessation of death. In Zurich, data collected in the first period of DCDD show no significant difference in long-term rate of graft survival in the case of kidneys when comparing with kidneys obtained after “standard” brain death (Weber et al. 2002). Data regarding liver and lung are preliminary, since DCDD for both organs only started in 2011. However, first results indicate that the short-term outcome for lungs is at least as good as for donation after brain death. And although the liver seems to be more vulnerable to the longer ischemia time associated with DCDD, the use of hypothermic oxygenated perfusion (HOPE) seems to improve early function after transplantation and the release of liver enzymes and kidney function. Furthermore, intensive care unit (ICU) and hospital stays were comparable to or better than in matched liver grafts emerging from donation after brain death (DBD). However, whether long-term results are the same as or worse than in DBD cannot be evaluated so far (Dutkowski et al. 2014). Nevertheless, the Zurich experiences indicate that integrating a brain death diagnosis in DCDD is compatible with an acceptable success rate for DCDD in the case of kidneys, and maybe also for other organs.

So far, following this practice in Switzerland, brain death has always been confirmed after the 10-minute no-touch period—which is by the way twice as much as the standard 5 minutes in most other international centers that practice DCDD. To our understanding, this relieves the second concern of Overby and colleagues, namely, that

DCDD practices may not ensure irreversible loss of brain function.² Furthermore, by explicitly including a brain death diagnosis procedure in DCDD, patients are likely to have more trust in the procedure as such and obtaining informed consent will be less challenging, as the analogy to “classic” organ donation is closer.

Nevertheless, premortem interventions remain a sensible ethical issue also in the Swiss context. An empirical study by one of us (Bastami) evaluating experiences of relatives of donors after DCDD compared to DBD demonstrated that the type of donation did not remain prominently in the memory of DCDD donor relatives. Whether this is due to a lack of information at the time of donation, the extreme stress situation in which relatives find themselves, and the complexity of DCDD donation, or whether the distinction is not important to them remains the subject of future research (Bastami 2014). Interestingly, it was found that DBD donor families may find the concept of brain death difficult and sometimes suffer from guilt because of what they perceive as their role in their loved one’s death, whereas DCDD donor relatives did not mention any such feelings.

More careful communication with patients and relatives, however, has led to increased acknowledgment of the special aspects related to DCDD, in particular regarding premortem interventions. Also regarding transplantation in general, the wish of family members to hear about the success of donation is acknowledged. Nowadays, in Zurich, transplant coordinators stay in touch with donor families and conduct a follow-up interview with them several months after donation. Also Swisstransplant, the Swiss organ procurement organization (OPO), now informs about the special procedures associated with DCDD. Furthermore, the pre-mortal placement of catheters—probably the most invasive procedure related to DCDD—is not part of the current Swiss practice focusing on Maastricht 3 donation. This demonstrates that DCDD practice and the informed consent procedure indeed can be improved.

Despite these measures, our findings support the observation of Overby and colleagues that much still needs to be done, in particular related to the information of potential donors by organ procurement organizations and similar institutions. In an ongoing study, we are currently assessing the international information practice related to DCDD by such organizations. Still very preliminary results show that 23 out of 38 websites of OPOs worldwide (61%) do not mention that DCDD may be the way donation actually could take place in a person who registers as donor;

1. In November 2013, Austria changed DCDD protocols and also requires the determination of brain death after a 10-minute no-touch period.

2. We note that the neurological determination of death may not in all cases demonstrate an irreversible loss of brain functions (see, e.g., Joffe et al. 2009; Webb and Samuels 2011; these findings have been controversially discussed) and that in some cases a cardiopulmonary arrest of more than 10 minutes still allows for neurological recovery of patients (Machado and Korein 2009). However, the patients that qualify for controlled DCDD are very unlikely to fall into these categories.

and only 5 websites (13%) provide detailed information on the particularities of DCDD. This indicates a substantial “information gap” that needs to be addressed.

In summary, we believe that the Swiss experiences allow improving the informed consent practice and the procedures related to DCDD in general by the following means: First, by including a brain death diagnosis into the DCDD practice, both trust of the donor and the analogy to “classical” organ donation can be strengthened. Second, by carefully communicating the particular aspects of DCDD to close relatives of a potential donor (who in most cases actually decide upon donation), improving informed decision making can be expected. Third, by abandoning the most problematic practices related to premortem interventions, the ethical difficult issues related to DCDD can be at least partly relieved. However, as our ongoing study indicates, there is still much to be done for improving general information on DCDD, in particular for those persons who want to disclose their wish regarding donation in registries. ■

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Death at the Door of the Operating Room

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In approaching therapeutic objectives around the end of life, doctors tend to focus on whether or not to use specific interventions. Ethical debates focusing on end-of-life issues often deal with the conditions under which it is permissible to provide symptom relief when this may risk hastening death (Schildmann and Schildmann 2014), or to withhold or withdraw interventions such as cardiopulmonary resuscitation, artificial ventilation, artificial nutrition, or hydration (Sprung et al. 2014). This literature mostly focuses on discrete decisions regarding specific interventions, and on the most ethically justifiable way of reaching such decisions. In contrast to health professionals, patients and their families do not seem to focus on specific interventions as much. Rather, they tend to focus on how best to fulfill the dying process as a whole—including

considerations such as life completion, affirmation of the whole person (Steinhauser et al. 2000; Miyashita et al. 2007), contributing to others (Steinhauser et al. 2000), or saying goodbye (Rietjens et al. 2006)—with appropriate support and without disruption.

These differing goals can lead to misunderstandings and difficulties in the practice of end-of-life care, as health professionals seek to obtain clear decisions regarding this or that interventions, while patients and their families attempt to reach a “good death” by seeking control of the circumstances surrounding death rather than of the interventions preceding it. This difficulty is likely to be exacerbated whenever the circumstances of death provide less space for family members. This, of course, is the case in situations of controlled

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