

Utility, Trust, and Rights in Swedish Governmental and Expert Discourses on Organ Donation Policy

Mixed Messages and Hidden Agendas

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The donated organ operates within a system of mixed metaphors. It is a “gift of life,” but more eminently the organ functions as a resource. *The utility* of the diseased donor—that is, the fact that, in our medically and technologically advanced world, dead bodies are, in the passage between living and the grave, invariably transformed into potential biological resources—challenges certain preconceptions we may hold about a dignified death. In many societies there are laws concerning crimes against the exhumation of corpses which prohibit the desecration or the damaging of a dead body. The legislation about transplantation, however, does permit such violation under certain conditions. The value of peace in death is subordinated to the “do-good” principle—i.e, the value of saving the life of someone or enhancing a person’s quality of life, at the same time as the contributory-value that such an act makes to a reduction of the costs of the health care system. This utilitarian understanding of the possibilities that the technology of transplantation opens up for, remains, today, almost unchallenged.

The value-potential of the dead and the modern, technified death, which seemingly only experts can define, has created a space for the public to voice their suspicions that the dying patients are being instrumentalized, transformed from an end in themselves to a means for others. Here, trust can be undermined, both in relation to the healthcare system as such as well as to the very value of public donation. Hence, legislative bodies and experts—like the community of medics—must balance two central principles: On the one hand *utility*, on the other *trust*. A field of tension exists between these two principles when the questions to be resolved are, for example, how the rule of consent regarding organ donation is to be formulated, how, in the eyes of the law, death is itself to be decided, and, not least, how to compel the public to donate their organs after death.

For the dead body to be considered legally available for transfer, a specific moment must be defined, a particular point in time where a body is legally pronounced dead. In that moment in time, the organ becomes what the anthropologist Margaret Lock calls *alienated*, passing over as a kind of “quasi-property” of public value, which is to be distributed to a chosen recipient who is then to take possession of it (Lock 2002, 9). In this process the organ is transformed from being a gift to becoming an alienated resource assigned to a suitable recipient, and ultimately incorporated within a new individual and invested with this person’s civil and social rights. This process entails a number of rules and directives of both legislative and ethical complexity (see Idvall this volume). The need to determine a specific point in time where one is declared legally dead is, however, com-

plicated by the fact that death is not a moment in time. On the contrary, death is a biological process which, rather, is extended over time. Successful refinements in transplantation techniques have meant that the question regarding the time of death—how death is to be defined—is under continual review and renegotiation.

Swedish welfare and its institutions are generally considered stable, reliable, democratic, and uncorrupt, with its citizens investing a great deal of trust in them. The national transplant law is predicated on presumed consent. On the basis of such a presumption, a further assumption is made, namely that, on the issue of the transplant enterprise, there exists no contradiction between the state and the individual.¹ Swedes show EU:s highest willingness to donate organs after death.² Still, the relatively low number of transplanted organs remains disproportionate to what, in principle, is the prevailing positive attitude that Swedes hold about transplantation. Possible explanations advanced about this incongruity are various. Such a situation has been explained on the grounds of poor organization, of a lack of information, in terms of an inadequacy in regulation or, even, that its social justification has been based on the wrong principles.

Since the late 1970s, the relationship between the state and the individual has changed significantly, with questions concerning the individual's right to autonomy taking centre stage. Not least in health care, where patients' rights have become a major policy area. In light of this shift, I would in this contribution like to investigate how, from the perspectives of utility, trust, and rights, Swedish authorities and its experts (doctors and ethicists) have, on the issues of the utilization

of the dead, publically sought to negotiate a way around, specifically, the threats to public confidence in the health care system, but, more generally, have needed to respond to a set of challenges raised against the prevailing moral order. This is especially true of new methods and practices that have opened up the space for more organ transplantations to be countenanced, regulated, and implemented.

THE GOOD STATE—OR “PUTTING LIFE IN ORDER”

Between the 1940s and the 70s the idea of social citizenship was greatly developed in Sweden. The hegemonic social democratic movement, which had been formative in shaping the welfare systems, was characterized by both a utilitarian rationalism and a strong belief in science (Ekström von Essen 2003, 176-206). The politicians and experts—welfare engineers—sought to combine value and an equal distribution of resources in a way that would secure its legitimacy. They rarely saw any ethical conflict in these ambitions. The overarching goal was to create a more fair society. Experts like doctors, psychologists, and social architects formed the foundation and were instrumental in drawing up the blueprints for the effectuation of comparatively extensive health and social policies, harnessed in order to emancipate the lower classes (*ibid.*). This has, by its critics, been described as a way of “putting life in order,” in which all areas of life became valued in accordance with the social gaze and the prescribed goals of the experts.⁵ Nevertheless, strong legitimacy for what was coined the “people’s home” was soon achieved. The Swedish national self-perception was that the social experiment was a “success story,” where no con-

tradition was said to exist between state and individual.

However, this emancipation had its flip side. The rational attitude together with a strong moral-value justified disciplinary practices, according to which, the citizen became, within a broader socio-economic perspective, a kind of biological resource. The extensive sterilizations of those who were considered a biological/genetic risk during the 1930s and 40s is an example of this (Tydén 2000; Broberg and Roll-Hansen 2005). In the 1950s and 60s there was a reaction that led to a shift in the view of the citizen. During the last decade of the 1900s what had been celebrated as a strong and stable set of moral-values in Sweden was being, in the fields of both social and health politics, critically interrogated by researchers and commentators. The image of the “success story” of social democracy was partly tainted. Materially, the life of the citizens had improved, but it had also been “put in order” by politicians that, albeit with good intentions, had developed disciplining techniques at all levels of society—from how to do the washing up to how many children one should have and, who should conceive them.

PEDAGOGICAL DIALOGUE

AND THE RHETORICS OF THE GIFT

Interwar Swedish sterilization laws might be regarded as reflecting the views that politicians and authorities had on the body of the citizen as a biological and social resource.⁴ The notion that people could freely dispose of his own body, was described by the State Population Commission as “an extremely individualistic view” (Tydén 1996). During the postwar period, however, individual rights came to be

strengthened, albeit gradually over time. Instead, political projects—which sought to shape the citizens and their behavior—were usually expressed through expert investigations into a given issue, which then led to extensive information campaigns.

Today it is politically impossible—at least openly—to use a rhetoric in which the population is perceived as a “given” source for state-defined public goods. Nevertheless, today it is the alienated organ that is interwoven into a utilitarian paradigm that sees resource-fulness as the main objective. It is of note, therefore, that the organ in contemporary studies, legal texts and in public information to citizens, is clearly communicated as a gift that all should give, and therefore in the literature comes to be overlaid with positive connotations (see Gunnarson and Schweda and Schick-tanz this volume). Here, an example might be helpful: when a transplant coordinator was interviewed on the radio during the Swedish “Transplant Week, during the fall of 2010, it was said that

An important role of the physician, when donation is possible, is to provide the opportunity for one to be allowed to donate. [...] [To make a] donation is [after all] to give life.⁵

If the organ is described as a gift in this way, it becomes framed as an altruistic act of will or of human generosity. If, however, it were described as a resource (in terms of organ shortage, lower health care costs, less dialysis, more productivity) then thought would instead be led to the instrumentalization of the dead body, which *de facto* the transplant itself represents. The sanctioned gift-metaphor speaks directly to

our compassion and our conscience, at the same time as it mitigates the threat of the moral order, which the utilization of the dead constitutes. The way in which the organ is communicated as a gift offers therefore a contemporary example of an appeasing rhetoric. The metaphor of the gift is perhaps good in a general strategy of a maximization of utility while, at the same time, maintaining trust, but it becomes problematic when confronted with the reciprocal exchange of goods and rights of the welfare state system, because a donor organ can never be an equitably shared resource. The proportion of people with a negative attitude towards the donation of either their own or a relative's organs after death is comparatively low in Sweden—the figures are 9 and 12 per cent respectively.⁶ Of those who still say no, 17 percent express a fear of the manipulation of their dead body. Another factor is a distrust in the “systems” (doctors, health care, welfare) undertaking the practice. The largest proportion of those with a negative attitude, 56 percent, do not know why they say no.⁷ These responses reflect both an unwillingness to think on and talk about death, but they also may reflect a certain dependence on traditional rituals surrounding death as well as the historically rooted fear of what doctors might do with the dead or the almost dead. Such resistance seems in the main to be difficult to articulate, addressing a certain obdurance in a person's mindset rather than as the product of rationally articulated ideas.

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THE HISTORY OF EXPROPRIATION
OF DEAD BODIES BY THE STATE

There is a long tradition of a gap existing between physicians and the public perception of the dead body. During the first half of the 1900s in Sweden, the widespread popular resistance against dissections as well as clinical and forensic autopsies, were described by doctors as harbouring old superstitions (Sanner 1992; Åhrén Snickare 2002, 59, 65-67). A modern, enlightened and rational mind should immediately realize the benefit. But the bodies used by medical institutions were also associated with shame; they were part of a state-sanctioned moral punishment, the practice of which has a far longer genealogy. These were bodies that had belonged to those who had committed suicide, to criminals and prostitutes, to the executed or mentally ill—in sum, to the “immoral and salacious,” who were not themselves able to fund their own funeral (Åkesson 1996, 172-173). Dissection was therefore conjoined with ideas of isolation, of shame and poverty (Åhrén Snickare 2002, 68-69).⁸

Advances made in medical science, which first took place in the 1800s, increased the need of dead bodies for research and training in anatomy and clinical autopsy. The more that the art of medicine could show its own usefulness, the greater the utility ascribed to the corpse. Further into the 1900s this requirement for bodies by doctors was provided for by various local ordinances and decrees, giving them access to the dead bodies of the “outcast.”⁹ This occurred in a parallel movement; the medical profession became bound up with the state apparatus, while its own bio-political power increased (Rose 2007, 25-26).

The rapid expansion of social rights—particularly, the rise of public health and social insurance during the 1940s and 50s in Sweden—resulted at the same time as the available corpses for medical science decreased in number. During the late 1950s it was acknowledged in the chambers of parliament that people living in social institutions had, without having assented to it—or even without having known about it—been used for medical science experimentation (Bommenel 2006). Several new laws strengthening the formal power the citizen could exercise over his or her body were introduced (Machado 1996, 168). An important watershed event was the legislative change of 1973, whereupon the practice of surrendering corpses to anatomical institutions was replaced by the procedure of donation.¹⁰ All citizens now had formal authority over their bodies, even after death.

SYMBOLIC, BIOLOGICAL,
AND LEGAL CONCEPTS OF DEATH

In every culture strict limits and customs about the dead are scrupulously observed by the living. This is particularly the case for the passage between the time of death and the ritual farewell—the funeral—where a person symbolically steps over the line to the dead. This liminal passage through which the body passes raises some challenges; old rural communities dealt with such a passage by observing traditional rites: the body was washed, wrapped, and laid in “wake” for some time. Today, the funeral agency has taken over the organization and management of the dead; so, the liminality of the body is something not directly encountered by us. And yet with the prospect of organ donation an actu-

ality, the liminal spacing between the living and the dead takes on a new tangibility.

A dead human being is no longer a legal subject and hence incapable of owning something—still, the next of kin often acts as if the body somehow “belongs” to the dead person, accordingly imploring that it must be duely treated with respect and consideration (Sanner 1991, 93-94). A further commonplace is not wanting the dead to be exposed to any more “pain” (SOU 1989:98, 107-108). In Sweden, despite the rule of presumed consent, families of the deceased have the veto-right to refuse donation.¹¹ There is a deeply rooted perception that relatives have the right to the dead body, a right which in practice may outweigh the deceased’s own will, so long as this will is not made official.

To make the gestalt switch from considering an immediate family member as an autonomous and unique person who owns his or her body to consider instead that the same body is a biological and, potentially, a public resource is difficult. Two incommensurable worlds, linked to our understanding of the dead, collide. The tension that exists between the symbolic and biological conceptual realms of death are further accentuated in the context of the “new death,” which began to be constructed in the late 1960s and which led to the adding of new layers of complexity surrounding the discourse of death.

People with extensive brain damage could, with the assistance of the newly developed respirator, now be kept alive by artificial means. People who were determined as dead in accordance with new brain death criteria, had bodies looking very much alive. They had a rosy complexion,

sweated, urinated, or could even have a developing fetus within them (Sanner 1991, 159). This created what Stuart Youngner has called a “cognitive dissonance engendered by the overwhelming signs of life” (Youngner 1996, 42).¹² An ancient vision of death—its uncertainty and unpredictability—was now juxtaposed with the unprecedented emphasis that was beginning to be placed on its potential use-value in the form of the transplantation of oxygenated organs. How these “living cadavers” could in a legitimate way be made useful, be alienated and commodified, has become a global issue (of equally great importance and controversy) during recent decades.

DETERMINING DEATH

There has always been uncertainty surrounding the determination of death. During the Middle Ages it was, in the West, commonly believed that the only absolute criterion on death was bodily putrefaction (Lock 2002, 41). The widespread fear of being buried alive led, for an extended period of time, the corpse to be buried with rattles, whistles, or a pipe that led up to the surface, providing thereby the body with oxygen (*ibid.*, 66). Indeed, even up to the 1950s, the question of when a human being is understood as dead was not legally regulated, neither in Sweden nor elsewhere. There was no need for it; sufficient was to follow the convention of declaring a person dead 15-20 minutes after the heart and respiratory system had stopped functioning. “He drew his last breath” or “he gave up his breath” are two common metaphors linked to the experience of death. Up to the middle of the twentieth century there was a stable scientific,

philosophical and public consensus about what death is and how to know when someone is dead (Youngner, Arnold, and Shapiro 1999, 20).

The introduction of the ventilator and the technological advancements surrounding intensive care units in hospitals during the 1960s would complexify the issue of death to a then-unimaginable scale. American neurologists claimed that some patients who, after a traffic accident or a serious stroke, were treated and kept alive only through a ventilator, were technically dead. Now that one could proclaim somebody dead even if the body showed signs of being “alive,” the line between life and death had become indiscernible.¹⁵ A new definition of death was advanced, based on the idea that the being of the person is locatable in the brain; the ability of the brain to coordinate the organism into a functioning unit is thus understood as a precondition for life. Death could thus be determined from brain-related death criteria, so that what it means to be dead is an irreversible loss of brain activity.¹⁴ These new criteria for determining death are inextricably bound up with the contemporary practice of routinized transplantation operations, where the majority of transplanted organs have been farmed from the brain-dead. They constitute a special category of donors whose organs are not destroyed—before being alienated and then procured—by any lack of oxygen (provided that the respirator remains switched on even after death has been determined).

In light of this, the living cadaver became a very valuable resource. The legal sense of death had been carefully mapped and managed by the medical profession (Lock

2001, 170). This led, unsurprisingly, to a reawakening of the old popular fears of being declared dead prematurely. The evocative image of the living cadaver was explored in cinema, where transplant surgeons were often represented as arbitrary organ thieves (Pernick 1999, 16). The dramaturgy was based on an archetypally western figure of the Faustian physician and scientist—such in the paintings of Leonardo da Vinci or in the gothic novel, *Frankenstein*—which without hesitation violates moral boundaries in order to gain access to dead bodies so that its inner workings can, in the name of exploratory science, be uncovered and demystified.

The more or less articulated reluctance amongst the public was nothing that could have stopped the circulation of oxygenated organs in a world where ethics appears more sensitive to the exigency of economic trends rather than to matters of principle. Towards the end of the 1970s, most Western countries had adopted legislation on brain death criteria and related provisions about for how long respiratory treatment could be extended after the pronouncement of death. In Sweden, for example, this is for 24 hours. Ironically, the number of brain dead donors decreased in the world soon after the emergence of brain death-related criteria. Improved road safety and better medication for patients at risk of strokes have contributed to this development.

An ageing population leads to increasing numbers requiring new organs, contributing thereby to the lengthening of waiting lists for transplants. With developments in immunosuppression and transplantation techniques, more and more transplants succeed, today. And yet “the shortage of organs” has become an oft-repeated mantra. Research on xenotrans-

plantation has stalled, and the cultivation of human organs is still not a reality. Living donation, where a family member donates one of his or her kidneys, has become more common (for example in Sweden). Required, nonetheless, is a developed healthcare system guaranteeing good aftercare. Additionally, we need also to consider the existence today of a comprehensive global organ trafficking network, of practices of organ tourism also, as well as a general urgency within the formal frameworks of national and legal systems to encourage more citizens to donate organs as being themselves symptoms of a more systemic failure regarding organ transplantation not meeting demand (Scheper-Hughes 2002b; Lundin 2010; Berglund and Lundin this volume).¹⁵

THE “AS-GOOD-AS-DEAD PATIENT”

Although, during its first thirty years, the concept of brain death gained validity, the idea has itself generated confusion about what, indeed, is meant by brain death. First, it has provoked dispute over whether people, who are artificially kept alive, can really be diagnosed as dead, and second it has raised questions about the safety of such a diagnosis (Joffe 2007). The neurologist Robert Truog claims that the concept of brain death “remains incoherent in theory and confused in practice” (Lock 2001, 174). He refers to how the distinction between “brain death” and “real death” is constantly being regenerated—an understanding that applies to the profession more generally. Even according to brain death advocates within the medical profession, who postulate that there is “only one death”—namely, the determination of death when all brain functions have ceased to function—there neverthe-

less remains an indistinction. If, for example, the heart stops beating, it may take as long as 15 to 20 minutes before brain activity ceases—and only then, is it the case that one is dead. At the same time, Truog argues that professionals often act as if the brain-dead patient is “really dead” only once the respirator has been turned off.

Another complex issue, subject to much debate, concerns patients who do not die “in the right way,” that is, in the order that prescribes when a patient is legally dead. They may be in an irreversible death process, with a permanent loss of consciousness, and yet, at the same time, they still exhibit some residual brain activity and, therefore, in accordance with the brain criteria as a whole, are not deemed brain dead—even though they have a hopeless prognosis and will soon die. In these cases, contemporary directives in most Western countries recommend that one should not “over treat” such patients. The respirator should therefore be turned off and the patient should be allowed to go into cardiac arrest in palliative care. At the same time, this means that the organs belonging to the patient run the risk of deoxygenation, rendering them useless thereby for possible transplantation. If the person, however, had for some time been cared for non-therapeutically on a ventilation unit, and had been able to develop total brain infarction, then the organs (still oxygenated) will indeed be utilizable for transplantation. In such a scenario, the expected advantages are always held in tension with the inalienable imperative to always care for the patient as an end in his or her own right, never as a means. In Sweden, however, it is no longer than a decade since the proscription of overtreatment has come

to be interpreted as a way to treat the patient as an end in his or herself.

In the late 1990s, a new category of potential donors was constructed: the “good-as-dead patient.”¹⁶ Truog argued that we should return to a clearer and more simple distinction between the living and dead, namely, the traditional heart-lung death, and allow instead the retrieval of organs, on the prior condition that consent had been given based upon the irreversibility of consciousness and “no harm” rule (see Truog and Robinson 2003). Such a consent could also include patients in PVS (permanent vegetative state); in this way, there would be many more “as-good-as-dead” patients to supplement those already defined as “brain dead.” Given the shortage of organs, says Lock, the next “logical step” is that we imagine even such as-good-as-dead patients as potential donors. This is a view which has been aired in the medical as well as bioethical world, and is a view to which I shall return later (Lock 2001, 171).

Such a new rubric for the procuring of organs would require relinquishing an almost sacred principle—the dead-donor rule, stipulating that anyone who gives a part of their body must be dead beyond any doubt. Since the early 1990s “the rule” has been contested. Stuart Youngner has shown that nearly a third of the doctors and nurses did not perceive brain dead people as dead, but agreed to treat them as dead because they were “irreparably damaged or death was imminent” (Arnold and Youngner 1993): “it’s not death, but it is an irreversible diagnosis which I accept” (Lock 2001, 172). Others have gone so far as to argue that when the urge for oxygenated organs encounters the principle that the donor

must be dead, the “noble lie” of the concept of brain death is told. It is such a “noble lie” that therefore in practice it already allows the organ to be taken from an as-good-as-dead patient (Greenberg 2008).

An abandonment of the dead donor rule could, in principle—and by extension—be defined as euthanasia, combined with donation. In the absence of the dead donor rule, the procurement of organs would be akin to murder. A killing which, according to Truog and Youngner, can be justified, so long as the patient is, first of all, terminally ill, second is not suffering and third has given consent. Both also claim that such a practice “is already happening” (Greenberg 2001, 3).

The argument surrounding the as-good-as-dead-patients, who might give their consent to donate (and thus their consent to the termination of their life) tends towards a more general shift in the view of death. Such a tendency is encapsulated in the contemporary debates on euthanasia. In keeping with ideas of individualism and the liberal ideal of autonomy, public attitudes about the right for an individual to decide when and in what form one’s life should end, has also developed.¹⁷ Such desires can be formulated in so-called “life-wills.” The essence of the advocacy of euthanasia is that if life does not offer any kind of quality, opportunity to be active, or even consciousness, then medical expertise should have the right to end that life, if one has expressed such a desire. Life is something that individuals own and control, it is not considered sacred, which is to say that all life is not worth living. The reverse-side of the liberal argument is that tropes about the futile, meaningless life are reinforced. If this is the case then this may constitute what

one critic has described as an “ethical paradigm shift,” the paradigmatic status of which should give us much reason for reflection.

DONATION AFTER CARDIAC DEATH

In the wake of the organ shortage, since the 1990s new methods to allow transplantation after cardiopulmonary death has been developed. More and more countries in the West have introduced DCD (Donation after Cardiac Death). The method involves that a patient with a hopeless prognosis—but one who does not develop a brain infarction fast enough—is disconnected from the respirator. Such a procedure is carried out in full compliance with directives not to over-treat a patient. Cardiac and respiratory arrest therefore have to occur rather quickly for the organs to be usable for transplantation. The patient is declared dead and after a short control pause of anywhere between two and ten minutes (times vary from country to country), organ extraction commences. When the body is no longer suffused with oxygen, it is a race against the clock to procure organs that will function for any prospective recipient.¹⁸ If permission for DCD has been granted by the patient, then any life-sustaining treatment is terminated in accordance with the requirements for the subsequent operation. Any relatives who wish to be present at the actual moment of death are prepared for the brevity of any farewells before the surgery must begin.

The ethical problems of DCD are partly about whether a control pause of, say, two or five minutes suffices to meet the dead-donor rule. We know that people have come back to life after cardiac arrest when a much longer time has

elapsed. But there are other ethical issues besides this one. For example, the donor-patient might be treated medically in various ways (such as with Heparin) before the procedure of organ extraction is underway, so as to increase the vitality of the organs and increase thereby the possibilities for a successful transplantation. In this case, the patient is treated not for his or her own sake, but for someone else's. A further complication is that DCD is difficult to reconcile with the methods of diagnosing death, methods which the brain-related criteria was responsible for introducing. In Sweden, it is even stipulated that when employing "indirect methods" for determining death, it will be the case that a person shall be considered dead once all brain activity has ceased, occurring 15-20 minutes after the heart has stopped beating (SOU 1989:99, 15). But such a statutory law is difficult to reconcile with the practice of DCD. After 15-20 minutes the coveted organs would, due to oxygen starvation, be irreparably damaged.

For those dying patients who do not easily meet the criteria for brain death, DCD can be presented by the authorities as an "option that support[s] patient preference in end-of-life care."¹⁹ In Sweden, DCD is not permitted, nonetheless many in the medical profession would wish that the method be looked into. It is often described as *an opportunity to have the right to donate*, for patients who do not die according to brain death criteria. A majority of Swedish doctors and ethicists emphasize that new ethical grey zones have arisen from those who do not die in the "right way." Such experts implore that such ethical complexities must be investigated, and are mindful that the present pace of this investigation

is far too slow. The problem is that the field is so ethically complicated that many politicians would rather bury their heads in the sand. Death, and the thorny issues associated with it, is no election winner.

SWEDEN—“PUTTING DEATH IN ORDER”

In Sweden, introducing brain death-related criteria was a long and drawn-out process. In the context of other Nordic countries, its comparatively late introduction may seem paradoxical in light of Sweden’s rationalistic and broadly utilitarian social and moral outlook, a world-view which had been integral in the construction of the welfare state.²⁰ But in Sweden there is also a national consensus tradition, in which important issues are thoroughly investigated in dialogue with key institutions and stakeholders. This is an important factor behind the delay in Sweden. Once the decision on the introduction of brain-related death criteria was taken, it was announced by the authorities with the usual bout of rationalism. It was urgent to respond to the cognitive dissonance that any encounter with this new death was bound to generate.

One of the most common ways to reduce this cognitive dissonance is to select, design and structure the information that resolves this contradiction (Machado 1996, 109). The investigation surrounding the death concept postulated that “there is only one death and it is brain death”—the very axiom, one could say, that the investigation had assumed. The definition of death with which the investigation concluded has been described by the philosopher, Martin Gustafsson, as “putting death in order” with a commercial

moral purpose, as well as by a supposedly scientific process which effected both a homogenization and simplification of it (Gustafsson 1998). Death was undoubtedly “put in order” for both health professionals and citizens in the handbook entitled *There Is Only One Death*, which the Federation of County Councils published as a way of drawing attention to the new law. The book was therefore intended to help to reduce “unnecessary fear.”²¹

In *There Is Only One Death* it was explained, quite categorically, that it was not about providing any new definition of death. By constructing the concepts of “direct” and “indirect methods” to determine total brain infarction it could be argued that death was still the same old death; it was just the way to determine death that was new. The “direct methods” defined death by controlling brain activity, either clinically or in contrast by way of radiology (cerebral angiography). The “indirect methods,” used in the majority of all deaths, stipulated that, after both cardiac and respiratory activities had been suspended for about 20 minutes, “all brain functions disappeared.” In practice, this meant using the old accepted method of confirming death, but now supplementing it with a further deductive principle, so that the doctor “concludes” that a person is dead when all brain activity has terminated irreversibly after 20 minutes (SOU 1989:99, 13).

The tone was confident and authoritative, and their methods were claimed to be entirely reliable: “the doctors have been agreed [on this] since the early 1970s.”²² The argument was illustrated by two pedagogical images of cerebral angiography: the first of a healthy brain and the second a brain affected by infarction. The image of the healthy brain

showed a distinguished fine-meshed net of veins and vessels while the other was a picture of grey stagnation.²⁵ It repeatedly tried to assure its readership that, in countries which have long applied the brain-related death criteria, there has not been “identified a single case of misjudgment.”²⁴ (The reader might well wonder how this can possibly be verified).

There Is Only One Death is a programmatic example of the kind of profoundly utility-oriented morality—appearing, *prima facie*, in an order-setting and trust-building tone—that have characterised Swedish public information campaigns targeting citizens since the 1970s.

THE OVER-TREATED PATIENT AND DIGNIFIED DEATH

The doctor is meant to save and sustain lives. This is the fundamental principle for the doctor. But in the 1990s the technical means to keep someone alive developed to such a level of sophistication that the question had to be asked: should life be maintained at any cost? First, such treatments were very expensive and there were often a shortage of intensive care beds available. Second, there exists a questionable ethical value about wishing to continue care despite a hopeless prognosis. If one took away the life-sustaining treatment—was this to be defined as murder or passive euthanasia, and either way could such an act be justified? A discourse on the right to “die with dignity” had arisen in the USA already in the 1970s; it focused on the possibility of a person not having to go through unnecessary treatment. Precisely, such a set of arguments were used in the discussion surrounding the employment of the brain death criteria—where it was said to be both unethical and totally unnecessary to treat some-

one who was actually dead.²⁵ In Sweden, already in 1973, the National Board of Health and Welfare gave physicians permission—without it being obligatory—to discontinue ventilation treatment of patients with total brain infarction. But, in this instance, the actual determination of death was made only *after* the respiratory unit had been turned off. With the introduction of the new law, the patient was declared dead already before the respirator was turned off.

The idea of a dignified death, however, came to have a detrimental impact on the supply of organs. By the end of the 1990s, Swedish medical practice, motivated by the dignity-argument, gradually changed.²⁶ Dying patients, with hopeless prognoses, would not be “over-treated” in intensive care units, but would instead receive either palliative hospice care, or would die at home.²⁷ It was no longer a matter of initiating mechanical ventilation in patients with a hopeless prognosis. Such a shift in approach towards the dying meant that heads of intensive care units were faced with a dilemma. In the early 2000s, intensive care doctors were also supplied with very clear directives from the authorities, such that it was now the duty of the *entire* health care organization to make donations possible (see Schweda and Schicktanz this volume).²⁸ Intensive care units had been in this respect a discretionary power, not considered to be used sufficiently in the accumulation of organs. With the Spanish organizational system as a model, it would now be a particular task assigned to both the physician and the nurse of the intensive care wards to identify potential donors and raise the issue of donation with the patients’ families.

One of the questions this provoked was the following:

were responsible intensivists meant to allow their patients to die or were they to keep them alive in order to save future lives in the form of organ transplant beneficiaries? Now, in principle, a physician might well wait with making the hopeless prognosis, and continue instead to care for the patient until the brain infarction was clearly discernible, so as therefore to make donation possible. But, according to this new perspective, this would constitute an example of an unethical and undignified “over treatment.” It obliged the doctor to “hide” from the families the truth, giving to those families thereby false hope: “it happens and it is frustrating for the younger colleagues who can then argue that ‘it’s illegal’. But that’s what you do.”²⁹

The idea not to over-treat a patient has now become the highest moral injunction. In combination with a shortage of beds in intensive care units, this concomitantly leads to a risk that people will be under-treated.³⁰ In some countries almost no donations at all are conducted.³¹ Repeatedly, the medical profession has turned to the National Board of Health and Welfare for clearer directives. Most recently, from 2007, in their “summer letter,” the National Board of Health and Welfare offered a “clarification” that referred to the most fundamental principle of the act of Health and Healthcare, namely that the patient must always be treated as an end in him or herself, and not a means for others.³² But the scope for interpretation about what is to be interpreted as “the patient’s own good” is elastic, shifting all the while. In the 1990s, “the right to a dignified death” was an argument for the suspension of life-sustaining treatment once a hopeless prognosis had been declared. During the 2000s, the

situation had once again changed. The argument promoting “the right to a dignified death” has today been replaced with “the right to donate.” This right would justify that a dying patient is to be cared for for the sake of someone else. In the case of living donors, there is already an exception to the rule that all treatment must be for the patient’s own good. Ethics is sensitive of changes in opinion, and we are now facing more complex issues in the regulation of death, dying and donation.

PUTTING DYING IN ORDER

—AN “ETHICAL PARADIGM SHIFT”?

The utilitarian philosopher Torbjörn Tännsjö initiated a debate in one of the major Swedish newspapers during the fall of 2010. He claimed that organ shortage depends on the fact that “fewer people are dying ‘in the right way’, i.e. by brain-death,” and suggested that more people, who wished to donate have to “be allowed” to develop brain infarction (Tännsjö 2010). Therefore we should be able to provide intensive care for people with a hopeless prognosis “for an extended period of time.” It should also be possible to initiate intensive care for the same reason, something not allowed in Sweden today. Tännsjö also raised the possibility of introducing DCD in cases where intensive care is interrupted, well aware that the Swedish criteria for “the only death” as brain death is difficult to combine with DCD, given that 15-20 minutes is too long to wait. He argued: “a common practice is 5 minutes. I think we should stick to it. And I think the public is prepared to think that by then one is ‘dead enough’, if this means that one’s organs can be effectively utilized” (ibid.).

The public could, however, be read in the rapidly expanding comment's field of the article, and showed themselves not to be as prepared as Tännsjö hoped they would be. At least not in any direct way that allowed for constructive discussion. Tännsjö's proposal was immediately associated with "euthanasia," "organ theft," and the "tampering of corpses," with the author himself compared to "Dr Mengele." The old fear of being declared dead prematurely and utilized by the Faustian doctor was easily triggered in the consciousness of modern subjects who nonetheless see no problem with the body being used after death:

After I die, it makes absolutely no difference what happens to my body. I have nothing against it being cut and distributed to the needy. I should therefore be a donor, right? But I'm not, because I do not trust doctors. There is no guarantee that I get the best possible care, if the staff see me as a body-gold mine.⁵⁵

Tännsjö's article is indicative of an ethical change of course in Sweden. A few months later, the same demands were repeated by the OFO (Organisation for Organ Donation) and in a statement from the advisory board of the Swedish Medical Society (SLS), which spoke of a "shift in practice" with regards to non-therapeutic intensive care, "without there being any substantial ethical and legal frameworks for the activity."⁵⁴ Instead of "non-therapeutic intensive care" the delegation proposed a different understanding of "donation preparatory treatment to (sic) dying patients," so as to make the issue more transparent and "easier to communicate [...] to the public."

The delegation stretched the interpretation of the basic principle of the Health Act, that treatment should only ever benefit the well being of the individual patient:

If one as a patient is in favor of organ donation and wishes to donate their organs after their death, then one can, on the other hand, argue that the health care system rather have an obligation to try to accommodate this request. [--] Society should ensure that health services are able to comply with such a desire.⁵⁵

The delegation meant that the person who gave consent for donation after death “usually also accepts a shorter time of donation preparatory treatment before death has occurred [...] in the case of a hopeless prognosis.” In accordance with recommendations advanced by SMER (The Swedish National Council on Medical Ethics) in 2008, so-called “living wills” or “end of life directives” should be introduced.⁵⁶ Such an “altered focus” would be preceded by “factual information, both open and honest, in order that confidence in medical care would not be adversely affected.” Further suggestions were: the possibility to verify the donation register before the patient died; an investigation of the time frames acceptable for donation preparatory treatment as well as an exploration of other medical procedures that might be carried through during this time, including the introduction of DCD. The delegation expressed its willingness to participate in investigations and to draw up ethical guidelines for the field.

Before long, in an editorial in *Göteborgs Posten*, transplantation surgeons were identified as “vultures,” which in “their eagerness to save the ill, want to keep the dying

alive for the only purpose of making donation possible.”³⁷ Reactions were swift; Daniel Brattgård, hospital priest and an expert for SMER, complained that the media, marred by “ignorance,” had nonetheless a “great responsibility for public opinion”—meaning that it frightened people (Brattgård 2010). An additional article, signed by sixteen transplantation surgeons at the Sahlgrenska University Hospital, stressed emphatically that “we only take care of the donated organs and receiver—others are responsible for the donor.” Those “others,” ICU doctors, were accused of acting “unreasonably,” and of preventing people from fulfilling their desire to donate:

[They] believe that the ventilation unit has to be switched off immediately when the situation is judged to be hopeless. In line with this, one could in principle be forced to close down the entire transplant operations in Sweden—which of course is absurd! This means in that case that we are the only modern country in the world which operates with an absurd interpretation of the law that actively prevents people who wish to donate organs from doing so! (Mjörnstedt et al. 2010)

The argument defending the right to donate discloses a tension between the medical profession’s specialists. SFAI (Swedish Society of Anaesthesia and Intensive Care) and SNF (Swedish Neurosurgical Society) opposed the SLS statement, complaining that:

SLS’s statement indicates a clear position on an issue that deeply affects the care of the most severely ill patients and

the public understanding and confidence in that part of care. Such a statement must have a very broad and deeply rooted support within the profession. In our common view, there is currently no support for such a clear position.⁵⁸

These organizations involved in critical care agreed with the demands for an inquiry and open discussion, but they did not want any legislative change that would allow the initiation of therapy by someone with a hopeless prognosis, or extended non-therapeutic intensive care. That would be an “ethical paradigm shift” and such a door would open to “a completely different world.” The clarification made by the National Board of Health and Welfare in 2007, gives, according to the authors, sufficient room for manoeuvre. A ventilator-treated patient with a impaired prognosis may already be cared for up to one day for a correct diagnosis. If a ventilator treated patient is rapidly deteriorating, “typically in the space of one day a total brain infarction should have developed” (Stål 2010). If it has not done so after one day, it might perhaps not. But, precisely, this is the problem in a world where, first and foremost, the body is regarded as a resource.

CONCLUSIONS

In Sweden there is a tradition in which experts, not least physicians, have had a strong influence not only on both social and health policy objectives but on the implementation of these aims. In the inter-war years, the population was taken for granted as a general resource for the common good. From a utilitarian moral position, life was “put in or-

der,” often in accord with dictatorial and disciplinary practices; generally, ideas about genetic risks and social norm-setting eclipsed individual rights. After the Second World War, individual rights and autonomy became increasingly important. Politicians and experts were still in the lap of each other, but the social agenda was instead communicated by way of extensive information and propaganda campaigns targeting the general public.

In comparison with other countries, the Swedish tradition for putting things in order effectuated rapid changes in cultural attitudes, such as the brain-related death criteria that were introduced into Swedish health care. It was done in both a programmatic and a corrective manner, where the experts defining brain death were “putting in order” (both for the profession and the public alike) society’s general understanding of death—though doing so through simplification and homogenization. Citizens were told that there was absolutely nothing new or revolutionary at stake, it was just about a new way to diagnose the same old death. This utilitarian understanding and cultural practice has soon been widely accepted.

The thorny ethical rules and practices surrounding the transfer of an organ from one human to another, is rarely discussed in public spaces, neither are existential questions about death, the soul, and the body. Directives and information efforts aim at increasing donations, where, presently, a discourse within which the gift-metaphor circulates has become central to such a strategy. The public are receivers of corrective campaigns, which clearly both communicate and facilitate the idea of donation as an altruistic act, a gift

that saves lives. The complexity associated with these ethical issues are aired almost exclusively in philosophical articles—whereas on the medical profession’s internal forum, the instrumental and utilitarian approaches characterize the discussion.

Improvement of transplantation techniques and new approaches to life-sustaining treatment in cases of hopeless prognosis, have led to the emergence of new ethical boundaries, in which many potential donors today find themselves. They are not “sufficiently dead” to become donors, but not “alive enough” for it to be considered ethical to keep them under intensive care. That these patients rather die at home or in palliative care, is by donation advocates perceived as an unethical waste of resources, which could be addressed by allowing for the prolonging of non-therapeutic intensive care, and introducing DCD in Sweden.

Characteristic of the recent ambition to maximize resources is the presence of the gift metaphor. The new slogan launched by influential actors on the level of experts is that “it is a right to donate that society needs to ensure the individual.” The cardinal principle of the Health Act, namely that each and every one of its citizens should be cared for for his or her own sake, is therefore interpreted to mean that this is not about the *life* of the individual. Rather, it is the individual’s expressed *will*, which determines how, to begin with, one is to understand the “for one’s own sake.”

When the tradition of expert governance and the established gift-discourse encounters the contemporary demands for individualization and autonomy, such a normative acrobatics as “donation is a right which society must

ensure” seemingly occurs. Are we facing a future scenario in which state authorities—in accordance with the experts’ line of argument—will put the very dying “in order” and where “donation preparatory treatment to dying patients” will simply be communicated as the right to give? This is hardly in line with contemporary ideas about how trust is created—through openness, transparency, and participation. Swedes, who at least on paper, are the most donation willing citizens in the EU, should be ready for a public, open and thorough discussion about donation, death, and dying that neither hides nor embellishes what is really at stake.