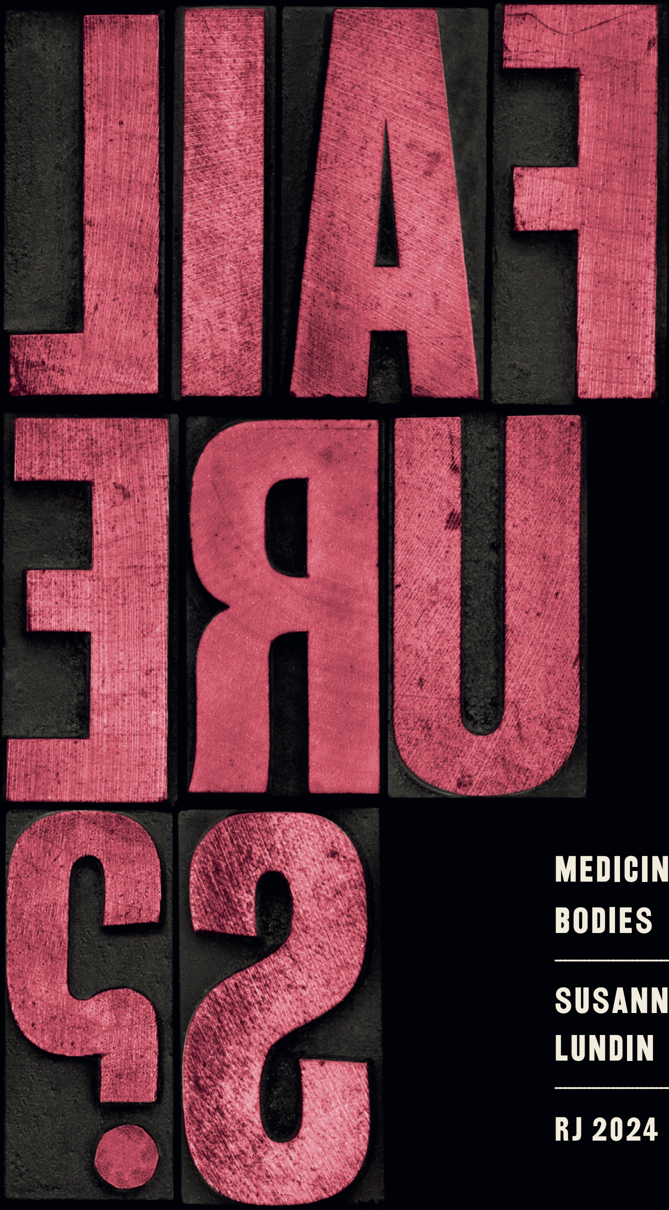

MEDICINE'S
BODIES

SUSANNE
LUNDIN

RJ 2024

FAILURES?

RJ 2024

Medicine's bodies

SUSANNE LUNDIN

Translated
by Clare Barnes

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Foreword: Failures?

"Try again. Fail again. Fail better." Samuel Beckett's words are now legendary. There seems to be no crisis, setback or adversity from which it is impossible to learn. Failure carries its counterpart – success – within. Listen to the countless biographical radio programmes about fiascos that turn to triumphs, Google for failures, see how self-help books are structured. Perhaps it has always been this way – or is this a consequence of our era's accelerating demands for success, growth, advancement and evolution?

The American historian Scott A. Sandage, who researched the cultural history of failure in the US, claims that failure has become personal since the mid-nineteenth century – you don't just fail, you are a failure. He even talks of a nation of winners and losers, in which everyone is either the one or the other. Failure is thus a constant and shadowy companion to the American dream, an ever-present component of the American experience. Sandage links this to several factors, including modern society's perpetual evaluation and our time's statistical exposure of private lives. In the nineteenth century, the innovation of statistics collection seemed to reveal in real time previously hidden – or at least obscured – connections relating to the population and society. In the US, this also coincided with the credit institutes' division of the populace into those who were creditworthy and others – which is to say, losers. In addition, Sandage sees a link with the rise of meritocracy. The statistics demonstrated, incontrovertibly, that the masses were nothing other than mediocre.[1]

Sweden is also a nation of mediocrity, just like every other nation, and here too – even if we are not as influenced by the idea of an American dream – mediocrity is associated with a lack of success, rather than a normal distribution. There are people who believe that we are now living in an age of perfectionism, placing sky-high expectations on ourselves. Nothing other than flawless will do, and everything that doesn't make it is pretty much a failure. These growing demands for ultimate excellence are regarded by the Public Health Agency of Sweden as one reason for the current rise in mental illness.[2] The same trend seems to be occurring in the rest of the West, and perfectionism is said to have increased since the 1980s.[3] In his most recent book, the British psychologist and researcher Thomas Curran writes of a hidden epidemic that is haunting the modern, capitalist Western world, where the tougher demands we wrestle with mean that we are increasingly likely to fail – and are particularly likely to dread this failure.[4] That fear inhibits us, Curran claims.

Our contemporary individualism, enthusiasm for evaluation and constant searching for something that is occasionally vague but better – yes, “more perfect” – makes us ever-more vulnerable to failure. However, in itself, of course, failure is nothing new. Quite the opposite, setbacks and adversity are part and parcel of being human.

Mistakes, errors and a lack of success have, for centuries, comprised the very foundation of science and research as we know it. Trial and error. We could even claim that, fundamentally, science is about daring to get things wrong and then learning from your mistakes. A researcher makes predictions and finds regularities, patterns and laws in what appears to be chaos. The periodic table and the discoveries of Newton, Linnaeus and Einstein are just a few examples; new theories replace old ones, errors are found, and systems improved or discarded. Faults and troubleshooting are part of the process, and what the Enlightenment, modernity, progress, was all about was this: taming and mastery through rules, predictions and – yes – finding mistakes.

We are now seeing indications that fewer scientific breakthroughs are occurring – at least if by breakthrough we mean scientific achievements that move our knowledge in a completely new direction. This is happening despite our faith in research and all the global resources invested in it.[5] Is the lack of breakthroughs a failure of our times? And, if so, is it our fear of failure that makes us less bold and thus less likely to explore new directions?

We could ask ourselves whether anyone now believes in progress and the future in the way that people did in the 1960s. In this way, we live in a darker world – or are we just less naïve? And there are fiascos, for individuals and for societies, that are difficult to learn from, and where the lesson is perhaps just to put it all behind you and move on.

Still, if we swept all those fiascos under the rug, if all our setbacks were hidden and forgotten, we would not have made any progress. We are somewhere between these extremities, daring to see the mistake for the shambles it is, sometimes with no lesson to be learned, and to use it. In this essay collection, six researchers from the humanities and social sciences take a closer look at failure and the unintended consequences of success.

They range from the allegedly unsuccessful 'Million Programme' for public housing, to whether or not nuclear power should be regarded as an unsuccessful technology. In this essay, ethnologist Susanne Lundins writes about how medical advances such as transplant surgery and in vitro fertilisation are inadvertently changing the way we view our bodies, and creating illegal markets.

Almost everything we do has unintended consequences, and it is far from obvious what constitutes a failure – particularly when little time has passed. According to Walter

Benjamin, the angel of history sees the past as a long chain of catastrophes, while being propelled back-first into the future on a storm called progress.

Someone who continues to read Samuel Beckett's famous lines on having another go, soon realises that he is not delivering an optimistic call for success, but rather a pitch-black description of failure:

> Try again. Fail again. Better again. Or better worse. Fail worse again. Still worse again. Till sick for good. Throw up for good. Go for good. Where neither for good. Good and all.[6]

Jenny Björkman

Notes

1. Scott A. Sandage, *Born Losers: A History of Failure in America*, Cambridge, MA: Harvard University Press, 2005.

2. Public Health Agency of Sweden, "Varför har den psykiska ohälsan ökat bland barn och unga i Sverige?", Solna: Folkhälsomyndigheten, 2018, www.folkhalsomyndigheten.se/publicerat-material/publikationsarkiv/v/varfor-har-den-psykiska-ohalsan-okat-bland-barn-och-unga-i-sverige/. See also "Young people drowning in a rising tide of perfectionism", *The Conversation* 5 February 2019, https://theconversation.com/young-people-drowning-in-a-rising-tide-of-perfectionism-110343.

3. Thomas Curran & Andrew P. Hill, "Perfectionism is increasing over time: A meta-analysis of birth cohort differences from 1989 to

2016”, *Psychological Bulletin* vol. 145, no. 4, 2019, pp. 410–429.

4. Thomas Curran, *The Perfection Trap: The Power of Good Enough in a World that Always Wants More*, London: Cornerstone Press, 2023.

5. Michael Park, Erin Leahey & Russell J. Funk, “Papers and patents are becoming less disruptive over time”, *Nature* no. 613, 2023, pp. 138–144.

6. Samuel Beckett, *Worstward Ho*, 1983.

ERRARE HUMANUM EST


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The unforeseen consequences of medicine

In the early 2010s, Sonja travelled from Sweden to Ukraine to hire a surrogate mother.[1] She dreamed of having a child of her own. At the same time, another woman, Asta, travelled to Iran in the hope of purchasing a new, life-sustaining organ. Both Sonja and Asta had their wishes fulfilled: one became a mother, the other regained her health. But they had moral reservations – was using another person's body in this way the right thing to do?

The cases of Sonja and Asta not only raise moral questions for those involved, but also at a more general level. What happens to expectations about our bodies and our lives when medical advances make more and more treatments possible?

Biomedicine is a modern success story, offering important tools for human health and wellbeing, but there is a downside. Successful medical technologies can create a number of difficult challenges for both society and individuals, not least ethically. Many treatments require human material in the form of genes, cells, tissues and organs, but what is entailed by medicine's tendency to turn individuals into objects? Another important question is whose bodies become these biological resources and who can access to healthcare and medicines.

In this essay, I will examine two technologies: one aims to result in parenthood through reproductive medicine and the other in a healthier body through organ transplants. While they have both improved the quality of life for many, they have also created problems due to their limited availability. One way of addressing this situation is cooperation between different countries' healthcare systems. Swedish citizens can use public health services in another EU/EEA country and, in some cases, also in Switzerland, the UK or Northern Ireland; reimbursements for planned care can also be applied for via the Swedish Social Insurance Agency. Agreements on reproductive medicine and organ transplantation are based on the principle of altruism, which means that the donor is not remunerated but is compensated for lost working time and possible sick leave. However, entirely different agreements are made in parallel with those above. In the wake of these successful technologies, there is a significant black market in medical treatments; people can earn money by selling their body parts, but are also at risk of exploitation.

Modern medicine thus seems to have a number of unintended consequences, but the question is how the medical black market is associated with people's desire for children and health. The premise of Western medicine is that bodies are made up of biological parts, which can be repaired or replaced to create, in the words of the social anthropologists Margaret Lock and Vinh-Kim Nguyen, healthy but also standardised bodies.[2] As more and more medical conditions become treatable, ideas are emerging in which deviations from an imaginary standardised body become something abnormal – perhaps even a personal setback that should be addressed. This tension between medicine, societal ideals and people's lives gives rise to dilemmas.

There are legal and ethical guidelines that address the quandaries caused by the demand for human material – a general principle is that people should be treated as individuals and not as objects. However, this rule is interpreted and applied in vastly different ways around the world, depending on a country's political and cultural structure. The perspectives on societal and personal responsibility thus vary, which affects the treatments people are offered. Another consequence of this clash between values is the emergence of moral and legal grey areas.

My approach is based on people's stories and examining their "ontological choreography", to use the sociologist Charis Tompson's term, which gives meaning and legitimacy to actions.[3] Negotiations about right and wrong happen in both individuals and collectives, as part of an interaction where overarching norms are intertwined with personal ideals. My interviewees' stories display this ontological, meaning-making choreography, while a clear connection emerges between the perceived shortcomings of the individual and society's failed strategies for taking responsibility for the consequences of medicine.

Reproductive medicine: Creating life

Having children and starting a family is one of the many expectations that organise people's lives – in Sweden and in other parts of the world. Although the image of parenthood and family has varied historically, many cultures have ideas about what constitutes an ideal family situation. In Sweden, the norm has been the nuclear family of mum, dad and children, but this pattern is increasingly being transformed by divorce, remarriage or non-binary relationships, family formations in immigrant cultures, and voluntary childlessness.

Nevertheless, the idea of the family remains for many people, making the parent-child assemblage what is natural. Around 10–15 per cent of all couples in Sweden are involuntarily childless; the causes are as often found in the man as in the woman, yet it is commonly believed that infertility is a female problem. In the 1970s, medical researchers Robert G. Edwards and Patrick Steptoe developed a method that has grown to be of huge significance for people with involuntary infertility, when they succeeded in creating a human embryo outside the body. Edwards was awarded the Nobel Prize in 2010 because of this. The method involves fertilising a woman's egg cells with sperm in a laboratory and then returning the embryo to the woman, where a foetus can develop. The treatment is colloquially known as assisted reproduction, in vitro fertilisation or IVF – in-glass fertilisation, meaning outside the body. Since the first test tube baby was born in the UK in 1978 (in Sweden in 1982), over nine million children have been born thanks to IVF.[4] Swedish citizens now have a right to this treatment, and IVF is used worldwide, albeit in different ways depending on each country's legislation.[5]

IVF research was controversial for many years; many people had religious or ethical objections. When I started my first research project on reproductive medicine in the early 1990s, there were comprehensive international studies examining the ethical and legal principles of assisted fertilisation.[6] However, my interest instead focused on the people affected by the treatment – those with involuntary childlessness. The project also reached out to patient organisations and fertility clinic staff. Two clear themes emerge from the stories of the childless women: one describes medical technologies as appropriate tools for having children – that is, the medical progress; the second shows how medicine is a tool for affirming their gender identity, how they perceive themselves as women. That involuntarily childless women are using technology to transform a perceived failure of femininity into successful motherhood must be regarded as an unforeseen consequence.

My first ethnographic observation took place in 1993 at a fertility clinic in southern Sweden. On an early autumn day, wearing protective clothing and a hairnet, I stepped into the surgical ward to witness an IVF treatment. The scene that greeted me was a woman, Lisa, half-lying in a gynaecologist's chair – her legs wrapped in green surgical sheets, her arms full of electrodes and injection needles. The doctor was sitting in front of the gynaecologist's chair, and at the back, an ultrasound screen showed how the doctor inserted a cannula in the fallopian tubes to capture the eggs, which were then sent to the lab to be fertilised by carefully selected sperm. The fertilisation was successful, so the embryo was transferred into the woman's uterus a few days later. When I spoke to Lisa some time later, she said that the pregnancy had failed. "My tiny eggs", she said, "carriers of life. They didn't settle in my womb. But", she added, "my longing and struggle aren't over."

Shortly after my visit to the clinic, I met Eva. Her story clearly illustrates the links between perspectives on technology, the desire for motherhood and female identity: "When we heard about IVF, we felt that of course we wanted to try it… here's a technology that can make it successful, now it's just as if it helps nature… to realise my true female self!"

Another woman, Karin, who was unable to become pregnant with her own eggs, expressed a similar view. When I met her in 2008, she had a ten-year-old daughter who had been conceived through egg donation in Romania, a treatment that was not permitted in Sweden in 1998: "I couldn't get the IVF I needed at home, and I've always known I would be a mum, a tiny 'defect' in my body didn't make any difference."

There was great joy about the child, but Karin, like some other women, also had a nagging feeling that the technology they relied on had a shaky moral foundation. Was there a risk that egg donors and other people who were involved could be exploited, they wondered. Sonja, whom I mentioned in the introduction, returned to her doubts several times. The method was prohibited in Sweden in the early 2010s, when she realised that her only chance of having a child was through surrogacy, so she travelled to Ukraine to hire a surrogate mother through an agency she found on the internet.[7] At the Ukrainian clinic, Sonja's eggs, fertilised by her husband using IVF, were transferred into the womb of another woman, who carried the child throughout the pregnancy. But Sonja's happiness at becoming a mother was clouded: "I wanted to do everything in my power to have a child, to become a mum", she said, wondering whether it had been a morally correct choice. "I think about what it means to, how should I put it, to use someone else. I saw a documentary about egg donors and surrogate mothers in India and it was terrible how they were used, locked up, but I hope that's not the case where I was."

Legal assisted fertilisation abroad often results in happy parents and satisfied donors. At the same time, there are examples of how fertility treatments can lead to an ethical grey area and a medical black market on which body parts are traded.

I encountered such activities on one of my research trips to the Middle East, where, at a volunteer organisation, I was told about "the Romanian egg affair" that had occurred a few years previously. In 2003, the Romanian authorities arrested thirty people, including Romanian and Israeli doctors, for illegally trafficking women's eggs. This all took place at a clinic in Bucharest where women, mainly from Israel, came to buy embryos. However, the customers were not only childless women, but also pharmaceutical companies and research institutes that needed biological material for stem cell research. The women providing the goods, the egg cells, were mostly from Eastern European countries: poor students who wanted to pay for their studies, single mothers and penniless young women. Two of them were Alina and Raluca, who worked in a factory in Bucharest. Nineteen-year-old Alina heard about the opportunity to sell her eggs as an 'egg donor' and wanted to do it to give her family a decent life. Raluca, a single mother, worked in the same factory as Alina and, like her co-worker, came from a poor background. At the clinic, they signed a contract, but neither of them understood its contents, which used complicated medical terminology. When the women suffered severe side effects during egg retrieval, it turned out that the contract excluded the clinic from any liability. Neither Alina nor Raluca ever received the promised amount of money.

The people who told me about the events in Bucharest belonged to an anti-trafficking organisation in Israel, and said that one of the actors in the Romanian egg affair was a well-established gynaecologist in Tel Aviv, who was still working. It turned out that the events in Romania were not unique; transactions with 'egg donors' from various countries in Eastern Europe and the Middle East were part of a large-scale operation. Some of the women had turned to the organisation for help with terminating their contracts with the clinic; one was Anat, who had been enticed into selling eggs to make money: "Suddenly I saw this advert on the internet and they said they would pay a lot. They told me that it wouldn't hurt me, that it was just like giving blood. [...] I managed to delay everything when I realised they wanted to send me to Cyprus to meet the couple who were the clients [...] it seemed strange and I was scared."

The organisation was also in contact with the clients, the involuntarily childless women who had bought treatment on the black market. Sara was one of the women who had unsuccessfully tried different treatments and decided to buy eggs: "If my only chance to have a child, to become a mother, is to go to Romania and accept an egg from a poor person who would be given a dollar for it, I mean, like something she could buy a jacket and boots for, and that this really isn't good for her… I'm quite convinced that, God forgive me, I would have done it. I would bring a life into the world because of my desire… it's not that I want a bigger house or nicer things – it's to bring a life into the world."

Another woman turned to a Ukrainian clinic with which Israel's health insurance agency had a contract. After several failed attempts using donated eggs, she chose a different strategy – she asked an acquaintance who was a doctor for help. "We pushed him", she said, "we had a way to do it, which I don't want to talk about, and he did it… just like that, he found eggs for me to buy…"

Rahel, another interviewee, had fewer concerns, explaining, "I wouldn't hesitate at all to do anything to become a mother, otherwise I'd be a sick and useless woman. You need to understand, I want a child. Nothing will stop me from becoming a mother!"

My interviews with involuntarily childless women, regardless of their nationality, have things in common. Motherhood is described as synonymous with being a woman, and medical technologies are simply tools that can help nature to realise female identity. At the same time, their stories provide insights into national and sociocultural differences that influence women's moral considerations and, ultimately, their actions. Israel, like Sweden, assumes that medical treatment involving third parties – such as various forms of assisted fertilisation – should be done through donation. However, the interpretation of the term 'donation' is different to that in Sweden. Israel emphasises motherhood as a fundamental element of society, which is reflected in the fact that the country has more fertility clinics per capita than any other country, and that every woman is entitled to treatment until two living children have been born.[8] These political and cultural guidelines mean that many Israeli women see motherhood through assisted reproduction as a personal right, one that must be enacted at any price.

The situation in Sweden is different. Although family and motherhood are basic models, the authorities here strongly uphold the principle that assisted fertilisation should not be performed for individual financial gain. The Swedish women I met also wanted to follow the norm of altruism, which ultimately made it morally problematic to pay for their much desired motherhood.[9]

Both legal and illegal reproductive treatments outside the homeland are based on a range of circumstances, such as high costs or lack of medical resources. There may also be bans on surrogacy, egg donation or preimplantation genetic diagnosis, or restrictions on homosexual couples, for example.[10] Globalisation is also significant, not least the increasing amount of information on transnational fertility treatments that is available online.[11]

As the social anthropologists Lock and Nguyen have pointed out, reproductive medicines are anything but neutral technologies; they arise from societies' normative ideas about female identity and motherhood.[12] This also means that healthcare is subject to ideas about what people should be and what tools and technologies are permitted in the process of having children. This is also evident in my conversations with healthcare professionals, with some advising their patients to go to foreign clinics with which Sweden has agreements. And, in some cases, staff advise people to look for alternatives on the internet, which can ultimately lead to ethical and medical grey areas.

As I have shown, many women feel that involuntary childlessness threatens their identity; their body's limitations appear to be both biological and personal failures that should be corrected. At the same time, the women's stories are full of doubt, as their maternal happiness is not only achieved using medical technology that helps to create a child, but also by using other people. Where is the line, they ask, between accepting assistance from other people's bodies or exploiting them?

Organ transplants: Preventing death

In parallel with research on the life-creating potential of reproductive medicine, I have investigated technologies that prolong life and prevent death – one of which is organ transplantation.

For centuries, medical science has sought ways to replace defective body parts and organs with new ones. Around 1900, important progress was made when the French surgeon Alexis Carrel used animal experiments to demonstrate how blood vessels from an implanted organ, the allograft, could be connected to the recipient's bloodstream. This was the first step towards learning how to manage the body's immunological mechanisms, as the immune system fights infections and thus rejects foreign organisms such as cells, tissues and organs.

The first successful organ transplant, in which a kidney was transplanted between genetically identical twins, to prevent rejection, took place in the US in 1954. However, it would be many years before the riddle of the immune system was solved. It was only in the 1980s that a drug called Ciclosporin was introduced; this revolutionised transplantation by preventing the foreign organ from being rejected.

Nowadays, transplants of cells, tissues and organs are well-tested procedures, although they also, like reproductive medicine, raise moral and ethical issues. For example, the success of medicine and technology reinforces the idea of what constitutes a normal and standardised body. Embedded in these values, another pattern emerges, one which entails a cultural imperative for individuals to take responsibility for their own health.[13] Ciclosporin also significantly increases the availability of organ donors, opening the door for an organ pool on the black market.

Between 2003 and 2007, I conducted focus group discussions with patients who had kidney failure, heart and lung problems or diabetes, with the aim of exploring their perceptions of the role of medicine in society and their views on the body. The interviews were conducted in eight European countries to uncover the relationship between medical developments, norms and values.[14] Quite quickly, the dialogues began to focus on the importance of developing transplantation technology to save lives. "It's how we can survive", said one participant. A man with a heart problem reflected on the relationship between donor and recipient, stating, "Someone has to die for me to get a new heart or, at least", gesturing towards another participant, "for someone to give you one of their kidneys [. . .] and it might not be easy."

Another wondered, "Is it a medical issue, or an existential or moral issue, or mostly a financial one?" For yet another, it was neither medical nor existential difficulties that mattered, instead it was healthcare priorities and whether Sweden should allow financial compensation for the provision of organs, rather than relying solely on altruism and donations.

"Who out of all the ill people should get new organs, who decides and how should transplant queues be shortened?" wondered the participant. "Because how am I going to get an organ if the queues are so long. Perhaps it's something I have to do myself to become normal, so to speak?"[15]

The participants were ambivalent. They hoped that medical science would save lives, but also felt discomfort at organs being taken from another human being. In addition, in a similar way to the stories of the involuntarily childless women, there were two common themes: one was the lack of organs and the second was the connection between health, normality and responsibility.

The years that the focus groups were conducted, there were 40,000–50,000 patients in Europe waiting for a new organ. During that period, 15 to 30 per cent of them died while waiting for a transplant.[16] In Sweden, in 2023, over 800 people were waiting for new organs, with the majority needing a kidney. More than 4,000 people in Sweden are receiving dialysis while awaiting a kidney transplant, while

Sweden has long been the European country where the greatest proportion of people want to donate their organs. However, the country is by no means at the top in terms of operations, as there is a gap between people's intentions and completed transplants.[17]

Internationally, there are differences in how countries organise their transplantation systems. Since 1996, there has been 'presumed consent' in Sweden, whereby anyone who has not explicitly refused to donate organs after death is expected to do so. In some East Asian countries, such as Japan, active consent and family approval are required. Some organs, such as hearts and lungs, come from deceased donors. Kidneys can be transplanted from deceased donors, but also from living donors, as humans have two kidneys and can live a full life with just one.[18] Receiving a kidney from a living person has proven to be much more successful, which is one of the reasons why kidneys from live donors are in demand.

A few years after the discussions with the focus groups, I came into contact with people in Sweden who had travelled abroad to buy organs. Medical staff had reported suspicions that patients were involved in organ trafficking, so my research team investigated patient attitudes to waiting lists at transplantation clinics. The staff had seen that patients who were registered on waiting lists for kidney transplantation suddenly left, later returning to the clinic. Some wanted aftercare for an operation that had been conducted in an unknown location, others wanted to be put back on the waiting list because the organ that had been implanted abroad was defective and had made them ill. When the clinic asked patients where they had been treated, their answers were evasive, perhaps claiming it was a gift from a relative in another country, while others suggested they had found donors through the internet, or that friends had told them about clinics in countries that have different laws to Sweden. Although they did not want to confide in the medical community, some were willing to meet with my research team, with one reason why the kidney patients shared their experiences being related to Swedish legislation. Although purchasing organs is illegal in Sweden, there are no legal penalties for doing so abroad; organ buyers are not penalised if they did so in another country.[19]

Sam, who bought a kidney in Pakistan, said that he "had to go even though I'm not the kind of person who wants to buy from others, but I had to choose between dying and leaving my family and my job, or starting a new life – I got no help in Sweden".

Another said, "I would rather die under the knife in a foreign clinic [illegal transplant, author's note] than during this uncertainty about when it will be my turn on the waiting list [. . .] I have a family to support and have to take responsibility for them and myself."

Everyone we interviewed had long experience of dialysis while waiting for a transplant. Dialysis is a method in which someone is connected to a device that helps their kidneys clean their blood. Each treatment session takes about four hours and is followed by physical reactions that include fatigue and itching. One middle-aged man, Joseph, said that he initially received dialysis every six days, but then it became three times a week. “All my time was spent either getting dialysis or feeling really bad after it”, he said, and went on to describe how awful it was to “be on dialysis – between life and death – impossible for a healthy person to imagine, but when you’ve lived in that hell for years, you’ll do anything not to live in such pain. So you’re alive, but you have no life, no normal life and no normal body.”

Rohan, a father of several children, said, “My sick body is so troublesome, not only because I’m so ill but also because I don’t fit in, I feel like my younger children are ashamed of me when I limp or can’t say hello to their friends. They want a normal family.”

Another, who was given a tip off about a clinic in the Middle East and eventually travelled there, put it this way: “The disease is completely crushing me, my body and who I am as a person, and so you grasp at every straw.”

One interviewee, Asta, told us that she did not want to continue with dialysis, but had decided to solve the problem herself by contacting an Iranian clinic. Iran is one of the few countries with a state-organised organ trading system. For example, the Medipars company offers kidney transplants at a cost of $14,000–19,000.[20]

Asta described how, while registering at the clinic, she looked for other and faster solutions, "I found several adverts on the internet where people were selling organs. I decided on a young man in Iran and paid him a lot of money, because he was poor and had several small children. Now I just hope he will manage with his one kidney."

The operation was performed at the clinic she had registered with, but because the organ did not come from the authorised facility, "I paid for my 'special treatment' – that's how it works and I understood that."

Asta, who bought a kidney from the young Iranian, hoped that everything would go well for him. However, in a follow-up conversation some time after our first interview, it turned out that things had gone very badly. The man who sold the kidney was unable to work for a long time after the organ was removed from his body, and did not receive sick benefits because the transplant was done outside the official system. He lost his temporary job as a labourer on a construction site and the family had to move out of their home.

The above incident is by no means unique, instead it is rather typical of the organ market. Several years after the interviews with kidney patients who had left Sweden to buy organs abroad, I talked to poor people who had sold their kidneys. I met them in Eastern Europe, the Middle

East, the Philippines and South Africa, and their stories show a consistent pattern in which illegal gangs use people from vulnerable groups for what they claim are donations. However, it is important to remember that these people are certainly not donors in the traditional sense. Quite the opposite, the word donor is used in a way that hides how they are sellers on an illegal market – and it is often poor and vulnerable people who are being exploited. The methods are the same as those used in other types of human trafficking, including promises of job opportunities abroad, threats and violence. Typically, people receive less money than was agreed and, in many cases, no payment at all. Just as frequently, organ sellers suffer post-operative complications, health problems and premature death.

There is also a pattern of 'black' organs being 'laundered', when operations are performed in well-established clinics in which bribed doctors perform the operation. This covers up the organs' origin on the illegal market. At the same time, most people – both the doctors and the patients – seem to know where the organs come from.

One transplant surgeon I met in the Philippines said, "Everyone knows, but turns a blind eye". Or, as another doctor involved in commercial transplants put it, "morality is negotiable".

In addition to legal transplantation travel, there is an extensive illegal trade in organs. According to the World

Health Organisation, it is one of the world's five most lucrative criminal activities.[21] This market has grown in the 2020s, with Interpol saying that one reason is the increasing refugee flows, where kidneys, for example, serve as payment for those without money. Another reason is that legal donations have decreased since the COVID-19 pandemic, and the socio-economic impact of the pandemic has also made it easier for criminals to recruit new organ sellers.

The people who travelled abroad for an organ transplant bought the hope of a healthy body at the cost of someone else's misfortune. In this way, we can speak of a general failure on the part of both the individual and society. Does this mean that the organ shortage should be tackled differently? Broadly speaking, there are two different positions: one favours allowing the sale of cells, tissues and organs; the other warns that when body parts become consumer goods, it leads to a slippery ethical slope that threatens to undermine human dignity.

Failures:
Moral displacement and the outsourcing of ethical problems

We live in a time when the notion of a normal body is shaped by biomedical sciences and the idea of medically standardised bodies. Against this background, childlessness, illness and disability may appear abnormal deviations. It may be tempting to see the stories of childless women and kidney patients as purely subjective, but in fact their views interact with the overall values of society, as do their strategies for coping with their situation. Alongside the normative images of the body, there are other messages that call people to action. For example, in today's individualistic society, there are clear ideas about the importance of being proactive and taking responsibility for yourself.

The sociologist Nikolas Rose has pointed to what he calls responsibilisation, which means that the state transfers responsibility to individuals who are asked to solve their own problems.[22] This leads to structural and social challenges becoming personal problems, because people, as individuals and as citizens, partly assume responsibility for their health. When this happens, each person becomes accountable for their own destiny and has to face a series of new moral considerations. For some, the solution may be to seek help through legal medical treatments abroad; others may find purchasing treatments and organs on the black market acceptable. In these processes, the body becomes an economic entity and an identity project, in which the individual bears responsibility both for their health and for the ethical challenges it poses.

All cultures have many different thought systems, which sometimes clash. The stories I collected in my projects clearly show that the path to motherhood or a healthy body is edged with uncertainty. Many people wonder whether it is morally right to use other people's bodies to achieve their own ends. At the same time, justifying these actions is equally common. One argument is, "In principle, I'm against 'exploiting' others, but it's me or them". Another is, "They are poor and the money probably saved them, so it's a win-win situation".[23]

To return to the sociologist Thompson, these stories demonstrate an ontological choreography that creates meaning and legitimacy in a new moral landscape. Biomedicine thus induces not only a new view of what is a normal body, and thus desirable, but also new interpretations of what people can and should do. Science thus opens a path to moral displacement.

So, is it the state's responsibility, as an institution, to ensure that medical successes do not become failures? The question cannot be answered with a yes or a no – the answer must be 'both'.

Moreover, societal accountability is complex and should be understood contextually. Israel is an illustrative example, with its recognition of motherhood as a civil right and the creation of systems that offer free IVF treatment. This affects both the behaviour of individual citizens and the healthcare system, as well as what is regarded as morally justifiable. The medical success of infertility treatment can, in some cases, be understood as a moral failure. Also, one country's legislation may clash with global and digital patterns; Iran adheres to the principle that people should not be treated as commodities, but at the same time the state authorises the health sector to buy and sell organs, creating a market with a different logic and possibly less regard for ethics and morality. Whose responsibility is this, and is the state obliged to regulate this market?

The principle that people should never be objects is thus constantly being challenged. Parallel to the idea of unique individuals is the way the medical sciences fragment the body, allowing eggs, sperm and organs to be perceived as entities with no links to individuals.[24] As such, the body appears to be a container for biological material, in which defective parts can (and should?) be replaced with new ones. But finding replacement parts is not always easy; in fact, resources are scarce. So society intervenes, such as through Swedish healthcare agreements with other EU countries, whose clinics provide what Sweden will not or cannot provide. This can include biological material, but also treatments that are not available in Sweden for legal reasons.

When I studied involuntary childlessness in the 1990s, Swedish law authorised a limited number of treatments. For example, egg donation was not allowed until 2003, partly on the grounds that it was unnatural. This meant that women travelled to countries with different laws. Over the years, legislation has changed to allow various forms of assisted fertilisation; at the time of writing, in 2024, surrogacy is not permitted.[25]

The organ shortage has led to collaborations, such as the Scandiatransplant organisation, which was founded in 1969 and brings Denmark, Finland, Iceland, Norway, Sweden and Estonia together in a joint organ exchange.[26] There are also other ways to expand the Swedish organ pool. In 2022, the Swedish Transplantation Act was amended to allow medical interventions to be given to an end-of-life patient, so they can donate their organs.[27] These treatments have been highly controversial in Sweden. Critics have argued that patients risk being turned into organ banks, while advocates have argued that more organ transplants will save the lives of sick people. My interviews with kidney transplant patients took place before the change in the law came into effect; some interviewees received operations in Sweden through Scandiatransplant, while others sought treatment outside the contractually regulated healthcare system.

Important medical breakthroughs, when applied in practice, can thus have a range of unexpected consequences, some of which must be considered undesirable. The consequences of medical success can be found at many levels – individual, societal and moral. Moral renegotiations take place gradually, including here; the shift from the principle of a unique individual to the idea of humans as a resource has come gradually, in the wake of medical progress. Perhaps this is one of the greatest moral failures of our new modern medicine – the difficulty in accepting that there is a contradiction, one in which life can be pitted against life?

When discussing the impact of biomedicine, it is common to describe the technology as difficult to stop once it has found a place in society. But technology is not an independent force and, for the future's sake, it is important to remember that new medical technologies and scientific advances are always charged with ideas about how life should and should not be organised. Notions that people's infertility and diseased bodies make them failed individuals leads to concrete actions – but also to a lack of active behaviour. Moral displacement and contradictory views of the individual pave the way for what can be called a 'blinkered' practice, whereby the state outsources its ethical problems to individuals and to other countries. This hides and perpetuates illegal medical treatments in which people are exploited – therein lies the greatest failure.

Notes

1. Interviews and ethnographic observations are transcribed. Unless otherwise stated, all quotes refer to material stored at Folklivsarkivet in Lund (www.folklivsarkivet.lu.se). Names of interviewees have been changed for reasons of confidentiality.

2. Margaret Lock & Vinh-Kim Nguyen, *An Anthropology of Bio-medicine*, Malden, MA: Wiley-Blackwell, 2010, pp. 43–54.

3. Charis Thompson, *Making Parents: The Ontological Choreography of Reproductive Technologies*, Cambridge, MA: MIT Press, 2005.

4. "IVF-barn mår prima som unga vuxna", forskning.se, 21 December 2021, www.forskning.se/2021/12/21/ivf-barn-mar-prima-som-unga-vuxna/.

5. "Ersättning för fertilitetsvård utomlands", RFSL, 18 May 2022, www.rfsl.se/verksamhet/foralder/att-bli-och-vara-foralder/ersattning-for-fertilitetsvard-utomlands/.

6. Lynn Åkesson & Susanne Lundin, "Creating life and exploring death", *Ethnologia Europaea* vol. 26, no. 1, 1996, pp. 37–49, DOI: 10.16995/ee.847.

7. Example of an agency: www.surrogacysweden.se/om-oss/omsurrogacysweden.

8. Daphna Yeshua-Katz, "Childless in an IVF-nation: Online stigma-coping strategies in support groups for childless Israeli women", *Information, Communication & Society* vol. 21, no. 10, 2018, pp. 1436–1452, DOI: 10.1080/1369118X.2017.1324504.

9. Cf. Susanne Lundin, "The valuable body: Organ trafficking in Eastern Europe", *Baltic Worlds* vol. 1, no. 1, 2008, pp. 6–8.

10. Preimplantation genetic diagnosis (PGD) is a technique for the genetic diagnostics of fertilised eggs (pre-embryos). PGD is done in association with in vitro fertilisation. See the description from the NHS Commissioning Board: https://www.england.nhs.uk/wp-content/uploads/2013/04/e01-p-a.pdf.

11. Marcia Inhorn & Pasquale Patrizio, "Infertility around the globe: New thinking on gender, reproductive technologies and global movements in the 21st century", *Human Reproduction Update* vol. 21, no. 4, 2015, pp. 411–426, DOI: 10.1093/humupd/dmv016.

12. Lock & Nguyen 2010.

13. Max Black, "Nothing new", in Melvin Kranzberg (ed.), *Ethics in an Age of Pervasive Technology*, Boulder: Westview Press, 1980, pp. 26–27.

14. Between 2004 and 2007, the project "Challenges of Biomedicine: Socio-Cultural Contexts, European Governance and Bioethics" (European Commission) conducted focus group discussions in eight European countries to examine the relationship between medical developments, norms and values. See https://sts.univie.ac.at/en/research/completed-research-projects/cob/.

15. Anna Johansson, Costas S. Constantinou, Katrin Amelang, Stefan Beck, Susanne Lundin & Violetta Anastasiadou-Christophidou, "Learning to eat strawberries in a disciplined way", *Ethnologia Europaea* vol. 41, no. 2, 2011, pp. 56–72, DOI: 10.16995/ee.1086.

16. "Statistics Report Library", Eurotransplant, https://statistics.eurotransplant.org.

17. "Statistik", Mer organdonation, https://merorgandonation.se/statistik-och-rapporter.

18. The tissues used are primarily skin, heart valves, bone tissue and corneas. "Join the Swedish National Donor Register", National Board of Health and Welfare, https://www.socialstyrelsen.se/en/apply-and-register/register/join-the-swedish-national-donor-register/. In some cases, all donations from dead donors are problematic for religious

reasons, which require a dead person to be buried without body parts having been removed.

19. Susanne Lundin, *Organ till salu*, Stockholm: Natur & Kultur, 2014.

20. "Kidney Transplant in Iran for Foreigners", Medipars, www.medipars.com/urology/kidney-transplant/.

21. Frederike Ambagtsheer & Roos Bugter, "The organization of the human organ trade: A comparative crime script analysis", *Crime, Law and Social Change* vol. 80, 2023, pp. 1–32, DOI: 10.1007/s10611-02210068-5; "North and West Africa: INTERPOL report highlights human trafficking for organ removal", Interpol, 30 September 2021, www.interpol.int/News-and-Events/News/2021/North-and-West-Africa-INTERPOL-report-highlights-human-trafficking-for-organ-removal.

22. Nikolas Rose, "Government and Control", *The British Journal of Criminology* vol. 40, no. 2, 2000, pp. 321–339, DOI: 10.1093/bjc/40.2.321.

23. Susanne Lundin, Charlotte Kroløkke, Michael N. Petersen & Elmi Muller (eds.), *Global Bodies in Grey Zones: Hope, Health, Biotechnology*, Stellenbosch: African Sun Media, 2016.

24. Cf. Lesley A. Sharp, "The Commodification of the Body and its Parts", *Annual Review of Anthropology* vol. 29, no. 1, 2000, pp. 287–328.

25. "Assisterad befruktning med embryodonation och dubbeldonation", National Board of Health and Welfare, www.socialstyrelsen.se/kunskapsstod-och-regler/omraden/organ-och-vavnadsdonation/assisterad-befruktning-med-embryodonation-och-dubbeldonation/.

26. Scandiatransplant covers a population of around 28.9 million. It is owned by the member hospitals, which perform transplants in these countries.

27. "Nya regler för organdonation – från den 1 juli 2022", National Board of Health and Welfare, www.socialstyrelsen.se/globalassets/

sharepoint-dokument/dokument-webb/ovrigt/organdonation-nya-regler-1-juli-2022.pdf.

Riksbankens Jubileumsfond: promotes, inspires and participates

Research within the humanities and social sciences is necessary to understand and manage societal challenges, nationally and globally. Riksbankens Jubileumsfond (RJ) is an independent foundation that supports and promotes high-quality research in the humanities and social sciences. This year, 2024, the foundation celebrates 60 years of its activities. Over the decades, thousands of research projects have received support, in various forms and to differing extents, and RJ has become established as one of Sweden's most important research financiers.

The foundation was created when the Swedish central bank – Riksbanken – wished to both mark its tercentenary in 1968 and to support an important national objective linked to science and research. Riksbanken thus made one donation to establish the Prize in Economic Sciences in Memory of Alfred Nobel, and another donation to support upcoming research. In 1964, the Swedish Riksdag decided to establish a foundation to manage this donation – Riksbankens Jubileumsfond.

In the years up to 2023, the foundation has provided a total of SEK 18.7 billion in research funding.

RJ 2024
Failures?
Editor: Jenny Björkman

Medicine prevents death and helps us create life. Organ transplants and in vitro fertilisation are successful medical treatments: we have happy parents and happy organ recipients. However, the demand for medical technology services often outstrips supply, creating ethical grey zones and black markets, where people can make money by selling their body parts.

Modern Western medicine has led to the body being seen as a collection of parts rather than a whole, which affects how our bodies are perceived and categorises us as successful or unsuccessful individuals.

In 2024, Riksbankens Jubileumsfond publishes an essay collection under the title *Failures?*. Ethnologist Susanne Lundin writes about the unintended consequences of reproductive medicine and organ transplants.

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