Withdrawal of consent by sperm donors

PERSONAL VIEW Peter D Sozou, Sally Sheldon, Geraldine M Hartshorne

Since 1991, sperm donors in the UK have had the legal right to withdraw consent for the use of their sperm in fertility treatment. This has the potential to adversely affect patients. It may mean that previous recipients of a donor’s sperm cannot have further children who are full biological siblings to an existing child, and that embryos created from the donor’s sperm and a patient’s eggs must be destroyed.

We have informally investigated withdrawal of consent by sperm donors donating after 1 April 2005, when lifelong anonymity for gamete donors ended. An email in November 2008 to colleagues at five UK fertility centres asked if recipients knew of cases where a sperm donor had withdrawn consent after his sperm had been released for use. One reported that this had happened at their centre. This was followed by an email in March 2009, kindly circulated by the Association of Clinical Embryologists, asking each recipient how many donors recruited at their centre since April 2005 had withdrawn consent after their sperm had been released for use. In response, two further centres each reported one donor who had withdrawn consent after sperm had been released, as well as several who had withdrawn after donation but before such release.

In total, therefore, we have found three centres where there has been an instance, since April 2005, of a sperm donor withdrawing consent after his sperm had been released for use. In one of these cases, the consequences included stored embryos and sperm reserved for creating siblings being destroyed. We have therefore established that withdrawal of consent by sperm donors is not just a hypothetical problem. It has serious consequences for patients. This raises the question of whether the laws governing sperm donors’ rights to withdraw consent should be re-examined. However, major amendments to UK fertility laws were made in the Human Fertilisation and Embryology Act (2008), and UK fertility laws do not seem likely to be revisited in the near future. Can steps be taken, within existing laws, to reduce the chances of these most serious consequences occurring?

We propose that a sperm donor expressing a wish to withdraw consent should be offered the following three options:

(a) No new families to be begun; embryos already created to be kept and sperm to create full siblings of children created from his sperm to be retained.
(b) All sperm to be destroyed but embryos already created to be kept.
(c) All sperm and embryos to be destroyed (with destruction of embryos subject to the mandatory 12 month cooling off period to be required from 1 October 2009).

We would expect some donors to choose options (a) or (b), resulting in less impact on patients than option (c). Presenting the three options as a standard menu would allow a donor to make a nuanced decision about withdrawal of consent. And our proposal creates a facility for a donor to make such a nuanced decision without his necessarily being given details about how his sperm had been used.

Why do sperm donors withdraw consent?

Positive responses to our initial email and subsequent email survey were followed up to ask if respondents knew why the donor had withdrawn consent, unless this information had already been volunteered. In two of the three cases, the donor indicated that he was withdrawing consent because of the influence of a new female partner. In the third case communication was limited between the fertility centre and the donor, and the donor did not offer a reason for withdrawal of consent.

Counselling of prospective sperm donors is probably effective at helping them work through any concerns they may have about donation at the time when they volunteer to be donors. However, it may be less effective at enabling donors to anticipate the impact of new events, for example new relationships, and in particular any resulting pressure from a new partner. While the number of cases we have found of sperm donors withdrawing consent after their sperm has been released for use is small, they do clearly illustrate the potential influence of new partners.

While the number of cases we have found of sperm donors withdrawing consent after their sperm has been released for use is small, they do clearly illustrate the potential influence of new partners. It is possible that a contributory factor in donors’ decisions to withdraw consent in these circumstances is the removal of lifetime donor anonymity, and the consequent prospect that a donor will be contacted by children conceived from his donated sperm when they reach the age of 18. The possible effect of such contact on the donor, his partner, and any children born to them is an understandable concern of the new partner, and her views may be expected to influence the donor’s actions. While donors are encouraged to discuss their wish to donate with their current partner, the influence of new partners on donors has not been considered and merits further investigation.

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Sci-fi medicine: an odyssey

The implications of medical technology, showcased in an exhibition, are tremendous for patients and doctors, says Ara Darzi.

Sci-Fi Surgery/Medical Robots
Until 23 December, Tuesday to Saturday, 10-5pm, free entry
Rating: ★★★★★

From aeroplanes to the desktop computer, the technological innovations of the past century have transformed the way we live now. It is therefore curious that, while it is considered perfectly normal to send people into orbit, there is a widespread expectation that traditional manual dissections should dominate the practice of surgery.

The Royal College of Surgeons’ engaging new exhibition trains a spotlight on this anachronism. Sci-Fi Surgery/Medical Robots traces the progress of medical robotics from its origins in the 1980s to the most current trends in research, and is designed as an introduction for clinicians and the general public.

Medical robots came to the fore in tandem with the rapid advance of computer technology, but as Sci-Fi Surgery makes clear, this concept was already circulating in the medical community and in popular culture. The exhibition deftly demonstrates the way in which the concept of medical robots carries an innately futuristic quality that both fascinates and frightens. However, medical robotics has the potential to revolutionise the field of surgery, and is already improving surgical accuracy, training, and, most importantly, quality of care.

The exhibition charts this progress chronologically, beginning with the first use of robotic technology in surgery—the PUMA 560, used in 1985 to orient a needle for insertion into a patient’s brain. The PUMA lay the foundation for today’s endoscopic camera pill, or of a future in which “nano-robots” could be deployed into the bloodstream, while David Keller’s Psychophonic Nurse presaged the robotic “nurses” currently in development.

The exhibition explores the evolution of medical robots and their presence in the science fiction genre. It illustrates the way in which authors, cartoonists, and directors have anticipated and reacted to developments in medical robotics. For example, the microscopic teams of physicians in Asimov’s Fantastic Voyage, based on the 1966 film, can be viewed as a prescientism of today’s endoscopic camera pill, or of a future in which “nano-robots” could be deployed into the bloodstream.

By tying this thematic element to the concrete advancements in medical robotics of the past 25 years, Sci-Fi Robots invites the viewer to meditate upon the wider implications of these developments for the medical profession, patients, and society in general. For all the hopes raised by the potential for more accurate and less invasive surgery, there are also fears that this physical distancing of surgeon from patient may corrode and dehumanise the unique nature of the doctor-patient relationship. Yet as Justin Cobb at Imperial College has observed, “Robots are designed to hold the surgeon’s hand in the operating theatre, not take over the operation.”

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Sanatorium blues

Tuberculosis is the literary disease par excellence but also the anti-literary disease. In the 20th century alone it killed Anton Chekhov at 44, Katherine Mansfield at 36, D H Lawrence at 44, and George Orwell at 46.

Other authors suffered from it without dying from it. Among them were Somerset Maugham and Eugene O’Neill (1888-1953), the US playwright who won the Nobel prize for literature in 1936. O’Neill instantiated in his life the connection between alcoholism and TB; he also exemplified the tragic bent of American theatre writing. Almost all his plays are tragedies; it is as if optimism, the semi-official ideology or doctrine of America, were the royal road to despair, at least for sensitive souls.

The Strave, an early play set largely in a tuberculosis sanatorium of the kind of which O’Neill was once a patient, tells us that hope is always illusory in nature. This is so, O’Neill implies, whether we are in full health or in the last stage of consumption. We are all in the same boat, and it is carrying us across the Styx.

Eileen Carmody is the eldest daughter of a widowed, working class, Irish American man of singular insensitivity. When her tuberculosis is diagnosed, her father and her fiancé virtually abandon her when she goes to the sanatorium, for fear of catching the disease themselves.

The methods employed by the sanatorium are of some historical interest and of personal interest to me too, for I used one of them—the weekly weighing of the patient as a measure of clinical improvement or deterioration—when I was in charge of a TB ward in a distant country. In O’Neill’s sanatorium, however, the patients seem almost to regard weight loss or gain as signs of moral depravity or election: their weight is a measure of their efforts to get well over the previous week.

As her health in the sanatorium continues to deteriorate, Eileen falls deeply in love with another patient, Stephen Murray, whose health improves to the point at which he is fit for discharge. He does not return her feelings, and the scene of the night before his departure will deeply move anyone who has felt unrequited love. The scene gave rise to an odd feeling in me, something between a sinking and a warm glow, in the region of the solar plexus.

Stephen returns to visit the sanatorium when Eileen is dying. A nurse asks him to give her some last happiness by pretending to love her, implying that such happiness will prolong her life; but in declaring his pretended love, he realises that it is real after all. When afterwards he tells the nurse that he really does love Eileen and that his love will triumph over TB, she disabuses him by the expression on her face. He cries out, “Oh, why did you give me a hopeless hope?” To which she replies: “Isn’t everything we know—just that—when you think of it?”

O’Neill’s father was a travelling actor, and he was born in a hotel. He also died in a hotel, and his last words were said to be, “I knew it. I knew it. Born in a hotel room, and God damn it, died in a hotel room.”

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MEDICAL CLASSIC

Diverticular disease of the colon

Neil S Painter Published 1975

In the late 1960s and 70s an interesting hypothesis was proposed—that dietary fibre, the “unavailable inert carbohydrate” defined by McCance and Lawrence in 1929 was, if not an essential nutrient, of importance for health. Dietary fibre was a panacea for the ills of the Western world. Peter Cleave had indirectly set the pace highlighting the benefits of dietary fibre, and then in Africa Denis Burkitt, Hugh Tryowell, and A R P Walker proselytised its virtues. Their credentials were impeccable. Each, particularly Denis Burkitt, had made great contributions to the aetiology of diseases. But in this campaign, the emphasis was on observation rather than hard facts. This was not a concern for them, but many others who preferred statistics were unconvinced.

This is where Neil Painter was so important. He had trained as a surgeon. He studied with the gastroenterologist Sidney Truelove in Oxford, where he measured intraluminal pressures in the sigmoid colon of patients with diverticulosis. Life had not always smiled on him. He had served as a Fleet Air Arm pilot. Unlike the other, more polished leaders in the dietary fibre campaign, Neil was a bloke rather than a chap. He worked as a consultant surgeon not in the NHS but in the Trade Union Manor House Hospital. His family did not enjoy the best of health. For years he was virtually the sole provider of sound facts supporting the claims for dietary fibre: that in this one condition, colonic diverticulosis, dietary fibre had an important role in the treatment and by inference the cause of disease. Previously the treatment had been a low fibre diet, so his ideas were radical. Later, with Adam Smith, he was to show that the type of fibre mattered, that wheat bran was effective, and that soluble fibres paradoxically increased intraluminal pressure.

His little book is a clear account of diverticulosis and even now is relevant to care. Norman Tanner wrote the introduction.

He described diverticulosis as one of the enigmas of pathology and commended Painter’s book as perhaps the most outstanding study of colonic diverticulosis since the work of surgeon Harold Edwards in 1939. Praise indeed. Painter follows the traditional list of contents for such a book, definitions, history of the condition, radiology, incidence, aetiological factors, intralumenal pressure studies, effect of drugs, epidemiology, and clinical manifestations of complicated and uncomplicated diverticulosis. Such a book at that time could not have been credible without mentioning the association between dietary fibre deficiency, diverticulosis, and the associated diseases. Unlike the other chapters, this chapter is rather light on supporting facts.

Neil Painter’s work and book changed the treatment and approach to this common, usually benign condition. He published over 50 papers, many in high quality journals, but they were in general a reiteration of the work in his book.

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The counsel of imperfection

I was born into a liberal home in a modest nation. One Friday night we watched the late night horror movie *Vampire Circus*. My mother almost choked on her biscuit at the full female frontal nudity. I was unable to meet her gaze for weeks. We shut our eyes during the sex education video of a screaming woman giving birth, and only the new romantic boys wore make up at school. Today, it’s all lipstick, crop tops, and thongs—and the girls are even worse. We endure Lily Allen’s blushing lyrics and endless mis-spelt Viagra emails that evade the spam guard. “We’ve become bloody Europeans,” says my wife. I nod. Today we are an immodest sexualised nation, so why is there a need for yet another call to widen HIV testing?

HIV was a dark spectre in the mid 1980s—there was no effective treatment, and death was slow and terrible. So the implications of testing were seen as significant. Thus, pre-test counselling was well meaningly spawned in hard to access specialist services. After prolonged sexual inquisition there was no guarantee of being tested, even if patients merely wanted reassurance. The General Medical Council enforced the need for extensive pre-test counselling with the threat of disciplinary action, which intimidated doctors. And the result? Testing just wasn’t done or indeed mentioned—paradoxically raising stigma and fear (which was illogical, since requests for chest radiograph for suspected lung cancer carried similar consequences). Doctors testing for HIV in general practice were considered deeply suspect. Many doctors are still paranoid and uncertain about testing even today. The easy option remains not to test.

But the argument has moved on. Antiretrovirals allow patients with HIV to stay well, living full and happy lives. Antenatal testing is a proved success and there is real hope for a vaccine. Regrettably, however, an estimated quarter of cases of infection are undetected, with lives at risk from opportunistic infection and unwitting infection of others. So the need for wider testing seems a no brainer. But the only true way to widen and normalise testing is by offering HIV testing routinely in general practice, because we have access to the whole population. This can be done, it is just a question of priorities. So it’s time to lose the inhibitions and get with it!

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Non-doctor in the house

What exactly is a doctor? Beyond their common gestation in medical school, what description embraces the roles and responsibilities of, say, the paediatric oncologist and the rural GP, the forensic psychiatrist and the hand surgeon, while strictly excluding other healthcare professions? Coming up with a succinct definition for something so seemingly fundamental is difficult.

Maybe this didn’t matter as much when the place of doctors was easier to recognise or assume, and harder to challenge. Such people used to be more easily identifiable and linked by activities that were their preserve or prerogative. But some of these criteria are less reliable discriminators nowadays. A good example is the prescription of medicines.

Acting as an independent prescriber (one that has full responsibility for prescribing decisions and can write prescriptions autonomously) remains a key part of what doctors may do. But it’s hardly a specific criterion. This isn’t just because dentists have long been independent prescribers too but is also a result of the changes that have allowed specifically trained other groups of professionals in the UK to become independent prescribers. These so-called non-medical prescribers (a catchy but potentially misleading term) are now an important part of attempts to ensure that patients have timely access to the treatments they require, without having to see a doctor first, if at all.

And this revolution is continuing. Since earlier this year, qualified optometrists have been able to train as independent prescribers. Also, a recently published Department of Health report has recommended that independent prescribing should be extended to physiotherapists and podiatrists. Moreover, it argues for further work to assess the need for radiographers to become independent prescribers. If (or when) these recommendations are implemented, any notion that doctors are inevitably best placed to prescribe medicines will be torpedoed again.

Unsurprisingly, the rise of the non-doctor prescriber has faced opposition from some in the medical profession. For instance, at the introduction of independent prescribing by nurses and pharmacists in 2006, there was much harrumphing along the lines of “How can these people who haven’t had our training, and don’t have our diagnostic skills, let alone our long and broad experience of disease management, possibly prescribe as appropriately and safely as we do?” So far, at least, these concerns appear somewhat misplaced and overblown.

Perhaps a main reason for this is how the new prescribers are relentlessly instructed and encouraged to prescribe only “within their competence” as dictated by their professional training and experience—if only many doctors were subject to similar forces.

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