reviews

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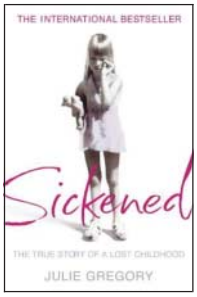
Sickened: The True Story of a Lost Childhood

Julie Gregory



Century, £12.99, pp 260
ISBN 1 844 13442 3

Rating: ★★★★

One variety of child abuse name-checked in the British media right now is Munchausen's syndrome by proxy (MBP): the infliction of suffering, symptoms, and signs upon a child by its "carer," facilitating some need that the latter may have to interact with doctors. Children may be maimed and murdered by their kith and kin, and all in the pursuit of medical interventions. Raised in Ohio, in the American Midwest, Julie Gregory survived such an upbringing as the proxy for her mother, a truly damaged woman, who put her daughter through the mill.

"The nurse at my feet says, 'Now this might be a little stick, Julie. We've got to get this plastic tube into the urethra 'cause Mom says you can't go.'

"My heart is pounding; what's urethra? What is she doing down there? I open my mouth to ask, but a startled scream rips out instead."

Later, her mother will elicit the same ordeal for Julie's brother: "I heard him scream and whimper clear down the hall into the waiting room. Nobody had to tell me what was happening. He was getting a tube shoved into his urethra . . ."

This traipsing between credulous doctors (their notes are reproduced in the text) occurs beneath the lurking shadow of the American Gothic summoned up by Gregory: a place where fat fathers lounge in trailers, shouting for food that they may eat off their bloated bellies, while women who poison children coerce them into saying that they see Jesus, and men "do things" to children in bushes, while other adults "turn a blind eye."

The book is compelling, not only because one wishes to see how the author will survive into adulthood, but also because the language is so often beautiful: "But the memories that hang heaviest are the easiest to recall. They hold in their creases the ability to change one's life, organically, forever. Even when you shake them out, they've left permanent wrinkles in the fabric of your soul."

Of course, there is no easy escape. For the one who leaves such a home must worry over those who are left: younger siblings, children fostered, the vulnerable. Gregory conveys the sheer emptiness of carrying on alone, away from a place that is necessarily associated with suffering: "The more I acclimate to the normal world, the more and more surreal and unbelievable the world I came from seems."

Eventually, she will find some release through learning of her condition, through reading works of literature, and by facing down her mother in full flight. The invocation of her inner voice may inspire the reader to stop and think: "Hey, you, with the frontal lobe, turn off the TV, stop the noise, and consider this deeply."

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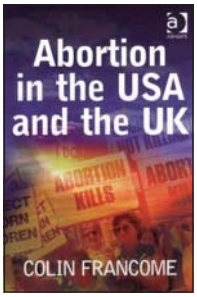
Abortion in the USA and the UK

Colin Francome



Ashgate, £35/$59.95, pp 188
ISBN 0 7546 3015 3
www.ashgate.com

Rating: ★★

The legitimacy or otherwise of induced abortion has been influenced by social, political, and medical perceptions. From the 13th century to the early 19th century induced abortion was legal under English common law, before the onset of quickening at 15 to 18 weeks gestation. However, to cause the death of an animate child in utero was considered homicide. The law changed fundamentally in 1803, making any attempt to induce an abortion at any gestation using a noxious or destructive substance a capital offence, largely because abortion was considered a major danger to women's health. Conversely, in the United States, where English common law still applied in many states, the first legislation to prohibit abortion at any gestation appeared in 1828 in New York state. At that time reports of 30% mortality among mothers after surgical abortion in hospital and 66% at the hands of non-medical practitioners were judged too high to allow the practice to continue. This legal position was atypical, as only five of 26 states had banned abortion by 1840.

Although abortion was an offence, the medical profession's use of abortion to safeguard maternal health was overlooked. As abortion became safer in the 20th century, demands grew for abortion laws to be liberalised. The British Abortion Act 1967 permitted abortions under proscribed conditions relating to maternal and fetal health and had a profound effect on subsequent extensions of abortion laws in over 40 countries between 1967 and 1982. A fundamental difference between the United States and United Kingdom is that US women have the right to abortion on request until fetal viability. Despite this difference there is little pressure to amend current legislation in Britain because women do not have difficulty obtaining abortion.

Ninety four per cent of abortions in the United Kingdom are done under clause C of the Abortion Act 1967, which permits termination under 24 weeks gestation on the grounds that termination is a relatively safe procedure and pregnancy is more dangerous than not being pregnant. One per cent are done because of fetal abnormality, and 1% because of medical complications in the mother. In 2000 the number of abortions per 1000 women of reproductive age was significantly higher in the United States (24.5) than in the United Kingdom (16.9). However, this difference may reflect the relative availability of contraception rather than the prevailing legislation.

Francome's appraisal of the circumstances that led to the current laws is enlightening. The views of pro-abortion factions and their opponents are explained, but evaluation of the ethical and moral dimensions is kept outside the scope of the book.

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The Good Body

Written and performed by Eve Ensler
Directed by Peter Askin
American Conservatory Theater, San Francisco, California, United States, until 1 August 2004
http://act-sf.org/

Rating: ★★★

In a darkened auditorium against a backdrop of loud gurgling and sucking sounds, a 35 year old woman lies on her back, talking about her latest cosmetic surgery procedure. It is the most recent in a long history of operations, which have included everything from liposuction to soy breast implants. Without a hint of irony, the woman says that she is in a sexual relationship with her plastic surgeon, a man who seems to regard himself as something of a Dr Frankenstein and his partner as his most fabulous creation.

In recent years, cosmetic surgery has eked out a whole new niche of reality TV programming, with ABC's *Extreme Makeover*, MTV's *I Want A Famous Face*, and Channel 5's *Cosmetic Surgery …Live* attracting frenzied attention in the United Kingdom and United States (*BMJ* 2004;328:1208). Until recently, cosmetic surgery was not a subject commonly tackled on the stage. But in *The Good Body*, a new play by playwright/performer Eve Ensler, nips and tucks are transported from the operating theatre to the live theatre as part of an attempt to dramatise the perpetually problematic relationship between women and their bodies.

Ensler is best known as the creator of *The Vagina Monologues*. Based on a series of interviews with women about their sexual organs, this award winning play explores women's sexuality in an alternately funny and disturbing way. Selling out off-Broadway in New York and in London's West End, *The Vagina Monologues* has since been translated into 35 languages and performed all over the world, both as a solo show by Ensler and by groups of celebrity actresses including Whoopi Goldberg, Susan Sarandon, Glenn Close, and Winona Ryder. The success of the play has fuelled V-Day, a global charity founded by Ensler to end violence against women and girls (www.vday.org).

In *The Good Body*, which is currently premiering at the American Conservatory Theater in San Francisco before heading to Broadway, Ensler embarks upon a journey to understand both her love-hate relationship with her own body (specifically her flabby tum) and that of women all over the world. Transforming herself expertly into a variety of different characters—from Helen Gurley Brown, the revamper of *Cosmopolitan*, who at 80 plus years old still performs 200 sit-ups a day, to Bernice, an obese teenager whom Ensler encounters while visiting a fat camp and who calls the playwright a "skinny bitch"—Ensler proves herself to be a consummate comic actress.

The play's most penetrating moments occur when Ensler veils her disgust and sorrow at the lengths some women will go to to achieve physical perfection, under a veneer of sharp characterisation and acerbic wit. In one scene, for instance, Ensler embodies a middle aged woman who undergoes a vaginal tightening procedure at a Beverly Hills clinic to rejuvenate her flaccid marital sex life. The character is funny because she is so credulous, yet the horrific pointlessness of the procedure and its disappointing results are there in the undertow.

Ensler: dramatising the relationship between women and their bodies

In *The Vagina Monologues*, Ensler achieved both a spectacular literal and figurative climax by presenting a thumping orgasm onstage. In *The Good Body*, a potentially rich closing scene set at a clandestine women's ice-cream parlour in Afghanistan fails to reach similar transcendent heights. In fact, it is slightly embarrassing: watching Ensler as she histrionically guzzles ice cream, offering vanilla flavoured libations to the women encountered on her journey before tearing off her tight black top and letting her stomach hang out in a final statement of defiance and freedom, gives one a pressing urge to hide behind one's burkha.

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Calculating the risk of disease

Online tools for working out the risk of individual diseases are almost as old as the internet. The web is full of sites devoted to assessing people's risk of cardiovascular disease, for example. But now the Harvard Center for Cancer Prevention (part of Harvard School of Public Health) has produced a site designed to calculate the risk of five of the most important disease groups in the United States.

Launched last month, Your Disease Risk (www.yourdiseaserisk.harvard.edu) is an expanded version of the centre's cancer risk assessment website; in addition to the 12 cancers covered in the original site, it now also includes heart disease, stroke, diabetes, and osteoporosis.

The site is an interactive educational tool that seeks to encourage healthy lifestyles, making a quick and dirty assessment of people's eating, drinking, and exercise habits, and offering personalised tips for disease prevention. Visitors choose their "disease," fill in an online questionnaire, and, assuming they don't lie, they should get a clear picture of their chances of being fit or sick in the future—or so the site claims.

The site began in the mid-1990s as a pen and paper risk assessment tool, and gradually evolved to its present format. Its contributors—epidemiologists, clinicians, and others from the Harvard medical community—identified established and probable risk factors for each disease based on the available scientific evidence. "This information was then used to develop calculations that generate a person's risk of disease compared to population averages by age and sex," the site explains.

Your Disease Risk is extremely clear and user friendly. With quick links to other educational information from Harvard University, it is a serious attempt to guide people through the intricate world of disease prevention.

Naturally the media have already dubbed the site a "hypochondriac's dream," but if the hits received by its predecessor site are anything to go by, there must a lot of hypochondriacs out there: Your Cancer Risk, launched in 2000, has averaged 900 to 1000 unique visitors daily for the past four years, making it Harvard School of Public Health's most successful website.

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Medical Mysteries

BBC 1, Wednesdays at 10 35 pm from 14 to 28 July

Rating: ★★★

Each of these three documentaries, which focus on rare medical conditions, is rather like a whodunit, where the mystery unfolds, is subsequently investigated, and, in a sense, solved.

The first episode covered the much debated madness of King George III. Professors Tim Cox of Addenbrooke's Hospital, Cambridge, and Martin Warren of Queen Mary's, London, set out to find the truth about the king's condition, which is widely thought to have been caused by acute intermittent porphyria. The story began with the recent unearthing of samples of the king's hair in a London museum vault. The hair was analysed and found to have 300 times the amount of arsenic when compared with controls. Painstaking searches through the history books revealed a number of odd findings: that many creams and oral therapies contained arsenic in the 18th century; that a distant relative of the king, who also had symptoms of porphyria, was once therapeutically injected with arsenic and almost died from an acute attack as a direct result; that the powder used to whiten the king's wig contained arsenic; that the drug doctors used to treat the king's condition (Dr James's fever powder) contained antimony, which contained arsenic.

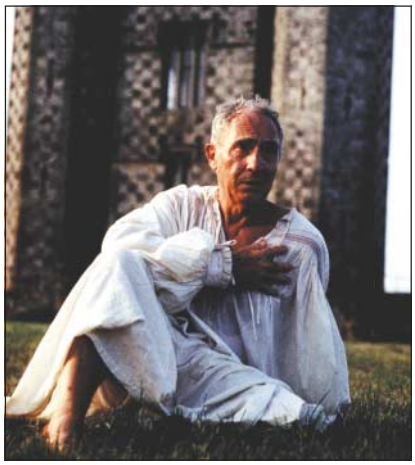
In addition to the fascinating detective work, there is a substantial human element in all three programmes. Julie Bradshaw has acute intermittent porphyria and her patient's perspective helped to illustrate the effects of the illness.

Programme two was about Lorenzo's oil, a medication used in the treatment of adrenoleukodystrophy (ALD), which is a progressive X linked neurological condition that leads to paralysis, blindness, and early death. It is caused by a relative excess of very long chain fatty acids and usually presents before the age of 8.

Lorenzo is the 26 year old son of Americans Augusto and Michaela Odone, both non-medics, who fought a battle against the medical establishment to find a cure for ALD. Not willing to accept that there was no treatment for the condition, the Odones did their own extraordinary research and proposed that mixing erucic and oleic acid was a potential cure. In the early 1990s their courage was captured in the Hollywood film *Lorenzo's Oil* which, like this programme, showed their journey from local libraries to an industrial firm in Hull, England—the only company that initially agreed to manufacture the oil. There was widespread dissent among the medical profession, but the latest research conducted in this programme showed that ALD, although not treatable, may be prevented by Lorenzo's oil in those who carry the gene but are asymptomatic.

Again the story of other patients served to illustrate the impact of the condition, and there was hope for one sibling who has so far kept the disease away by taking the oil since positive genetic testing. The narrative technique of following patients and their relatives on their medical journey—a technique that runs through all three programmes—is intensely powerful and occasionally overwhelming.

The final episode appears to have been made over several years. It tracks the research of two medical teams into the cause of encephalitis lethargica, a strange neurological condition causing coma and catatonia, of which there was a pandemic between 1917 and 1928. The next reported batch of cases was in New York in the late 1960s. These are gracefully discussed by neurologist and author Dr Oliver Sacks, who first experimented treating these patients with L-dopa. The condition randomly reappeared at Charing Cross Hospital in 1993 with the case of Becky Howells. There is footage from her admission and a sense of helplessness as her consultant describes her initial despair when Becky first presented.



KOBAL

Does porphyria explain George III's madness?

The initial theory of influenza virus as the root cause (there was a flu pandemic in the 1920s at the same time as the pandemic of encephalitis lethargica) was discounted after Professor John Oxford of Queen Mary's, London, was unable to isolate the virus from brain segments of sufferers from the 1920s. Amazingly, scientific and historical research carried out at the Institute of Neurology and Great Ormond Street Hospital, London, respectively, showed that encephalitis lethargica was almost certainly a post-streptococcal phenomenon.

Each programme ends on a positive note, with new knowledge or a heartwarming glimmer of hope. Yet an odd sense of darkness overshadows the whole production, amplified by the choice of music, title sequences, and a dramatic voiceover.

The difficulty with making this kind of series is its sheer enormity in terms of time, research, consent, planning, and making it palatable enough to appeal to a wide viewership. There are interesting slivers here for everyone—for those who enjoy history, epidemiology, documentaries, the patient's story, medical advances, and much more beyond.

The series is also a refreshing reminder that solving medical mysteries is not just a thing of the past, and that in the future similar programmes might be made about curing AIDS or the common cold.

KOBAL

Fighting the establishment: actress Susan Sarandon as Michaela Odone in the film *Lorenzo's Oil*

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PERSONAL VIEW

The legal aid folly that damages us all

In medical matters it is surprising how often the law, in Mr Bumble's words, proves to be "an ass," as two recent prominent cases demonstrate.

The first was a claim against manufacturers of the MMR (measles, mumps, and rubella) vaccine. As long ago as 1994 legal aid was granted to a group of parents who were opposed to immunisation (and who were strong believers in homoeopathy), for an action claiming that MMR causes brain damage, epilepsy, arthritis, and autoimmune disease. After Andrew Wakefield's 1998 *Lancet* article (*Lancet* 1998;351:637), the number of plaintiffs was expanded and the claim concentrated on the allegation that MMR causes autism. Legal aid for the claim was eventually withdrawn in September 2003 on the grounds that the action was unlikely to succeed. By then it had cost the taxpayer £15m.

Legal aid in claims for damages for personal injury, which is granted by a committee of lawyers, is mainly restricted to claims for medical negligence and is normally granted only if there is a good chance of success. In the case of MMR it was granted to finance scientific research to find out if a case existed. In fact it had been known for many years that epidemiological research showed no evidence of any link between MMR and autism. Further, in 1998, at the request of the claimants, the Committee on the Safety of Medicines re-examined the claim that MMR causes autism and duly found that the evidence did not support it. Nevertheless, legal aid was continued.

> This team was quite clearly not adequately qualified to investigate possible causes of autism

What did the lawyers who grant legal aid think they were doing? At vast public expense a team of 16 lawyers was established that included three people with basic science degrees but no experience of postgraduate or scientific research. This team was quite clearly not adequately qualified to investigate possible causes of autism, an issue which has so far baffled medical science. Indeed, the Legal Services Commission finally admitted that it was "inappropriate" to have granted legal aid and that the courts were not the place "to prove new medical truths."

The second example is the claim for damages against hospitals for unauthorised retention of tissues and internal organs after autopsy. Formerly, these were often retained for research. Relatives' consent was not always obtained, although clearly obtaining consent was best practice. In 2001 the public learnt that samples from thousands of children had been retained in the pathology departments of a number of hospitals without their parents' knowledge. There was a huge outcry, particularly about a pathologist at Alder Hey Children's Hospital in Liverpool, who had retained more than 2000 samples from hundreds of dead children (*BMJ* 2001;322:255). The then health secretary described it as one of the most shocking events he had ever heard of.

Lawsuits followed. One was settled by the payment of £5m compensation out of NHS funds. Another, on behalf of more than 2000 relatives, is still in train. In an interim ruling last year, a judge capped the plaintiffs' litigation costs at £500 000, compared with their claim that they would amount to £1m. Costs of £1.45m had already been incurred. The legal basis for the action includes a claim for negligence, breach of statutory duty, interference with a body, and infringement of human rights.

No one has stopped to ask what possible rational grounds there can be for awarding damages at all. To dare to question the outcry about the "body parts scandal" is almost to commit sacrilege. Burial rites are, of course, an old established observance and play an important part in allowing relatives and friends to express their grief. It was wrong, certainly insensitive, not to obtain relatives' consent.

In the past, parents were generally ready to allow the use of samples for medical research. Yet we have now gone back to the primitive rituals of pre-classical times as if our human rights are infringed if any part of a body is missing. The press invariably refers to internal organs and tissues as "body parts," as if a child's body has been dismembered—indeed, some pathologists have received hate mail accusing them of murdering children. The result is that the recruitment of pathologists has declined and waiting lists for organs are becoming longer.

Both cases demonstrate that we live in a climate of increasing irrationality, as the fashion for alternative medicine confirms. They also show that the law promotes this trend. The public suffers twice over: it pays millions for legal aid and the health service has to pay huge damages it can ill afford.

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Competing interests: DT is chairman of the monitoring board of AXA Sun Life, chairman of a consultancy concerned with good governance in South East Asia, president of the Research Defence Society, and chairman of the charity Alcohol and Drug Addiction Prevention and Treatment Ltd.

SOUNDINGS

Unsung heroes

I often feel besieged by all the guidance documents from various committees. The difficulty is both the volume and the fact that they rarely tell you *not* to do something. I should apparently be urgently referring everyone with a sore throat of more than six weeks' duration and anyone with any dysphagia (even a teenager with tonsillitis?).

A recent editorial in this journal referred to general practice as the "risk sink" of a publicly funded health service (*BMJ* 2003;326:234-5). Every day hundreds of thousands of investigations are not done because generalists, or specialists, accept that the risk-benefit balance doesn't warrant it. These people are the unsung heroes that maintain the viability of the NHS.

In the 1980s the guidance was for general practitioners never to initiate angiotensin converting enzyme (ACE) inhibitors in patients with heart failure. It had to be done in hospital. Even a few years ago the guidance defining those patients who must be admitted into hospital to have ACE inhibitors initiated included most patients I would ever see with heart failure. It was necessary to ignore the unrealistic guidance, with the associated medico-legal risk, or else burden unnecessarily an already collapsing hospital system.

It is quite rare to come across guidance that states explicitly that there must be some threshold of risk at which the investigation should not be done. But there must be such a threshold and, as it is a threshold, there will necessarily be some diagnoses that will be missed. The corollary of this, I suppose, is that if a clinician never misses a diagnosis then they are either not seeing enough patients (an old adage), or they are over-investigating those they do see.

The real problem is that the downsides of over-investigation—the patient anxiety generated and the resources clogged up—are hidden. It is the one missed case of colorectal cancer, even though its finding may have been incidental to the presenting symptom, that leads to charges of incompetence. But whoever hears criticism of the doctor who refers everything?

We need realistic guidelines. We try to capture as many early diagnoses as possible. But it is necessary to recognise that, unless we medicalise the whole of society, there will be occasions when, as the Americans say, shit happens. And it is not necessarily our fault.

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