Practice A Patient's Journey

At sixes and sevens: prostate cancer

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The patient recounts how two months after radical prostate surgery he developed a thick walled and deeply embedded abscess, which required difficult and complicated surgery

As the car swung into Swing-Swang Lane, on our final approach to the clinic, I still felt symptomless but had the eerie knowledge that the next day my abdomen was going to resemble a cage fighter's and I would be doped up to the eyeballs. At the age of 53, my prostatic tumour had been diagnosed early, and I had opted for surgical extirpation.

There are some 34000 new cases in the United Kingdom every year, and it seems everyone from the Lockerbie bomber to Adrian Mole (aged 39¼) has prostate cancer; it may be the most common internal malignancy for Western men, but when they break the bad news to you it comes as a complete surprise. After several years of fluctuating prostate specific antigen values (settling around 6.1 µg/l), and despite two negative PCA3 urine tests, I finally underwent biopsy needle sampling, the results of which showed that I had a bulky adenocarcinoma (Gleason score 6-7) at clinical stage T1c. Hearing this was one of my life's low points. In Aidy Mole's phrase, "I felt like a ghost of myself."

Numbly, I considered the options. I kept perusal of internet mumbo-jumbo to a bare minimum, studied the helpful National Institute for Health and Clinical Excellence (NICE) website, and was finally convinced by consultant urologist Christopher Eden that the default option should be interventional surgery, keeping radiotherapy as a possible back-up. He proposed a laparoscopic radical prostatectomy, and it sounded quite alarming (I am notably squeamish). The location of the offending gland is most inconvenient—how much simpler if it were in the left ear lobe—and faced, during the preoperative briefing, with nappies, bags, and straps, I wondered queasily if I had plumped for the right treatment. Roll on the day when it can be tackled with a retrovirus vaccine or high intensity focused ultrasound. Perhaps I should have popped into my local Chinese herbalist for a nice cup of golden lock tea. In the middle of all this, Dr Donald Gleason himself died in Minnesota, which I found strangely unnerving.

On the appointed day, I trudged towards the anaesthetics room like a Junior Colts batsman going out to face the first eleven's demon bowler. "I'm not awfully good with needles or blood," I confessed to one nurse. "You're in the wrong place today, then," she joked. When I came round, I was supine (certainly not prostrate), catheterised, and windbound. In my sleep, someone seemed to have punched me five brand new belly buttons. It was Friday the 13th, and Comic Relief Day, to boot.

The procedure had gone well, and Mr Eden had skilfully even managed to preserve my neurovascular bundles. I was hugely relieved. Before long, I was coping with my gory thigh bag, shuffling like an oldster along the corridor (distinctly unathletic in my tracksuit bottoms), and beginning pelvic floor exercises. "Did anyone mention the risk of swelling," asked nurse Marie, "of the testicles?" Now they tell me. I longed to go home, but even so there was a glimmer of Stockholm syndrome when the time came to leave the safety of the clinic's facilities.

Back with my family I was cantankerous and exhausted. The home hydraulics of drainage tubes and sponge baths temporarily distracted me from the long road ahead—an obstacle course combined with snakes and ladders. I had the usual worries (though drastically new to me): Did they get it all out? Will I ever be continent again? Have I kissed goodbye to my love life? I made some feeble joke about my career as a porn star probably being over. My scrotum resembled two purplish figs, and I had chronic constipation. Then, 10 days later, I returned to the clinic for my decathaterisation, miraculously voided a healthy stream, and was released to convalesce in the Scottish Highlands.

I was feeling nicely on the mend, when one morning in early April I simply could not pass urine. After phone advice from down south, we drove for the accident and emergency department in Perth. They had no urologist, but, at 30 miles away, it was considerably closer than Dundee, and the matter was becoming urgent. Major road works en route caused an unwelcome blockage of another type, and by the time we reached the Royal Infirmary my kidneys were aching and I thought I was going to burst. Recatheterised in the nick of time, it seemed a small clot must have clogged my waterworks. I was gloomy about getting the bag back, but, as one of the nurses said, I wasn't about to do much mountain biking anyway.

On 28 May—more than two months after surgery—I suddenly became febrile. For a week I had malarial-style night sweats, spiking temperatures, and general debility. Like an idiot, I was in denial about these symptoms because I was determined to go on a trip with my angling club. Soon after, I could ignore the situation no more, and, fearing I might have caught swine flu (then all the rage), I was admitted to London's Cromwell Hospital with "pyrexia of an unknown origin." Tests ruled out several countryside related possibilities, such as brucellosis and Lyme disease, but subsequent imaging showed an infected pelvic collection. This was aspirated percutaneously, antibiotics were applied, the fever disappeared, and I was duly discharged.

That weekend, my temperature again undulated, and topped 105°F (40.55°C) (I possess elderly thermometers). My new surgeon, Michael Dinneen, admitted me at once to the Chelsea and Westminster Hospital, a few streets from our house, where a further scan showed ongoing accumulations in what was probably a retropubic abscess. Another small drain was inserted under local anaesthetic—not much fun—and some gruesome matter, which looked to this layman like rancid yoghurt, was siphoned out.

What with all the blood tests being taken and chemicals being fed through cannulas, I was now cured of my old squeamishness, but we were baffled by what was going on in my nether regions. My already weakened bladder, continually being topped up before scans, was also seriously confused. Antibiotics weren't really working, so Mr Dinneen presented the option of drainage by open surgery—no fun at all—but this was now beyond a joke.

When he went in, he found “an extremely thick walled indurated collection of dead purulent matter,” a deeply embedded lymphocele the like of which he had rarely encountered. It proved obdurate, and required “a difficult and complicated operation.” When I came round this time I had a stapled wound six inches wide (there goes my bikini line) and yet another urethral catheter. Talk about snakes and ladders. For a fortnight I lay there, enervated, demoralised, and altogether mystified. My second convalescence was slow, and by the time I was allowed to take a bath again I had even forgotten the automatic routine for drying myself.

The wound culture showed carboxyphilic streptococcus, but no one seemed to know the cause of the complication—my own guess is that the obstruction I had while in Scotland must have caused a tiny leak of urine through the mending tissue, which infected the fluid in my abdominal cavity. When I described all this in an email to an American friend, he merely responded, “Yikes!” I think that just about sums it up.

Given its physiological “zip code,” prostate surgery is quite a big ask of the human body. I still experience occasional enuresis, and I continue to be ably supported by vardenafil, but in retrospect I would say that the side effects are a worthwhile swap for the cancer. Recent trips down Swing-Swang Lane have indicated that I have not had any biochemical relapses, and my final histology showed only Gleason grade 6s—so I remain hopeful. Right now, whenever I am told the results of a prostate specific antigen test, my favourite word in the English language, definitely, is: “unrecordable.”

A clinician’s perspective

David Profumo recounts his journey through screening, diagnosis, and management of organ confined prostate cancer. With the exception of developing a rare complication, which presented in a most unusual and convoluted way, he describes a journey typical of that taken nowadays by many men throughout the Western world. He is continent, potent, and apparently cured, albeit at a relatively high cost in terms of morbidity, of a condition that had not bothered him to any great extent and the course of which is neither predictable nor fully understood.

The presentation, investigation, and management of prostate cancer have undergone dramatic changes in recent decades. Huggins won a Nobel prize in 1945 for discovering that the disease was hormone sensitive. It was not until the 1980s, however, when Patrick Walsh described the modern version of radical prostatectomy and prostate specific antigen was discovered that it became possible to detect and safely treat the disease before it became locally advanced or metastatic. In parallel with these advances, huge changes have come about in the delivery of radiation to the prostate, both with implantable seeds (brachytherapy) and via external beam. These treatments are delivered with curative intent and acceptable morbidity.

As a result of screening, greater awareness of the condition, and the early investigation of lower urinary tract symptoms secondary to presumed benign prostatic enlargement, more and more men in the United Kingdom are being diagnosed with early prostate cancer. They are faced with difficult decisions at every step of their journey, from whether or not to undergo a transrectal ultrasound and biopsy, to which treatment to opt for if the biopsy is positive. Matters are further complicated by the fact that the histology has to be interpreted in terms of the grade of the tumour, the number of positive cores, and the proportion of cores involved. Once the diagnosis is confirmed the disease has to be staged, in selected cases with further imaging, usually a bone scan and an magnetic resonance imaging scan. All this information then has to be processed while crucially taking into account the patient’s age and

comorbidities.

Nowadays, in the UK, all patients with a diagnosis of prostate cancer should be discussed at a multidisciplinary team meeting (urological surgeons, radiotherapists, oncologists, pathologists, radiologists, and nurse specialists). One of the roles of this group is to make recommendations to the patient as to what options are suitable for them. In many cases all options are suitable—from active surveillance formerly known as “watchful waiting,” through radiotherapy, to surgery, which can be a traditional radical retropubic prostatectomy by the laparoscopic route (as chosen by this patient) through to robotic surgery (not to mention high intensity focused ultrasound and cryotherapy, where available).

I do not envy those who have to make the decision, and at the end of many consultations I am asked “but what would you do if you were me?”

David Profumo’s journey, with the exception of his rare complication, is one that is being undertaken by more and more men up and down the country. I think his own guess as to the aetiology of the complication is probably correct. Huge advances have been made in minimally invasive surgery and non-invasive treatments, which has raised expectations, but when complications—especially rare ones—occur, the already vulnerable patient can be further demoralised. This story highlights the fact that more than ever we must try to identify those men who truly need to be treated and which intervention is best for them.

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Notes

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Footnotes

- This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.
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