A Papillon patient's journey

The default setting in the treatment of lower rectal cancer is radical surgery. This is the story of a patient who said no to surgery and was more concerned about his quality of life post-treatment than the fear of his death.

In 2003 I was diagnosed with a T3a rectal tumour and was given the stark choice of having a permanent stoma or 12 months to live. Ten years later, I have a nice little place in Manchester and am very happy that I decided to decline that kind offer and look for an alternative. The sad thing is, 10 years on, hundreds of patients are still being confronted with these stark choices and are still being told these are the only options available to them when this is patently not the case for some. Before we get onto the subject of patient choice I think it is best we go back to the summer of 2003 and a chance meeting of man and toilet.

The beginning

At 31 years of age, life was pretty good. I lived in a plush pad in north London, had a beautiful girlfriend and owned a small sales company. With my hours of work my lifestyle was not the best; late nights, fast food and alcohol came with the package. Looking back is the only way I can identify my symptoms; without doubt not knowing I was ill at all, let alone having rectal cancer or any cancer for that matter, was by far the scariest part of my journey.

I had been tired over the previous few months but with a 10–12-hour day and travelling between my offices in London and Glasgow this was not a surprise. Toilet visits had become more regular but the increase was gradual and so less noticeable – not to mention my diet was not the best so again no great shakes there. I was not even that worried about the little bit of blood on the loo roll as, just like a sore nose when you have a cold, friction and loo roll make sense of that scenario. The symptoms were at worst an inconvenience and easily ignored, especially when busy.

An evening out with friends and a rather spicy portion of Singapore noodles put me on course for a meeting with my GP because the reaction was, let's say, robust! Having outlined my symptoms to the GP, with added male moaning and notes on tummy cramps, I returned to work and promptly forgot about it – let's be honest, we have all had a dodgy take away. To my surprise the GP actually listened to me and didn't dismiss my ramblings. Over the next 2 months I was digitally examined by a consultant (who I think was related to ET) and sent for a computed tomography scan and a colonoscopy. I was eventually called back to Homerton Hospital in London and told I had adenocarcinoma of the rectum. 'I have what?' I replied. 'You have cancer Mr Davies!' While this was obviously a shock, I just wanted to know how to go from 'having cancer' to 'not having cancer'. I was told to come back in 2 days to speak to the consultant who would tell me what the best course of action was; and so I went home (well actually I went to the pub, but I digress).

This was 10 years ago and I know some things have changed but in reality ask yourself 'have they?' The concept of a multidisciplinary team is to give the patient a better choice in his/her treatment. However, and this is the case with the hundreds of patients a year who call and email me in tears, it seems the 'choice' is made for the patient in the multidisciplinary team and the patient is still told what is going to happen to him/her. This was my experience. I was told that 50 years ago a procedure called an abdomino-perineal resection was developed which cut you open, removed your entire colon, had a 30% chance of affecting your ability to get an erection and would leave you with a permanent stoma. Should that not appeal, I would die. I was told in no uncertain terms there were no alternatives, this was the 'only' way and even if we tried radiotherapy there could be side effects in 20 years' time.

I stupidly asked why they couldn't 'shrink the tumour and use the hole that was already there?' Apparently this was not possible, so I declined their kind offer and left. This was the most important decision of my life to date and I was expected to make it there and then. I understand there are time targets that clinicians need to hit between diagnosis and treatment but time is something that is the patient's to have, not yours to take. The patient should be given as much time as he/she needs (as long as it doesn't endanger his/her life) to come to terms with the news and/or ask for a second opinion, without feeling pressured or in many cases threatened to have the surgery, no questions asked. When giving lectures I make the point that I am given more time to chose the toppings for my pizza than I was on the course of my life in regards to the treatment of the tumour. This is paramount in what is now called 'survivorship'. Survivorship does not start after treatment finishes, it starts 2 seconds after diagnosis, and the choice being made will directly affect the quality of life post treatment and all the issues associated with survivorship.

I was lucky enough to stumble upon a doctor working at Clatterbridge Cancer Centre, just 8 miles from my parents' home in Chester. Dr Myint, now Professor Myint, was the neighbour of a friend of my mum's who had popped into her work for a coffee. Upon hearing of my illness she mentioned that Dr Myint was an oncologist who may be able to help. It turned out that Dr Myint, with his surgical partner Mr Mike Hershman, had this treatment called Papillon which delivered high doses of X-rays directly onto the tumour and he'd had this radical idea of 'shrinking the

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tumour and removing it via the hole which was already there' – I wish I had thought of that! It was really meant for elderly patients who were not going to survive radical surgery (the mortality and subsequent morbidity in the elderly is terrifying and a disgrace) and really designed for early stage tumours but I thought I would see if it would work for me. I was interested in the fact that, when combined with existing external beam and chemotherapy treatments, it would give me time and another option.

I had 25 sessions of external beam radiotherapy while on a 5-fluorouracil infuser which did had some nasty and painful side effects but it was a short-term price I was willing to pay. At the end of this I was restaged and the tumour had shrunk considerably. Only then was the Papillon administered, two fractions of 30 Gy 2 weeks apart, in an attempt to kill off any remaining tumour. At the end of each stage of my pathway I was re-examined and should I have not reacted well to the radiotherapy or chemotherapy and Papillon I would have gone for the abdomino-perineal resection. This offered not only time but a feeling of empowerment over my life – if the tumour came back I knew I had tried and I would go, albeit reluctantly, for the surgery. If I had just gone for the abdomino-perineal resection there would be no going back.

After the Papillon I underwent transanal endoscopic microsurgery to remove the tissue where the now completely nuked tumour had once been – no cells were found in the histology post surgery. I had gone from no options or hope to Papillon, transanal endoscopic microsurgery and a real chance of being cured. The value of that to me, and to the patients I talk to every day, is immeasurable both physically and mentally. The financial value, however, is measurable from the NHS's point of view. The cost of pre- or post-surgery adjuvant treatment plus the surgery itself plus the weeks in hospital bedtime plus stoma bags and care ongoing for, in my case, 30–40 years *vs* adjuvant treatment plus Papillon plus transanal endoscopic microsurgery and Professor Myint sticking his finger up my bum on a regular basis for a couple of years – I think we can all do the maths on that one; which is why Professor Myint is getting his own wing at Clatterbridge. It is very rare to get a treatment option which offers the patient a real choice and better quality of life post treatment and is better for the NHS.

Almost without exception, patients tell me that their fear of the stoma bag and/or surgery is greater than their fear of cancer; I am sure that this is not isolated to rectal cancers. I know lots of patients want to be told what to do, and surgery is the gold standard in treating this cancer, but none of the surgeons I know and talk to has ever said the abdomino-perineal resection is 100% guaranteed and the cancer will not return. More to the point, patients cannot make an informed decision if they are not told the options upon which a decision is to be made; this is directly against National Institute for Health and Clinical Excellence recommendations. Papillon is not a new technique but technology has moved on both in delivery and in surgical techniques. Combining adjuvant treatment and surgery is not a new idea, but its use in offering rectal cancer patients a better quality of life seems sorely lacking in many cases.

I am a very fortunate man, mainly because of stubbornness, dumb luck and having a friend whose neighbour happened to be the only person in the UK doing Papillon X-ray brachytherapy. Over the past 10 years I have had ups and downs with the consequences of my choice of treatment but it was my choice. I am very proud that I have written a book and helped hundreds of others in their fight for a third option – whether they have taken it or not has not really been the issue.

I was diagnosed in 2003 and to date only two centres, Clatterbridge Cancer Centre and Castle Hill near Hull, have the Papillon 50 machine. Professor Myint treated over 150 patients last year and Dr Dhadda treated nearly 20 in his first year. Both the major bowel cancer charities – BCUK and Beating Bowel Cancer – think that with the roll-out of bowel cancer screening, intended to detect exactly the early stage tumours Papillon is designed to treat, potentially a couple of thousand patients a year could be treated. This is why the Royal Surrey Hospital is about to start treating patients, and interest is being shown, and business cases being drawn up, in several other cities around the UK and globally.

My fears are twofold: first – elderly patients who may be too frail or scared to question their consultant are not being offered rectal saving treatments such as Papillon and not surviving the surgery or the comorbidities arising from it. This is going to become an ever greater issue with an older population. Second – patients are going to start self diagnosing via the internet if they are not happy with or believe they are being given all the options.

I sometimes joke in my lectures to clinicians that surgeons are the only people who don't use Google. Patients want choices, not in where they are treated, but what the treatment is. There is a good chance that you are paying for patients to travel to Clatterbridge right now and their numbers will only increase as bowel cancer screening identifies more early stage tumours. The only question is: what are you going to do about them? **BJHM**

Conflict of interest: Mr M Davies is the sales and patients advocate for Ariane Medical Systems Ltd who make the Papillon 50 system.

KEY POINTS

- The default treatment for lower rectal cancer is surgery.
- This patient was offered abdomino-perineal resection or 12 months to live – 10 years ago this July.
- By combining 5x5 external beam and 5-fluorouracil to shrink the T3a tumour, Papillon X-ray brachytherapy was used to treat the remaining area before transanal endoscopic microsurgery removed it.
- Many patients are not being made aware of their options; the decision is still being made by the multidisciplinary team.
- If you are going to save a life you need to take some responsibility for the quality of the life saved.